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Keywords

leprosy, disease, social stigma, marginalization, epidemiology

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DE PROFUNDIS: UNMASKING THE CLINICAL PATHOLOGICAL AND SOCIOCULTURAL ASPECTS OF LEPROSY

Mark Dolson

"Collective representations are the result of an immense co-operation which stretches out not only in space but into time as well."

(Durkheim 1915:16)

For centuries the concept of disease has been fettered with ecclesiastical overtones synonymous with immorality, sin, and excess. From Biblical times to the present, one of the most misunderstood and widely stigmatized diseases is leprosy, also known as Hansen's disease. During the medieval age, leprosy, with its terrible physical deformations, was seen as divine punishment for committing cardinal sin. One was thought to contract the disease by not washing, or maintaining proper hygiene, thus it was associated with the poor and destitute. The unfortunate stigma attached to leprosy has been perpetuated since time immemorial through many mediums, particularly those of literature, art, folklore, and mythology. Owing to these disparate agents, leprosy today carries the same stigmatizing connotation as it did centuries ago. Although the disease can be grossly disfiguring, it also carries with it an equally burdensome social stigma: the stigma of turning the afflicted into moral and social outcasts who, upon manifestation of the disease, are immediately shunned from society. That

the stigma associated with leprosy is an apparently moral and social consequence is understandable: society feels a need to protect itself against aberrant and misunderstood concepts--if it does not, anomie ensues. Does this reality arise from the physical horrors of the disease or does it come from the socio-cultural contexts in which the disease exists? Are these socio-cultural ideologies universal? Is the leprosy stigma connected to particular historical and social conditions specific to each society? In this essay I will explore these issues and seek to find the cause and effect of leprosy, both pathologically and socially. More specifically, I will delineate the key aspects of leprosy, including the epidemiological and pathological characteristics of the disease; the social and moral consequences faced by the afflicted and the community; and lastly the cause and perpetuation of social and moral marginalization of the afflicted.

LEPROSY: AN EPIDEMIOLOGICAL AND PATHOLOGICAL PERSPECTIVE

It was not until 1873 that the believed cause of leprosy--*Mycobacterium leprae*, a schizomycete of the order *Actinomycetales*, from the family *Mycobacteriaceae*--was discovered by Norwegian physician Gerhard Armauer Hansen (Carpenter and Miller 1964:15). Although a direct causal relationship between the bacterium (*M. leprae*) and leprosy itself has not yet

been found, the bacterium is assumed to play an important role in precipitating the disease. Until Hansen's discovery, the cause and spread of leprosy was thought to be a corollary of poor hygiene, causing widespread misconceptions regarding its pathogenesis and transmission.

According to the World Health Organization, the geographical distribution of leprosy is quite cosmopolitan. They state that of the 10 to 12 million patients suffering from leprosy at present most of the concentration is located in developing countries in the tropical and sub-tropical belt. Although the disease was endemic nearly one thousand years ago as far north as the Arctic Circle--especially in regions such as Scandinavia--it is now considered completely extinct in the region. This extinction is considered one of the great epidemiological paradoxes of any disease's history. The World Health Organization offers some possible factors contributing to this fortunate outcome: it is thought that improved socio-economic conditions provided for improved nutrition and higher living standards; genetic isolation of the population owing to their northerly geographical position; and lastly, the selective mortality of leprosy patients during plague epidemics (W.H.O. 1988:5). Although selective mortality of leprosy patients may be seen as an inhumane means of dealing with the disease, it is a method used to clear a population of its infected--to eliminate transmissions entirely and leading to complete control and suppression of the spread of the disease. The concomitant factors associated with this method, as simple as they seem, conspire to make the sick only sicker--eventually fatally--so the healthy can remain healthy and stable.

The current standings on leprosy distribution, according to the World

Health Organization, are as follows: In Northern Asia, although endemicity of leprosy is quite low in areas such as Russia, China (especially in the western provinces) has a caseload of over 100,000 patients and the number is rising. South and Central America's leprosy status is endemic at a low level of prevalence but has had, in the past, large numbers of cases when the disease was brought into the region by the French, Spanish, and Portuguese at the beginning of the 16th century. In the Pacific Islands, the prevalence of leprosy is still endemic and has led to outbreaks known to last ten years or more. In Australia, leprosy still persists among the aborigines of the Northern Territory. During the 18th and 19th centuries, leprosy was introduced into the United States and Eastern Canada by Chinese, French, German, and Norwegian immigrants. Leprosy persisted in these areas in several clearly-defined foci for several decades--especially in Hawaii during the outbreak of the 1850's--then declined rapidly, although some cases are known to be in existence (W.H.O. 1988:5). According to Waxler (1998) "an average of 100 new cases of leprosy...[were]...reported each year in the United States during the twenty-year period following World War II..". Prevalence of leprosy is extremely high in areas such as India, Sri Lanka, and regions in Africa such as Nigeria, Tanzania, and Ethiopia.

Transmission of leprosy is usually spread through human-to-human contact. Although the most generally accepted reservoir of leprosy is thought to be human, the nine-banded armadillo and Mangabey monkey have been said to provide possible zoonotic transmission due to the detection of large bacillary loads found within both animals. It has also been found that *M. leprae* can

produce a mycobacterial infection in mice foot-pads (Carpenter and Miller 1964:23). Arnold and Fasal (1973) suggest that there may be vectors responsible for the transmission of leprosy: mainly bedbugs, mosquitos, fleas, and possibly cockroaches, although there is no direct causal link between cause (an effective bite from one of the aforementioned insects) and effect (a diagnosable case of leprosy in any of its forms). Contrary to myths and legends regarding leprosy, it is not as highly contagious as it has been thought. In actuality, approximately 95 percent of those persons exposed to the bacterium are immune, a concept contrary to public opinion. Therefore the disease is now considered to be 'very mildly contagious' (Grolier 1992). Leprosy's main route of transmission is thought to be through nasal emissions and skin-to-skin contact. Although the specific process of how the bacillus enters the skin still remains unknown, it is thought that one must have a pre-existing lesion in which the bacilli can enter and multiply. Bryceson and Pfaltzgraff (1979) also suggest that tattooing, and intradermal injections may also create possible portals of entry for the transmission of *M. leprae*. The ideal growth temperature for leprosy is usually between 30 and 36 degrees celsius, thus its preference for the cooler sites of the human body such as the extremities and regions away from sweat glands (Ridley 1988:45). In terms of dissemination of *M. leprae* through nasal emissions, it is transmitted as an aerosol, a means of transmission strikingly similar to that of tuberculosis. As a result of the bacterium's slow development, the incubation period can range from as little as one year to an upwards of thirty years. The pathological manifestations of leprosy usually appear in the peripheral nerves, skin, and mucous membranes.

Upon contamination with the bacterium, the first indications are said to be neurological: the patient experiences patches of numbness or anesthesia throughout the body. The early physical indications of the disease manifest themselves as simple or vague alterations in the skin, usually in the form of hypopigmented patches or macules (Brody 1974:25). The patient may also experience slight paralysis or atrophy of muscles in the hands, feet, and face. Owing to the disparity and variability of these symptoms, prognosis is quite difficult to infer, thus this stage of leprosy is often termed indeterminate (Brody 1974:26). This indeterminate group is usually stable and is rarely bacteriologically positive, though the form may progress into either tuberculoid or lepromatous leprosy, or may even remain unchanged indefinitely (Arnold and Fasal 1973:19).

The specific advanced state leprosy may evolve into depends upon the degree in which somatic tissues are able to set up an adequate defence against the bacilli. If the somatic tissue response provides an effective barrier against the bacilli, the condition is termed tuberculoid leprosy. Although a benign form, tuberculoid leprosy is still capable of bodily disfigurement. Bryceson and Pfaltzgraff (1979) state that tuberculoid leprosy is associated with erythematous skin lesions which are usually elevated marginally or more extensively. There are also groups of epithelioid cells which are surrounded by lymphocytes present at the site. This arrangement is termed a tubercle. In the skin, cellular infiltration may even extend up to the epidermis and involve the basal layer. The cutaneous nerve bundles, both sensory and autonomic, are then destroyed by cellular infiltrate, and as a result, larger nerves bundles usually

become swollen, compressing and ultimately damaging Schwann cells (Bryceson and Pfaltzgraff 1979:5). When the Schwann cells are destroyed the myelin sheath degenerates and is thus incapable of axon regeneration. Loss of motor function and sensation are usually a result (Benjamin *et al.* 1997:363).

In a patient where cell mediated immunity fails to eradicate the rapidly invading *M. leprae*, the form of leprosy is termed lepromatous, a malignant and progressive form (Bryceson and Pfaltzgraff 1979:6). The two forms of reaction in lepromatous leprosy are termed erythema nodosum, and progressive lepra reaction. In terms of gross pathology, the lesions of erythema nodosum manifest themselves as elevated and inflamed 'rose spot' nodules. They may also appear as dark-red or copper coloured macules with complications such as ischemic necrosis and eschar formation, conditions which cause the skin to appear almost putrefactive and cancerous. The lesions of progressive lepra reaction, are characterized by small pyogenic nodules located subcutaneously (Bryceson and Pfaltzgraff 1979:7). These lesions are usually in the form of large crater-like nodules located on the extremities of the patient. Progressive lepra seems to be more severe than does erythema nodosum as the complications associated with it are not only deforming but in the long-run, deadly. Secondary pathologic complications are quite diverse and range from ophthalmic diseases to tuberculosis.

The histopathology of lepromatous leprosy--concerning both erythema nodosum and progressive lepra--is characterized by large numbers of the bacterium *M. leprae* present in Schwann cells of cutaneous nerve fibres within perineurial, cells and in vascular endothelial cells (Bryceson and

Pfaltzgraff 1979:7). In a typical case of lepromatous leprosy, the histopathological process starts with fluid, consisting mostly of macrophages, leaking from the perineurium into the nerve itself. The Schwann cells reduplicate in an attempt to repair and reconstruct the damaged axon. The damage occurs at a more accelerated rate in non-myelinated fibres due to the lack of insulation that the myelin sheath provides. In myelinated neurons, the damage progresses much more slowly: it begins with axonal degeneration which is then followed, sometimes many years later, by hyaline degeneration and fibrosis of affected nerves (Bryceson and Pfaltzgraff 1979:7). Finally, the Schwann cells rupture due to the rapid rate of multiplying bacilli. Brody (1974) adds that upon rupture of Schwann cells there is tremendous swelling and degeneration of nerves. In areas involving tendons and joints (primarily fingers and toes), dislocation, rigidity, paralysis, and ultimately resorption of affected bone are usual pathological responses to the disease. In cases of severe anesthesia, as a result of axonal destruction, the patient's ability to sense or feel pain disappears completely, rendering the patient unable to detect any form of bodily trauma. If the trauma were to remain unnoticed by the patient, Depending on the severity of the injurious insult, infection would ensue and--if medical attention was not sought--would result in dermal, muscle, tendon, and bone marrow inflammation. The end result is often complete loss of the affected area, which is usually confined to the digits of the hands and feet.

The disease is usually not localized and spreads very rapidly throughout the body via the circulatory and lymphatic systems. Affected areas tend to be the skin, nerves, mucosa of the

upper respiratory tract, eyes, testes, lymph nodes, the marrow of the phalanges and most organs of the body (Byceson & Pfaltzgraf 1979:7).

In the occurrence of the third form of leprosy, dimorphous, the patient usually exhibits a combination of both tuberculoid and lepromatous leprosy. The two categories of dimorphous leprosy are macular and infiltrated. Both characterize a generalized distribution of lesions throughout the body and may or may not precipitate anesthesia and ultimate loss of localized function (Brody 1974:28).

Whether it be tuberculoid, lepromatous, or dimorphous leprosy, the physical deformity produced by this disease is the catalyst precipitating widespread stigma and fear. With the exception of minor pathological alterations associated with tuberculoid and dimorphous leprosy, it is the advanced stages of lepromatous leprosy which cause the most hideous and deforming changes in the body and face. Lesions of the face are usually in the form of erythemous and edematous boils. Cytopathologically, macrophages packed with *M. leprae* infiltrate and destroy the bony and cartilaginous structures of the nose along with mucous glands. The ultimate collapse of the nose, as seen in many patients with advanced cases of lepromatous leprosy, is facilitated by a secondary infection by a pyogenic infection, which eventually leads to destruction and loss of architecture in the septal cartilage. In some cases this complication leads to exposure necrosis of the nasal region. Upon advancement of pyogenic infection, resolution of the inflammation--the body's attempt at correcting the pathological situation--results in fibrosis, a reaction which leads to contraction of the nose further in towards the face, resulting in the typical

'flat-nose' deformation associated with many victims of leprosy (Job 1994:211). Edema of facial tissues accompanied by chronic inflammation causes erosion and necrosis of nasal bone and cartilage. Brody describes:

"In advanced cases, extensive nasal involvement presents a tragic picture, with a foul-smelling discharge giving rise to a heavy and musty odour, and with distressing symptoms of nose blockage due to extensive edema of the mucosa, ulceration, and septic complications with marked crust formations."

(1974:31)

Lesions and deformations associated with the mouth are quite severe and are capable of hideous results. The lips and gums usually swell quite considerably, sometimes to twice their size; gingivitis is usually a secondary reaction leading to bleeding and ulcerating gums. The tongue is also affected and may develop large nodules or ulcerating lesions sometimes producing large fissures on the surface of the tongue. The hard and soft palate are also involved along with the uvula, displaying considerable degrees of deformity and destruction depending on the advancement of the bacterium. Adding to this gruesome illustration, Brody (1974) describes that not only is the architecture of the face and body deformed drastically, but the voice is also affected. As the bacilli invade the larynx, the vocal cords become paralyzed. If the case is progressive and ulcerative, secretions invade the pharynx and larynx, producing not only hoarseness of speech and dyspnea, but

also creating a possible means of suffocation.

In all of its bacterial magnitude, it is probably the extremely slow progression of *M. leprae* it one of the most successful parasites. Perhaps the most horrible quality of leprosy is that it gives its host a slow and silent death, disfiguring him/her centimetre by centimetre, until he/she becomes but a ghastly symbol of living death.

THE CAUSES AND MECHANISMS OF THE MORAL AND SOCIAL DEFINITION OF LEPROSY

It was Emile Durkheim, the French sociologist, who stated in his landmark paper, *Division of labour, crime and punishment*, that social solidarity in its simplest form is based on people with like interests, appearances, and motives; hence his definition of the social concept, mechanical solidarity. Although the term mechanical solidarity was intended to be definitive of a small, 'primitive' society, the term is still expressive of the way in which medieval peoples organized themselves: communal units based on the family, controlled by the doctrine of the Bible and priest, to which every man, woman and child was subject. Durkheim succinctly explains the concept of mechanical solidarity:

“Thus they [people] are solidly joined together...[because of this]...results a solidarity *sui generis* which, deriving from shared characteristics, directly links the individual to society. ...[This state of affairs requires] from each of us a minimum of similarities, without which the

individual would be a threat to the unity of the social body...”

(Durkheim 1893:45)

Adhering loosely then, to Durkheim's theory, it would appear that a society views the social 'other', (those displaying different physical characteristics, interests, beliefs, or any other form of behaviour which sets them apart from the common social matrix in which they are part) with apprehension and as a threat to their existing solidarity. This reality presents itself in myriad ways in societies across the globe and it has been thus since time immemorial. Whether the scenario be Nazism in pre World War II Germany, Racism in North America during the 1950's and 60's, or the contemporary, ever-growing stigma of AIDS patients globally, the fear and ignorance of the 'other' is still present with as much force as ever.

It was in ca.1749 that the Norwegian leper, Peder Feidie, wrote on the social misery and physical pangs of leprosy:

“We lepers here can no doctors get:
Here must we stay and wait and fret
Until our time is up...
Because on God's grace...[we]...did wait;
O God, break now the chains
Which bind our limbs with pains.”

(Richards 1977:76)

Pathologically and socially, leprosy is a very unique disease deserving special attention. As a result of its physically deforming attributes, it can be the ultimate social curse one can receive in any society. By force of appearance alone leprosy sets the

afflicted aside from the collective without sympathy or consideration. When anyone defies the social order by contracting a deforming disease he or she transgresses the culturally constructed ideologies of public image and endangers society simply with their presence. Because this disease transforms the 'natural' state of one's physical self, the afflicted are seen almost as deranged monsters. It is this primary fear of turning into a 'hideous monster' coupled with the fact that the disease is communicable that transforms leprosy into a distinct social classification. The most common and basic characteristic a society shares amongst its organizational qualifications is a semblance of appearance, or some form of physical homogeneity to which all can relate. When anyone opposes this socially intrinsic law, he or she is placed in somewhat of a liminal category. The afflicted become social spectres stripped of all their social attributes. They are, in essence, marginalized to the edges of society. These deep psycho-social complications upon which each society's mental organization is based provide for the feelings of aversion and tension concerning anyone 'abnormal' or physically deformed. This is sometimes evident in instances where children first encounter someone who is physically 'different.' At first children may seem mesmerized and stare--not out of ignorance but out of sheer bewilderment at what they are observing. It is only by following their mother's or father's reprimand that the child's curious gaze is broken. Ostensibly, we, as a North American society, place extraordinary emphasis on physical appearance, a concept that is burgeoning and extremely prevalent in fashion magazines, television shows, and mass advertizing campaigns. Our appearances, especially

our faces, (in North American society) are perhaps the most important means upon which human communication is based. Thus, when our faces betray us in disfigurement our entire essence seems threatened, and anyone unfortunate enough to contract a disease such as leprosy is retaliated against by a fearful society that attempts to adjust to the situation accordingly. It feels the need to protect itself from contagious 'deviants' who pose a threat to the community in some way or another. The impetuses responsible for these moral ideologies sometimes have historical consequences. That leprosy was seen, as in medieval times, to be the personification of dirt, filth, uncleanness and poverty, is the result of historical forces having their roots in Biblical law.

It is in Levitical law that concepts of purification and cleanliness as they pertained to medieval society were propounded. To medieval man/woman, leprosy was a dreadful taint; it was the epitome of all that was unclean and undesirable and a horrible means to an end through complete segregation from society. It is in Leviticus 13: 44-46 that the best description of the metamorphoses of the leper from a normal citizen to a social pariah is found.

“Now whosoever shall be defiled with the leprosy, and is separated by the judgement of the priest, shall have his clothes hanging loose, his head bare, his mouth covered with a cloth, and he shall cry out that he is defiled and unclean. All the time that he is a leper and unclean, he shall dwell alone without the camp.”

(Brody 1974:60)

The aforementioned passage clearly denotes the austere social and moral consequences of leprosy as seen in Biblical and medieval times. As leprosy was seen to be some sort of sign from God, it was usually assumed that whoever received this sign was morally corrupt and in dire need of salvation. Whether that salvation was death or banishment was left for society to decide. Under the hegemony of the church, it was customary to banish any potential threat to society, thus lepers were either burned alive or in some cases banished to leper colonies to exist in a social purgatory.

The ritual based on Levitical law used in the banishment of medieval lepers consisted of allegorical acts symbolizing the lepers' death and rebirth, relegating him/her to eternal life far away from society. The priest--the connection between the leper and God--was given the right of examination of all lepers in his community. This was a problematic and thoroughly biased procedure as, irrespective of the actual diagnosis of leprosy, if the patient examined exhibited any signs of skin blemishes, he was immediately deemed a leper. Although the ritual of banishment differed from region to region within the Christian world, it retained the same characteristics in whichever medieval European country it was practiced. The ritual itself usually involved the leper, the community, the priest and the rest of the ecclesiastical body. The procedure consisted of the symbolic pouring of dirt (obtained from a church cemetery) onto the leper's head or any other part of his/her body as he/she knelt, adorned in a black veil and robe, at the altar. This act was symbolic of the leper's death and ultimate departure from society. Upon completion of the ceremony, the leper was prohibited from attending the church, market, or any

other place where he could endanger the rest of the faithful community (Brody 1974:66-67). Although purely hypothetical, I think it would suffice to add parenthetically to the concept on ritual that, according to Durkheim's functionalist notions on mechanical solidarity, that the ceremony used to banish the leper acted first as a means to protect the community from the leper; and second, to maintain group solidarity by means of latent levels in ritual function. According to Durkheim (1893), the latent functionalist use of ritual was used to sustain social solidarity, especially in times of social anomie. In turn, the ritual of banishment would not only rid society of the threat but also draw the community closer together, strengthening ties between people; however, historical catalysts in the form of religious doctrine are not the only means of generating stigma. As would appear likely, the methods of generating social and moral stigmas are culture-specific.

Although medieval European treatment of leprosy was prejudiced and harsh, the causal factor involved in its perpetuation was primarily religious ideology based on Biblical law. The picture of cause and effect regarding social stigma in different regions of the world is often quite different. For example, contemporary India's treatment of lepers bears striking resemblance to the medieval European method of treatment both in theory and practice. As in medieval Europe, India's caste system is based on hierarchy: If one contracts leprosy, regardless of social position, the unfortunate immediately drop to the status of pariah. The treatment of lepers adheres closely to the format of medieval banishment: whether by personal prerogative or blatant rejection from society, the leper is left with no choice

but to either admit him/herself to a leper hospital or manage life as a beggar on the street. According to Waxler, the primary catalyst invoking a sense of fear in Indian society is the fear of contagion. She describes contemporary accounts in India of people wearing handkerchiefs in front of their faces in order to protect themselves from contagion when in the presence of a leper (Waxler 1998:150). Before 1950, India passed laws similar to those of the Levitical law declaring that all lepers, regardless of level of infectiousness, be segregated, adding to the perpetuation of the leprosy stigma. Lepers were not allowed to inherit land, serve in the military, or to travel using normal modes of public transportation. Lepers in India were more easily rejected due to its caste system: justified by the ideology of impurity and sin, those of the upper classes were able to equate leprosy with the same notion of uncleanness and sin as was seen in medieval Europe (Waxler 1998:151). This reality is very similar to that faced by African-Americans in the United States during the 1950's and 1960's. The spread and perpetuation of almost any form of prejudice seems to have inherent psychosocial connections. It appears when someone is not like the collective whole, they possess an aura of danger somehow threatening the social whole with their presence alone. In defence, the society retaliates and does what it thinks is right-it has the potential threat removed. The prejudice against the African-American of the 1950's and 1960's seems to be, for the most part, based on the lingering concepts of 19th century biological determinism and the paradigm of unilinear evolution conceived by the anthropologist Lewis Henry Morgan. Although now seen as a naturalistic fallacy, the concept of biological determinism and racial hierarchies was

the impetus responsible for the spread and perpetuation of racism of African-Americans amongst minorities.

The Hawaiian epidemic of the 1850s and 1860's produced some differing moral and social results when compared with those of medieval Europe and India. At the time, native Hawaiians and white Americans alike believed that leprosy was a hereditary disease confined to the household and family, free of any religious association. Contrary to historical or religious ideologies responsible for the stigma of leprosy, the Hawaiian epidemic and its subsequent social backlash was based on socio-cultural, racial, and economic ideologies thought to be catalyzed by the immigration of Chinese wage labourers. During the height of Western imperialism, Hawaii experienced an economic boom which later brought in an influx of cheap Chinese wage labourers to man the thriving plantations (Gussow 1989:111). During the 1850's, Hawaiian authorities noticed a drastic increase in leprosy. By the early 1860's there was a major outbreak of the disease (Waxler 1998:151). Due to the influx of Chinese wage labourers and the subsequent outbreak of leprosy, native Hawaiians and white Americans could no longer put faith in the notion that leprosy was a hereditary condition (as it had been viewed previously). Belief in contagion became chief concern.

The marginalization of the Chinese was brought on by the fear of economic dominance coupled with the doctrines of 19th century biological determinism. These concepts acted as a safety net to cushion the Americans from the threat of economic takeover by the Chinese. According to the Americans the threats were evident: the Chinese were abundant in number, hard-working, industrious, and cheap to employ; this

spelled social anomie to Americans searching for a living during times of economic boom. Incidentally, American researchers found that the Chinese may not have been responsible for the transmission of leprosy to the native Hawaiians and Americans. The Chinese, irrespective of whether they were totally responsible for the leprosy outbreak, came to bear the full brunt of Hawaiian and American accusation. In essence, they became the ultimate scapegoats for the American's social and economic insecurities. It seems that the physical manifestation of leprosy itself was only a subtle variable in the interplay between social, cultural, and economic ideologies involved. The cause for the marginalization of the Chinese was two-fold: first, it gave the Americans the right to isolate and relegate the looming economic threat--the Chinese, and, second, it strengthened the racial ideologies of the time period, giving white Americans confirmation of the racial inferiority of the Chinese. The role of leprosy in this complex chain of events acted as a double-edged sword: First, stigmatizing both the Chinese for supposedly bringing leprosy to Hawaii, and second, the disease itself became stigmatized because it was highly prevalent among the Chinese (Waxler 1998:152).

The events of the Hawaiian leprosy outbreak in the latter half of the 19th century carried a different sense of stigma compared to the historical and religious connotations common to leprosy in medieval Europe or contemporary India. In the Hawaiian example it was the economic and social insecurities of the Americans that provided a milieu for the creation of a moral definition of leprosy.

Perhaps one of the more unique aspects of leprosy in attaining a specific

moral definition arose out of northern Tanzania. This is an instance of leprosy inadvertently attaining a stigmatizing moral definition by means of Western medical intervention from the west. Before the advent of Western medical intervention in Tanzania, leprosy received little stigma: lepers were assimilated in society as though they had not contracted the disease. Owing to vastly different religious, social, moral, and cultural systems, Tanzanian society viewed leprosy with little fear and rejection. It was not until the introduction of the *Geita Leprosy Scheme* in 1966 that the social climate of acceptance changed drastically. The task of the Scheme, according to Waxler (1998), was to focus not only on cases of leprosy and their treatment, but also on public education--aimed primarily at young school children from grades five through seven. A research survey completed in 1971 showed that the previous view of leprosy as a product of heredity or witchcraft had given way to the Western mode of thought: that leprosy was caused by certain bacteria and that transmission was achieved through bodily contact. Contrary to what Western medical practitioners had been advising--that there was no need to isolate patients from society given that certain modes of hygiene were carried out--the children acquired newly learned entirely different notions regarding the treatment and status of lepers. Waxler (1998) states that the children were diametrically opposed to the Western view of the assimilation of lepers. They believed that all leprosy patients should be segregated, not being able to intersperse, at any level, with non-infected patients.

In this instance, the previously held view of leprosy--that lepers be integrated and not separated from

society--was transformed directly and drastically by Western scientific medical intervention. The previous notion had been altered inadvertently from a state of tolerance to a state of stigmatization by means of a change in public attitude. This case displays how circumstances completely unrelated to religious, historical, or economic factors can influence the moral definition of a disease. In the aforementioned cases of leprosy in medieval Europe, India, and Hawaii, the moral definition and social stigma of the disease were inextricably linked with steadfast ideologies built primarily on historical, religious, and/or economic scaffolding. Western medical intervention in Northern Tanzania illustrates the fact that the social climate can be changed indirectly, even through benign forces: The status quo in this case was modified negatively by means of education. Instead of succeeding through education and focusing on a cure for leprosy, Western medical practitioners instilled a new climate of fear in the school children they were trying to reach. Where lepers were once accepted in the society, they are now seen--by the school children--as a potential threat of contagion. It seems leprosy sits atop a precarious social perch tottering back and forth through the winds of social, historical, economic, and religious influence. For the most part, depending on what social, historical, economic, and religious circumstances are influencing a particular society, the perception of leprosy is a provisional concept, subject to change with the vicissitudes of the social climate.

PERPETUATION OF THE MORAL
DEFINITION: THE PARADOX OF
INPATIENT LEPROSY ORGANIZATIONS

With the advent of modern technology, the progress and development of the health industry has wrought remarkable solutions to age-old medical quandaries. Although there is still no known cure for leprosy, an effective treatment, a sulphone, namely DDS (Dapsone) was found in 1908 by Fromm and Whittman of Freidburg University (Yawalkar 1968:80). Other drugs such as rifampine, clofasimine, and thalidomide are other drugs used to treat dapsone-resistant cases (Gorlier 1992). Perhaps one of the most pertinent questions regarding the spread and perpetuation of the moral definition and social stigma of leprosy is, why do people vehemently fear the disease? One would think with scientific advancement and the introduction of a viable treatment, the fear and stigma of the disease would subside. Unfortunately, this reality has not yet been attained. Paradoxically, of the causal factors contributing to the perpetuation of the moral definition and social stigma of leprosy, the most dominant contribution has been the leprosy organization, or the leprosarium. The leprosy organization takes in lepers the society in question does not want. As a means of providing care for them. As Waxler describes, these leprosy organizations are sometimes autonomous social units unto themselves, completely segregated from the uninfected, normal society:

"Inpatient facilities are often completely constrained villages providing not only treatment, but also employment, education, and recreation. There is often no need for a leprosy patient to leave this "asylum" and, in fact, it is sometimes physically difficult to do so because leprosy hospitals are

often found on islands...or in the remote countryside. "

(1998:155)

Unfortunately, this scenario is what perpetuates the stigmatization of leprosy. As it would seem, emphasis is placed on treatment and rehabilitation, rather than on education regarding prevention and reduction of stigma (Waxler 1998:155).

In order to obtain funding, leprosariums must implement a tactic directed toward charities emphasizing the threatening, disfiguring characteristics of leprosy. This invokes a certain sympathy which may appear to have its benefits: Philanthropists the world over, affected by the silent pleas of lepers seem to contribute extensive amounts of financial backing. The more leper hospitals receive funding, the longer they will exist, inadvertently perpetuating the stigma.

I think the current means of dealing with a disease such as leprosy is both problematic and backward. Segregation of any group within society not only insinuates to society that there is something wrong with the group being segregated, but also signals to the group--especially when they are placed in separate areas--that there is something wrong with themselves. To combat this disease effectively and thoroughly, emphasis must be directed from inpatient care (treatment and rehabilitation), to outpatient care. To attain a level in society where outpatient care is accepted, education must be foremost. When society is educated about the transmission of the disease dispelling all myths of contagion, it can attempt to keep hospital treatment at a minimum. Efficacy of treatment is based on keeping the patient at home with as little time spent away as possible. If this is

attained, then social restoration of the patient can be completely invalidated. Bryceson and Pfaltzgraff (1979) also add that the concept of early treatment rapidly reduces the level of infectivity so that transmission dissipates and ceases after a few months. If this is done, the home unit acts as a barrier providing what Bryceson and Pfaltzgraff (1979) call a "chemical isolation". Adhering to these suggested steps greatly reduces patient estrangement and allows the infected to carry on with social relationships uninterrupted. Regardless of the artillery of chemicals used in the fight against leprosy, a true and effective beginning should start with widespread education and understanding. Although this concept appears to be an ivory tower considering the seemingly inexorable state of affairs regarding cultural, social, religious, economic, and historical constructs, this type of design is possible with planning, effort, and perseverance.

INFERENCE: DISCLOSING THE MISUNDERSTOOD CHIMERA

Within the dynamic interplay of social variables regarding leprosy, it has been demonstrated that the disease, as deforming as it may be, is only mildly communicable and really not a threat to any society as long as proper hygienic precautions are followed. The salient factors contributing to the moral definition and social stigma of leprosy are deeply rooted in historical, religious, cultural, social, and economic systems inherent in society. In this essay, I have delineated the pertinent physical and social issues of leprosy, ranging from the bacillus thought to cause leprosy, to gross and micro-anatomic (histo/cytopathological) complications. At the beginning of the essay, I generated

specific questions such as: Is leprosy universally stigmatized? What factors allow for the creation of the leprosy stigma? Do all cultures treat leprosy the same way? The answers to these questions remain varied and complex. I have pointed out that the social stigma attached to leprosy arises from particular historical, religious, cultural, and social issues peculiar to each society. This was illustrated in examples from medieval Europe, where particular historical and religious factors--specifically Levitical law--played the major role in the moral definition and social stigmatization of the disease. In India, particular cultural and social factors helped define and maintain the moral definition and stigmatization of lepers. In Hawaii, it was the particular economic, political, and racial milieu which provoked the stigmatization of the Chinese--whether they were responsible for bringing leprosy to Hawaii or not. In Tanzania, it was the implementation of an educational program designed to combat leprosy which inadvertently perpetuated the stigma. By surveying these particular cases, I have been able to discern that the moral definition and social stigma of leprosy is unique and particular to each society. I have also attempted to show why and how the moral definition and social stigma is perpetuated through the paradoxical concept of leprosy organizations.

It would appear that to alleviate the social taint associated with leprosy, concentration must be placed on the particular ethnographies of each society in question. Hopefully, the inclusion of education will clear society of its remaining ethnocentric conceptions. A fundamental factor in the perpetuation of the leprosy-stigma is the existence of the leprosarium. This contributes to the segregation of members of society, forcing both patient and society to view

leprosy as a major physical and social dilemma. If inpatient care can be transformed into an effective version of outpatient care with the infected remaining at home, the disease can then be viewed on an individualized basis, rather than on a generalized, biased one.

Giving leprosy an individual face, instead of viewing it as an anonymous scourge, should eventually dissolve the cultural, social, religious, economic, and historic barriers time and society have constructed, providing non-infected patients with needed insight and understanding into such a misunderstood disease.

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