

Following Stigma and Segregation of Individuals Afflicted with Lepromatous Leprosy

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Abstract

Modern Western society tells a tale of fear and exclusion of individuals with leprosy on a global scale, yet case studies from across the globe tell a tale of compassion, not of stigmatization. The effects of leprosy can be crippling and cause disfigurement, and many cultures had their own beliefs associated with the disease. In the 19th century a rise in the prevalence of leprosy incited fear in the population and historical methods of treatment were sought, namely *Leprosaria*. In this case fear of contracting this disfiguring disease cultivated a repulsion from those affected. Originally, *Leprosaria* were founded because it was believed that those who had contracted the disease had sinned, and through living a life of piety would be redeemed. Modern Western society believed that this had inadvertently helped to isolate the contagious disease. The model was mimicked but isolation and segregation were forced, propagated by the idea that this was the method to which all afflicted populations had eventually turned, finding no effective alternative. Archaeological and ethnographic accounts from Japan, India, and Europe, demonstrate that in most cases, segregation was not a method practiced, and when it occurred it was through individual choice; many infected individuals chose to remain with their families and communities until death.

Introduction

Leprosy, now known as Hansen's disease, is associated with social stigma, fear, and hatred in both life and death. Visceral reactions occur to the disfigurement and effects of this disease and its slow and prolonged progression. This is a disease present in the Old World (Asia, Africa, and Europe) at least since the rise of urbanization. It has spread to all parts of

the world and continues to persist in certain regions. My query is when the stigma that is so commonly associated with lepers and leprosy in modern Western society (Europe and North America) originally arose. Is it possible to assess social marginalization or ostracism through burials and archaeological remains? In many cases, what could be perceived as evidence of discrimination

could in fact be much more complex. The case of leprosy throughout human history illustrates this very well, in finding both normal and abnormal burial practices of individuals with the disease. Through an understanding of the diseases effects, archaeological findings, and the visible changes in perception it can be hoped to gain a better understanding of the opprobrium associated with the disease, and of the human ability for compassion.

The first section will discuss limitations, the second section will introduce the bacterium that causes leprosy, and will be followed by terminology. The fourth section discusses what social stigmatization of leprous individuals was believed to look like. Then the pathologies found in archaeological remains of leprous individuals and leprosy's physical manifestations will be discussed, and how it has been determined if an individual lived with leprosy. Then specific archaeological examples from Western and Eastern contexts will be examined in order to ascertain if the modern Western belief that leprosy is a globally stigmatized disease holds any truth. How these modern Western beliefs came to existence will lead into the conclusion on whether leprosy holds social stigma on a global scale.

Limitations

A limitation that I faced in conducting this research was access to sources I wished to consult. Some limitations were due to the limits of the University of Manitoba's library resources for undergraduates, such as F.O. Touati's influential works, cited in the work of Brenner (2010), Roffey and

Tucker (2012), and Rawcliffe (2006), which revised the ideas on stigma associated with medieval lepers. Further, research conducted in other countries was often published in the national language, and has yet to be translated into English, such as further information on the peculiar Nabe-kaburi burials from Japan to be discussed later (Suzuki et al. 2014).

As well, the query in itself has limits to what it can achieve. Today there are a multitude of feelings and attitudes towards leprosy, individuals have different reactions and the same scope and complexity can be thought to have occurred in the past. Attempting to understand the complexity of this issue historically through an assemblage of archaeological sources and historical references can only be reflective of a small portion of the ideas and practices that occurred and are subject to individual interpretation. The archaeological data gathered cannot ascertain the nuances of an individual's everyday life. Bioarchaeological examinations are largely limited to qualitative data and cannot produce verifiable qualitative data.

For example in isotopic analysis diet can be ascertained, but not the quality and freshness of the food when consumed, which could be affected by stigma; food may have been given to individuals with leprosy only after it was no longer suitable or desirable for others to eat (Linderholm and Kjellström 2011). Further, the bones and burials themselves, while being a large source of information, may also pose many limitations. The osteological paradox comes to mind when assessing the apparently healthy skeletons from numerous leprosaria (Wood et al. 1992). Were a number of the individuals interred

at the cemetery of the hospital at Chichester, England healthy as it would appear from their bones (Lee and Magilton 1989), or were they weak and the disease caused their death so quickly that osteological changes did not have the time necessary to occur? Empirical evidence from DNA analysis has proved useful in positively identifying suspected victims of *Mycobacterium leprae* (Suzuki et al. 2010). However, to do such an analysis on all skeletal material would be costly, both in time and money, as well as destructive.

Finally excavations of burial sites are often only partial excavations, and can give only a glimpse into the data that may be available; this could easily produce sample biases. For example, the study by Lee and Magilton (1989:275) demonstrates this possibility as the hospital cemetery that was excavated extends at least beneath the modern road, and perhaps even further north. Further, as my research occurs through secondary sources, I only have access to data that has been excavated and published on, and the data is presented in a manner that may limit or aid in my research efforts.

Overview of *Mycobacterium leprae*

Leprosy, or Hansen's disease, is caused by a pathogen called *Mycobacterium Leprae*, which has affected human populations for at least 4,000 years (Maiden, 2009). This is confirmed through archaeological evidence from an ancient skeleton from India, which dates to 2,000 BCE, which shows pathology consistent with a diagnosis of leprosy (Robbins et al. 2009). This disease may have affected populations for generations before that, as

the speculated origin of *M. leprae* is approximately 40,000 years ago (Robbins et al. 2009:6). Skeletal manifestations of a more ancient origin may be found in future excavations.

The bacillus has a single clone origin, as suggested through analysis of the genome which has observed nearly identical strains in numerous location across the globe, although it was possible to classify these into four types (Maiden 2009, Suzuki et al. 2010, Grimm 2005). The current theory, based on the large portion of inactive genes in the chromosome of the bacillus, is that *M. leprae* underwent extreme evolutionary selection, and is the outcome of bottleneck selection and reductive evolution (Maiden, 2009:1265). The gene decay present has caused leprosy to be an almost uniquely human disease, and the only other organism to-date who has been found to be susceptible is the nine-banded armadillo (Maiden 2009:1265). Regardless of the endemic presence of this disease over the course of human history, research on *M. leprae* has been difficult and requires much persistence. The bacillus reproduces slowly and resists artificial cultivation, hampering our understanding of the disease's aetiology (Maiden 2009).

Terminology

The terms "leprosy" and "leper" are controversial today, as the opprobrium associated with this disease in a time of misunderstanding continues to exist today. This has resulted in the disease being renamed "Hansen's Disease" in order to free contemporary sufferers from such negative connotations (White 2005:318). Leprosy refers to the chronic

infection caused by *M. leprae*, and the term “leper” refers to individuals who were afflicted with leprosy during the medieval period. My choice in using these terms is influenced by my desire to include and understand the origins of this stigma as well as my desire to maintain a tie to the history of the disease. Using these terms maintains these metaphorical associations, and in re-examining historical attitudes can perhaps influence contemporary responses to such terms. In some cases, the terms “leper” and “Hansen’s disease” have become associated, bringing the prejudices of the past into the present. As stated by White (2005:318) “if popular meanings of *hanseníase* reproduce those of *lepra*, the name shift could be rendered irrelevant.”

The Latin term “*lepra*” resulted from a translation of the Hebrew “*Zara’at*,” a word for skin diseases found in the Bible, and originally was similarly used for skin disorders which “turned the skin rough, scaly, or flaky” (Brenner 2010:390). The definition of leprosy did not become solidified until later, with translations from Greek and Arabic medical texts dating to the 11th and 12th centuries CE (Brenner 2010:390). Rawcliffe makes the valid point that, even with the medical diagnosis, in medieval times there were “many leprosy: of bodies and souls, of saints and sinners, of men and metals, of animals and plants” (2006:43). Because this is a study of a disease’s history, any sources from the past must take into account the variety of meaning ascribed to the term. Stripping the term from the disease can only serve as a limit to our knowledge and understanding, as the knowledge contemporary western biomedicine offers often does not reflect

historical interpretation of disease causation.

Stigma Associated with Leprosy

It has long been believed by the general population, myself included, that leprosy is a disease that carries the heavy baggage of social stigma, fear, hatred, and misunderstanding wherever it is found. Terms such as the “living dead”, and depictions like Richard Cooper’s painting “Medieval villagers scrambling to get away from a leper” (as seen in Rawcliffe 2006:15) aid the propagation of such ideas. Alongside these reports there are various pieces of literature that vilify lepers, or potentially fabricate rituals of separation and social death associated with the contraction of such a disease (such as the “Leper Mass” so willingly quoted by Covey [2001:318] which is of a questionable source [Rawcliffe 2006: 20]). This propaganda on the social prejudice and cost of this disease has likely only aided in creating more fear of infection among the population.

This disease was not feared and dreaded because it was fatal, but more likely, because it was not. Fear of the effects of this disease, which is amongst the most crippling and potentially is the most physically disfiguring infectious disease, is a large contributor to the stigma associated with leprosy. This infection could persist for the remainder of the individuals’ life, becoming more debilitating and disfiguring as the infection progressed, with no known cure until the 1940s (Sato and Narita 2003). For some with a stronger immune response the infection would be paucibacillary and could be limited to a small lesion.

Due to these factors, leper-houses or *leprosaria* were believed to be places of isolation for the victims of leprosy. These individuals may have been thought of as “unclean” or “untrustworthy” and were seen as evident of divine punishment for sin, and served to remind others to live a life free of sin (Covey 2001:320). *Leprosaria* were also cited in the 19th century as the only effective management of the disease, and were ascribed with the decline in leprosy seen in the 14th century in Europe (Rawcliffe 2006:13), which aided in justifying isolation practices at the end of the 19th century when a rise in the prevalence of leprosy occurred. Recent research on medieval *leprosaria* has shown that this degree of ostracism and fear, which we associate with poor medieval sufferers, may in fact be a much more recent development, occurring most acutely in the colonial era. The segregation policies while at first were voluntary, later became enforced, and forcible separation from society occurred in many places, and rewards were even offered to those who brought a leper in (Small 2009:36).

Palaeopathology of Leprosy

There are several characteristic lesions that occur in the skeleton that can be used to diagnose multibacillary leprosy. Unfortunately paucibacillary leprosy does not often have these characteristic lesions and the effects on a skeleton may be overlooked or similar to other pathologies and therefore incapable of producing a positive diagnosis. When contact with *M. leprae* occurs, there is a significant amount of variation in individual reactions that depend on the immune responses to the

assault (Gilmore 2008:73). The paucibacillary form, also known as tuberculoid leprosy, occurs when there is a strong immunological response, and does not have the same devastating and disfiguring effects on the body as the multibacillary, or lepromatous, form may have, in which the bacillus encounters little to no immunological reaction (Gilmore 2008:73). The multibacillary form, if left untreated, can lead to loss of sensation that may result in lesions subject to secondary infection (Gilmore 2008:73).

Multibacillary Leprosy

The most characteristic features of multibacillary leprosy involve the rounding and abnormal enlargement of nasal aperture, disappearance of anterior nasal spine, and antemortem resorption of the alveolar process of the maxillae (Suzuki et al. 2010:3). Degenerative and reactive changes on the palatal process are also descriptive of the disease process, and these rhino-maxillary changes are exclusive to the lepromatous or near lepromatous forms (Mariotti et al. 2005:213). Further elements that can aid in the diagnosis of lepromatous leprosy involve periostitic changes of tibia and fibula (Suzuki et al. 2010), and “resorptive changes to phalanges, metatarsophalangeal joints, diaphyseal remodelling, cupping and remodelling of the joints” (Mariotti et al. 2005:313). Another element useful in diagnosis (if preserved) would be in changes to the hyoid, as leprosy often causes lesions of the larynx; Gilmore (2008:82) observed skeletal changes in 36.6% of untreated multibacillary cases to the hyoid as well as to the 3rd through 6th cervical vertebrae.

Archaeological Examinations and Consideration

Through an examination of knowledge garnered from archaeological excavations, it is possible to illuminate some of the intriguing and varied social reactions to this almost uniquely human disease. Beginning with the suspected area of origin and moving onwards to various periods and regions, the stigma associated with this disease throughout history is blurred and questionable, until modern times.

India

The earliest archaeological evidence of multibacillary leprosy comes from the suspected area in which *M. leprae* originated, India. The individual found is a male approximately 37 +/- 5 years of age, and dates to approximately 2000 BCE (Robbins et al. 2009). The skull of this individual exhibits all the diagnostic criteria of lepromatous leprosy. Antemortem tooth loss, remodelling of the alveolar process of the maxillae and of the nasal aperture and pitting in the palatine process are all easily observable and support a diagnosis of multibacillary leprosy (Robbins et al. 2009). This adult was found in a flexed position inside a stone enclosure and was buried in vitrified ash from cow dung, which may be from funerary rites (Robbins et al. 2009).

The remains were found in northwest India, and the presence of new pottery styles and monumental architecture suggest this large settlement was in contact with the Indus civilization (Robbins et al. 2009). This connection could explain the abnormal presence of an

adult burial; in Vedic tradition (originating with the Indus civilization), cremation of the bodies of individuals with leprosy was not practiced, as their bodies were not considered appropriate offerings to the Hindu Gods. Individuals afflicted with leprosy were buried, and occasionally buried alive in parts of India (Robbins et al. 2009). Given this information with no further research into the cultural context, it would be simple to identify this case not only as the earliest evidence of lepromatous leprosy, but also as the earliest case exemplifying stigmatization of an individual with leprosy through the denial of normal burial practices to the deceased, or even murder in cases where an individual is buried alive.

Looking at an ethnographic account dating from 1869, by A. Campbell, we can perhaps understand this not as an inhumane act, but one of compassion. The individual who was afflicted with leprosy, when feeling that their decaying state was too much of a burden on relatives and friends “expresses a desire to bury himself alive” (Campbell 1869:195). The relatives who care for the sufferer would try to discourage this thought, until eventually, they would agree. Once the relatives acquiesced the request, a funerary rite appears to have commenced, the entirety of the village may present themselves, a pit was dug, which the leper voluntarily entered, then the individual's friends proceed to bury him or her, and finally a few days later opium water was shared at the home of the deceased (Campbell 1869). Considering the individuals probable knowledge, due to the endemic presence of this disease in India, of the abysmal existence of a leper once the

disease progressed to a significant extent, requiring aid with quotidian activities such as feeding, bathing, and dressing, this practice seems analogous to contemporary practice of euthanasia, in which a suffering individual may ask for aid in ending their life if they lack the ability to do so themselves. Although this practice is not without controversy, it can be viewed as a method of harm reduction.

Campbell's (1869) account is extremely ethnocentric in this regard, and does not take into account the societies desires and customs, which may hold meaning and provide purpose to the leprosy sufferers. For example, Purein Singh, an individual with leprosy, was voluntarily burnt to death in 1866 (Campbell 1868:196). When an individual with leprosy was burnt to death, it was believed to provide safety to their entire family from the infection, and so Purein Singh may have honourably sacrificed himself for the sake of his kin, whereas Campbell (1869) portrays the family's aid in his death as a terrible crime that became punishable by law.

Japan: "Nabe-kaburi"

Nabe-kaburi burials from the 15th to the 19th centuries found in Japan translate to "pot – put on", and are very descriptive of what these burials entail; an individual is buried with a pot of iron or of mortar over their heads, for some yet to be determined reason (Suzuki et al. 2014:1). There are 105 burials of this type found to date, and 5 out of 21 skeletons examined displayed pathologies consistent with leprosy (Suzuki et al. 2014). Suzuki and colleagues (2014) noted similarities between the *Nabe-kaburi* burials and leprosy patient burials, and believe their study can shed light on social discrimination from the

Late Middle Ages. The meaning of the pots covering the heads is speculative, but it has been hypothesized that it offered a form of protection for the living from the leprosy individuals.

Individuals from *Nabe-kaburi* burials from two sites were analysed, two from "Tawara-ga-yatsu" and one from "Usukobo", both sites dating to the 18th century CE (Suzuki et al. 2014). The individual TK5 from "Tawara-ga-yatsu" was buried with two iron pots and one mortar pot covering his head as well as some currency and three glass beads, and the head of individual TK6 was covered with one iron pot, while a mortar pot covered his feet, he had five pieces of currency, and also displayed skeletal lesions characteristic of leprosy (Suzuki et al. 2014). At the "Usukobo" site, individual K48 was examined; buried in a bent position, with an iron pot on the head, and containing a smaller iron pot, a pipe, and an iron tablet, this skeleton also showed skeletal changes characteristic of leprosy (Suzuki et al. 2014). DNA analysis confirmed the presence of *M. leprae* in both individuals showing osteological evidence for leprosy, and returned negative results for individual TK5, who did not display skeletal lesions associated with leprosy (Suzuki et al. 2014), indicating these burials occurred not only in leprosy patients, but also in a broader range of the society.

According to Suzuki et al. (2014) there are two hypotheses in circulation on the meaning of these burials. One hypothesis is that these pots were a burial method to block disease. The second hypothesis is that these individuals died during a three-day ceremony for the ancestors to return. The ancestors would find this rude and

would have beaten their heads if they encountered them on the passage between worlds and so the pots were used to protect the deceased (Suzuki et al. 2014:1).

Suzuki et al. (2014) also note the grave goods in these burials are similar to those found in common cemeteries, and these burials are often found with ceremonial devices used for cleansing the spirit and offering salvation in the case of an unusual death. Further, these individuals were buried with valuable items, such as the iron pots, provided with currency (possibly for the passage to heaven), and lived long enough to develop palaeopathologies indicative of leprosy, suggesting palliative care (Suzuki et al. 2014). The only difference in the burial treatment of these individuals from the burial treatment of others is the “*Nabe*” on their heads (Suzuki et al. 2014:7). Further these theories are not mutually exclusive, as an individual afflicted with leprosy could pass away at any given time. If the prevalence of leprosy was high in this population a number of individuals may display skeletal markers, yet could have lived without social stigma. Cross-examination of all *Nabe-kaburi* burials with non-*Nabe-kaburi* burials is a future research area that would help elucidate this burial method’s meaning.

Europe

There is speculation that a skeleton dating to approximately 2000 BCE from Scotland had leprosy, due to changes in the rhino-maxillary region (Roberts 2007). This would stimulate a change in the believed spread of the disease to Europe, currently held to be approximately 4th century BCE (Mariotti et al. 2005). Although DNA analysis has proved inconclusive, the suggestion that this disease has been

present for millennia in Europe without stigma evident in burials can be insightful. This may reveal that it may not have been due to the increased prevalence of the disease, but because of migrations of peoples and their beliefs.

The earliest palaeopathology with a determined diagnosis of leprosy in Europe is from Italy, and is found in a skeleton dating to the 4th century BCE, which is consistent with the current stance on the spread of the disease (Mariotti et al. 2005:321). The skeleton displays lesions and bone remodelling in the metatarsals, and reduction in their medio-lateral diameters, the tibia and fibula show signs of periostitis, and the hands show features which indicate hyperflexion, all of which are usual manifestations of leprosy (Mariotti et al. 2005:314-316). Some other typical manifestations of leprosy are not present, such as the resorption of the anterior nasal spine and of the alveolar process of the maxillae, but the palatine process does show pitting and porosity, which is equally if not more important, in the diagnosis of leprosy (Mariotti et al. 2005). Mariotti et al. (2005) stated the intent to obtain DNA from the remains, which would determine without doubt if the individual had leprosy, and which could also uncover the type of leprosy. Currently no further articles have been published on this specimen, which would help to elucidate the spread of the disease.

This burial is the same orientation, and placement as the other burials of the period, and thus at such a point in time, perhaps at the point of introduction of the disease into Europe, no prejudice or spatial segregation can be seen (Mariotti et al. 2003). The conclusions drawn from the early burials conducted by Mariotti et

al. (2003) is mirrored in the findings of the research conducted by D.A. Lunt (2013) on two individuals from Scotland dating from 600-1100CE, which show evidence for leprosy, but no spatial segregation. These individuals are found in cemeteries for the general public, and are actually located at the centre of an area in the graveyard showing “the most careful arrangement of the graves” (Lunt 2013:317). Lunt (2013) states that the Scottish burials are similar to the majority of archaeological data from Britain, where most skeletons diagnosed with leprosy are buried in contextually normal settings. While literature on leprosy burials in “normal” cemeteries in England is difficult to locate, there are many leprosaria cemeteries that contain a high percentage of apparently healthy individuals (Lee and Magilton 1989), and there is no spatial segregation of leprosy sufferers in England at Blackfriars Friary, Ipswich (Mays 2009).

Mays (2009) speculates that in some cases, due to familial relations, the custom of burying leprous individuals in leprosy hospital cemeteries could be disregarded. This is based on a rare genetic scapula anomaly found in two lay burials within Blackfriars Friary, one of which showed leprous lesions, involving changes to the rhino-maxillary, region, the tarsals, the fibula and the tibia (Mays 2009). The religious order is dependent on donations to maintain function, and so Mays (2009) believes that if a benefactor relationship would be sacrificed, the custom could be overlooked. According to the data published in Mays’ (2009) study, another 4 cases of leprosy are present in the burials of this friary. It seems that Mays (2009) did not take into account the importance that leprosaria placed on religion and

piety, such that if an individual became afflicted with leprosy while leading a religious life, it may have been deemed unnecessary to relocate them from their brethren (Rawcliffe 2006:254-256). The foundation of leprosaria was influenced by beliefs that the afflicted had sinned, and the physical illness represented an ailment of the soul, and therefore could be seen as important sites of conversion (Brenner 2010). Rawcliffe (2006:264) mentions the religious devotion necessary to maintain residence at such institutions, and states, “far from attempting to detain unwilling or difficult residents, most leprosaria had always moved quickly to evict possible troublemakers”.

The medieval hospital and cemetery of St Mary Magdalene, at Winchester in England, shows the almost exclusive presence of lepers. Roffey and Tucker (2012) argue that this was not a practice of exclusion, but an example of sufferers wishing to pursue religious vocation being provided with a place to do so, which also provided the necessary care. The individual most afflicted with the disease was an adult male, between 26-35 years of age, who would have needed daily care with feeding, dressing and bathing due to the extreme progression of lepromatous leprosy (Roffey and Tucker 2012). The burials in the cemetery of this hospital, dating as early as 1066 CE, are carefully laid out, with anthropomorphic graves, similar to those seen in high-status ecclesiastical sites, and there is a broad distribution of age along with the presence of both sexes (Roffey and Tucker 2012). There is also the burial of a pilgrim present in this cemetery, demonstrating further that this was a religious site of some importance (Roffey and Tucker

2012).

While burials in “normal” cemeteries in England may be difficult to locate, there was a study conducted in Odense, Denmark that shows many burials of individuals with leprosy alongside healthy individuals (Boldsen and Mollerup 2006). The prevalence of leprosy lesions in ordinary cemeteries ranges from 14-17% before 1400 CE, after which rates decline (2006). The researchers suggest that segregation did take place, as well as discrimination, based on the separation of the individuals with the most advanced facial lesions to the *leprosarium* (2006). This is based on the foundation of the *leprosarium* between 1270 and 1280 CE, the high prevalence of leprosy present in its cemetery (95%), and the following decline in leprosy burials in normal cemeteries, although this also coincides with a decline in the prevalence of leprosy in the population (2006). While this may be a factor of segregation, it may also be a question of care, and the quantitative data provided by these burial locations does not provide the qualitative data that the study by Roffey and Tucker (2012) provides. A study focused on using qualitative data in this location may show that those with facial lesions were those most in need of care, and therefore housing within the *leprosarium*.

In Sigtuna, Sweden, Anna Linderholm and Anna Kjellström (2011) conducted an isotopic analysis of 6 individual skeletons showing evidence of leprosy in their remains. These individuals were buried at the periphery of the churchyard and thus are believed to be of a lower social stratum (Linderholm and Kjellström 2011). Linderholm and Kjellström (2011) proceed to contrast the data obtained from these

individuals with data obtained from an isotopic analysis of 19 other human skeletons from the same cemetery, but located closer to the church, to test the notion that these individuals were treated differently in life as well as death, in this known stratified society. The data obtained indicates that all of these individuals had the same diet, even though the leprosy individuals were buried at the periphery of the churchyard, a place reserved for the low status individuals (Linderholm and Kjellström 2011).

In this case, the burial place is not reflective of the deceased's life, as we would expect to see differences in the diet if these individuals were social pariahs, although quality and freshness of the food eaten cannot be assessed. There is mention of burial regulations, and a law assigning areas farthest from the church for the burial for the poor and outcast (Linderholm and Kjellström 2011:925). This is the cause for the spatial segregation, which may simply be due to reserving the areas closest to the church for those who are more likely to be, or to become, benefactors. This law has no bearing on the life of these individuals, and they were cared for long enough to develop skeletal lesions, perhaps by the church, perhaps by family, or perhaps by the community.

Summary

These cases all illustrate the need to understand more than the spatial arrangement of a cemetery, which may or may not be indicative of the life of the individual. Spatial segregation in burial practices can express social segregation, but practices vary in different regions. There is no clear universal way in which leprosy was treated, and no clear signs

that stigma was associated with it in all cases. In order to attempt to understand the complex emotions this disease could produce, it is necessary to take many instances into account, and gain as much knowledge as possible from the burial itself, to the biological remains, to the institutions available to provide care, and to generally held beliefs of the societies. These can raise more questions than answers, but in due time these questions may be resolved.

The two similarities which I can garner from many of these cases seems to be: a general fear of contracting the disfiguring disease, as seen in the use of pots to cover the head of the afflicted in Japan, and the sacrificial actions of individuals in India; and the huge amount of human compassion expressed through the care and evidenced by the skeletal lesions on the unfortunate individuals. The evidence here is at odds with the expectations I had on the treatment of these individuals, and still leaves my initial query, when the stigma associated with leprosy arose, largely unanswered. In order to answer this question it is necessary to look at what Roffey and Tucker call a “*Victorian biomedical and segregationist agenda*” (2012:178).

19th Century Fabrication of History

“Who controls the past controls the future: who controls the present controls the past”

-George Orwell (Rawcliffe 2006:27).

The above quote by George Orwell is a brief analogy of what happened to the history of leprosy in the 19th century. Fears

of contagion and contraction of the disease spread throughout Europe with new incidences occurring, likely due to colonization (Rawcliffe 2006). Some argued that only certain people were susceptible to the disease, and isolation during the middle ages had accidentally eliminated a “race of lepers” (Rawcliffe 2006:19), others felt that environmental factors had a large role, highlighting the “less civilized” areas of the world as areas in which leprosy could thrive, while religious factions seized the opportunity to obtain converts.

This mass of fear and confusion was solidified into a decision for the confinement of lepers due to three circumstances. The prevalence reached 54/10000, the discovery of *Mycobacterium leprae* by Armauer Hansen in 1873, and the death of Father Damien who was living amongst a group of lepers in Hawaii, and thus confirming it’s contagion (Jacob and Franco-Paredes 2008; Small 2009). The idea that in the medieval period people had reduced the prevalence of leprosy through isolating the lepers was propagated in pieces such as that written in 1897 by Albert S. Ashmead, titled “Leprosy over-come by Isolation in the Middle Ages” (Rawcliffe 2006:13).

These ideas and misinformation created a push in which lepers were isolated and segregated in a more severe manner than ever seen before, as seen in the leper colonies in Canada and the United States. In Canada, blatant racism was exerted as Chinese immigrants who contracted the disease were quarantined to D’Arcy Island, given food, shelter, and coffins and left on the island for the remainder of their lives with no health care or ability to contact their families

(Small 2009). In the US, the national leprosarium at Carville was initially run more like a penal colony than a health care facility, and individuals were often collected and forcibly removed from society (Rawcliffe 2006:27). The extreme fear of contagion persisted, even though this is not a highly contagious disease, until the 1940s when a cure was found. It was not until much later that many countries changed their policies and closed their leprosarium (Sato and Narita 2003).

Conclusion

The history of leprosy was almost certainly rewritten for a majority of countries and cultures, and in order to fully understand the history of leprosy it is almost necessary to again rewrite its tale. Archaeological examinations showing individuals with pathologies associated with leprosy often are not spatially segregated or isolated, as was expected from reports such as Manchester and Roberts' (1989:267) which states that "the afflicted were segregated in life and death". Fear of the disease has been present for much of its existence, as seen in superstitions about prevention, such as living a life free of sin, placing a pot over the head of the deceased, or self-sacrifice to shelter loved ones... But, compassion, care and provision were given to individuals suffering from the disease, and only in the colonial era, when fear fostered by propaganda and spread through colonization, were strict segregation and practices of isolation put into place. Through understanding the diseases effects, examining the archaeological

findings and changes in perception, a better understanding of the origins of the disease and the associated stigma can be gathered into a multifaceted tale, dispelling simplistic ideas of visceral reactions and hatred.

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