Leprosy or Hansen's Disease?

On the Importance of Terminology for the Study of Disease in the Past

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1.0 Introduction

A tension has always existed when trying to understand the past from the present, as we can never truly understand any time period other than the one we are currently experiencing. The aim of the disciplines of history and archaeology is to work through this tension in order to shed light on and articulate the experiences and events of the past. But how do we lend words to a long silent past? And does it matter what concepts we choose? The study of disease is a particularly interesting area in this regard as it can involve an overlap between these two disciplines, which exposes the inherent struggles of navigating the past and present ideas of disease. This thesis draws on elements from discourse analysis (described in more detail in Section 2) to provide a framework to talk about: (1) the tension surrounding concepts of disease between the past and present, and (2) the importance of terminology in addressing and easing this tension within the scholarship on disease. Due to its long and complex history, leprosy, currently also known as Hansen's disease, is an effective subject with which to explore these two concepts.

For the first part of this thesis (Sections 3 to 6), I explore how ideas surrounding leprosy have changed over time, and emphasize how past notions of leprosy are not equatable to what we know today as Hansen's disease. I do this by contrasting what I describe as the "medieval discourse" and the "modern discourse" of leprosy. Introducing the medieval discourse involves giving a preliminary overview of the history of leprosy from its ancient roots until the medieval period, focusing on different forms of the discourse surrounding leprosy (including the Ancient East, Middle East, Western Europe, and Medieval England). I then contrast this against the modern discourse, which includes a brief summary of the discovery of Hansen's disease and its physical expression. I consider the recent history of the disease from the past century, with the aim to shed light on the continued stigmatization experienced by its sufferers. By contrasting these two discourses, it becomes clear that the complex socio-cultural aspects of medieval leprosy differ greatly from the modern biological understanding of the disease.

The second part of this thesis (Sections 7 to 9) will examine the language and terminology used in the academic discourse of medieval leprosy, which in this case will consist of both an "archaeological discourse" and a "historical discourse". It addresses some of the

issues with the current scholarship, and how there has been little sustained effort in distinguishing between the concepts of "leprosy" and "Hansen's disease", which I will show are not necessarily the same. It is inherently problematic to apply the term "Hansen's disease" to discussions of leprosy from the medieval period, as the concept of "Hansen's disease" did not exist before 1879, with the discovery of the mycobacterium causing the disease. When discussing the experiences of people who lived in the period before this official discovery, I argue that it is more accurate to use the term "leprosy". This stems from the notion that "leprosy", as a historically contingent concept, is more closely aligned with the past discourses surrounding this disease.

I will also examine the broader implications for how terminology choice impacts the effectiveness of academic discussion when studying other diseases in the past (Section 10). I will do this by briefly examining the history of tuberculosis, in order to demonstrate that the challenges involved in studying diseases over time is not restricted to leprosy. I consider as well whether the inconsistent ways in which scholars interchange "leprosy" and "Hansen's disease" has meant that the longstanding stigma and discrimination that was historically associated with this disease persists to this day (Section 11). I argue against the continued use of the terms "leper" and "leprosy" when referencing modern sufferers of the disease, as it plays a role in perpetuating this stigmatization. Ultimately, the aim of the second part of this thesis is to provide a platform for a critical discussion over the terminology used both in the academic and popular discourses. By providing new guidelines for terminology usage, it should be possible to both clarify how the disease is discussed academically in historical contexts, as well as to alter how this disease is experienced today.

2.0 What is Discourse Analysis?

> Discourse in this sense is not an ideal, timeless form […] it is, from beginning to end, historical – a fragment of history […] posing its own limits, its divisions, its transformations, the specific modes of its temporality.[1] — Michel Foucault

In order to use discourse analysis as a framework for this thesis, it is first necessary to explain the concept of "discourse", and outline the two main theories that I draw from. Simply put, "Discourse is a form of social action that plays a part in producing the social world – including knowledge, identities and social relations – and thereby in maintaining specific social patterns."[2] In other words, a discourse is created as a way to understand and categorize our experiences and the patterns we see within the social world. It is challenging to offer a narrow definition of discourse because an integral part of the idea is that it has to be agreed upon by those who are using the term, so in that way there are many different discourses within discourse theory. Despite the many different theories used within the field of discourse analysis, this thesis will be drawing mainly from Discourse Theory by Laclau and Mouffe[3] and will also bring in some concepts from Critical Discourse Analysis by Fairclough.[4]

The field of discourse analysis is relatively fluid, in part to reflect the complex and ever-changing nature of discourses, and one of the main reasons that I use discourse analysis as a methodology in this thesis is because it allows for a loose theoretical framework which includes the combined use of aspects from different discourse theories.[5] To this point, one of the clear distinctions between Laclau and Mouffe's Discourse Theory and Fairclough's Critical Discourse Analysis is that Discourse Theory allows for the examination of discourses as *socially constructed* concepts, while Critical Discourse Analysis is more focused on *textually produced* discourses.

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[1] Foucault, Michel. *The Archaeology of Knowledge*. London: Routledge, 1972, 117.

[2] Jørgensen, Marianne W, and Louise J. Phillips. *Discourse Analysis as Theory and Method*. Sage, 2002, 5-6.

[3] Laclau, Ernesto, and Chantal Mouffe. *Hegemony and Socialist Strategy: Towards a Radical Democratic Politics. Verso Trade*, 2014.

[4] Fairclough, Norman. *Critical Discourse Analysis: The Critical Study of Language*. Routledge, 2013.

[5] Jørgensen and Philips 2002, 4.

For this thesis, I rely more heavily on Discourse Theory for conceptualizing the broad concepts of medieval versus modern discourse, and take more elements from Critical Discourse Analysis when addressing the textually produced academic discourses of medieval leprosy.

One of the defining characteristics of Laclau and Mouffe's theory is that everything experienced within the social realm is contingent, meaning it is possible but not necessary.[6] This theory states that there is no objective material reality because all our (human) experiences are mediated entirely by discourse.[7] It is important to emphasize that Laclau and Mouffe are not saying that external reality does not exist independently of human knowledge. Instead, it is that our way of accessing reality is through structures that we create for ourselves, and these structures[8] are created through "discursive processes"[9] which are constantly under negotiation.[10] This implies that the way we categorize and structure our society is, to some degree, arbitrary because we are the ones to assign meaning and, most importantly, this meaning *can* and *does* change over time. It also means that both people and society are considered to be historical phenomena that depend on these existing structures that are created through discursive processes. Within this thesis, this idea is applied in the first section as a way to explore the changing identity of leprosy, with an emphasis on the variable experience of this disease over time and from place to place.

Fairclough's theory, Critical Discourse Analysis, applies the concept of discourse specifically to text, speech and other semiological systems, which differs from Laclau and Mouffe's theory in that it keeps the idea of discourse removed from other aspects of social practice.[11] In this theory, the use of language becomes "a form of action which is socially and historically situated", which means that by using it people can create change in the world.[12]

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[6] Jørgensen and Philips 2002, 38.

[7] Rear, David. "Laclau and Mouffe's discourse theory and Fairclough's critical discourse analysis: An introduction and comparison." *Unpublished paper.* 2013, 4.

[8] Discourses are understood as the fundamental structures that makes up the world, meaning there is no relationship between discourses and something else. Jørgensen and Philips 2002, 19.

[9] Laclau and Mouffe's discursive processes include, not only systems of signs (e.g. language in text, speech, and visual communication), but the entire social field. Jørgensen and Philips 2002, 32.

[10] Jørgensen and Philips 2002, 6, Rear 2013, 4.

[11] Jørgensen and Philips 2002, 18.

[12] Jørgensen and Philips 2002, 62.

This theory is often applied in a research context that involves examining both the discursive practices which help to represent the world, and also how these discourses are employed to promote the interests of particular social groups.[13] One of the benefits of this theory is that it can be a particularly useful tool in examining and challenging inequalities that exist within, and between, different discourses.

There are two concepts used in this thesis, one is the concept of "discursive practices" taken from Critical Discourse Analysis, and the other is the idea of "discursive struggle" taken from Discourse Theory. Discursive practices can be understood as the process through which texts are created, received, interpreted, and are understood as contributing to the construction of the social world, including ideas surrounding identity.[14] The idea of a discursive struggle is based off the notion that no discourse is a "closed entity", meaning that it is constantly being changed and transformed through contact with other discourses, with each one struggling to achieve a position of dominance.[15] In this sense, the current discursive practices within the academic study of leprosy are part of what shapes the identity of "leprosy", and influences how it is currently being experienced. This thesis puts forth the basis for a discursive struggle over the terminology usage within the academic discourses of leprosy. The goal of this struggle is to challenge the pejorative connotations of the current discourses surrounding this disease, which will hopefully result in a reshaping of the identity of leprosy. The discourse theories outlined in this section will be used only as a general framework to explore the different discourses surrounding leprosy, rather than as strict theoretical guidelines.

[13] Jørgensen and Philips 2002, 64

[14] Jørgensen and Philips 2002, 61.

[15] Jørgensen and Philips 2002, 6-7.

3.0 The History of Leprosy

The disease known as "leprosy" is considered one of humanity's oldest diseases and therefore has a long, complex history.[16] As the following section will explore, it has gone by many names (including *kushtha*, *lail|li* 癘, *judhām*, and *elephantiasis*) during a period that spans over two thousand years. It will start by examining the origin of the term "leprosy", with an aim of showing how this concept has transitioned over time. It will also explore the earliest possible references to the disease from ancient India and China. As well, it will as look at how understandings of leprosy differed in the Middle East compared to Western Europe during the medieval period (AD 500-1500). The prevalence of leprosy in medieval England and how it was understood and experienced within society during that period is also examined. The section will conclude by giving an overview of how attitudes towards the disease in the West transformed during the post-medieval period until the 20th century. All of this will be done with the aim of showing how the discourse surrounding a disease varies based on where and when it is being studied, and will emphasize the importance of acknowledging the natural shift in ideas that occurs over time when studying the past from the present.

3.1 Origins of the Term "Leprosy"

The origin of the term "leprosy" comes from the ancient Greek word, *lepra*,[17] which was used as a translation of the Hebrew word, *tsara'ath* in the Septuagint in the 2nd century BC.[18] There is a consensus among scholars that t*sara'ath,* which occurs throughout the Hebrew scriptures, was "a generic, nonscientific term denoting ritualistic defilement rather than a specific disease of the human skin."[19] The word *lepra* appears multiple times in the Septuagint and Greek New

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[16] While there is some debate among scholars, there appears to be evidence of *Mycobacterium leprae* from as far back as four thousand years. Zias, Joe. "New Evidence for the History of Leprosy in the Ancient Near East: An Overview." *BAR International Series* 1054 (2002): 259-268.

[17] The term *lepra* means "scaly" in latin. Dols, Michael W. "Leprosy in Medieval Arabic Medicine." *Journal of the History of Medicine and Allied sciences* 34, no. 3 (1979): 314.

[18] Brenner, Elma. "Recent Perspectives on Leprosy in Medieval Western Europe." *History Compass* 8, no. 5 (2010): 388-406, Rawcliffe, Carole. *Leprosy in Medieval England*. Woodbridge: Boydell Press, 2006, 73.

[19] It is interesting to note that this connection with spiritual uncleanliness may have contributed to the "sinner" connotations that the disease had during the medieval period, something that will be explored further in Section 5. Browne, Stanley G. "Some Aspects of the History of Leprosy: The Leprosie of Yesterday." *Proceedings of the Royal Society of Medicine* 68, no. 8 (1975): 487, Grigsby, Bryon Lee. *Pestilence in Medieval and Early Modern English Literature*. V. 23. *Medieval History and Culture*. New York: Routledge, 2004, 11, Zias 2002, 259-268.

Testament, and usually references a “defiling skin disease” which turns the skin “white as snow”.[20] In one important passage, Leviticus 13:2 (KJV), God tells Moses how to identify someone with leprosy, and describes the condition as “a rising, a scab, or bright spot” on the flesh, which would turn white. There is not an extremely clear overlap between these descriptions of *lepra* and the known symptoms of Hansen’s disease. In the biblical context, it was understood that leprosy was something that could be spiritually cleansed from the body,[21] and there are multiple passages where Jesus healed people of the disease.[22] It is therefore difficult to know to what extent leprosy was considered a disease in a biological sense (the descriptions correspond closely to many skin conditions including Hansen’s disease) or more symbolic of a spiritual uncleanliness, though it seems likely that it frequently involved both aspects.

While there is scientific evidence from both archaeological and DNA sources that the mycobacterium that causes Hansen’s disease has been around for thousands of years,[23] it has been difficult to identify possible examples in textual sources. The main reason for this is that the symptoms of Hansen’s disease are very similar to a myriad of other dermatological conditions.[24] The earliest references we have to a disease that closely corresponds[25] to Hansen’s disease comes from the ancient Greeks (1st century AD).[26] Rufus of Ephesus (d. AD 117) was one of the first to

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[20] Grzybowski, Andrzej, and Małgorzata Nita. "Leprosy in the Bible." *Clinics in Dermatology* 34, no. 1 (2016): 4.

[21] For example, Deuteronomy 24:8 (King James Version) it states “Take heed in the plague of leprosy, that thou observe diligently, and do according to all that the priests the Levites shall teach you: as I commanded them, so ye shall observe to do.” There is also a full passage on how the priests can spiritually cleanse a person in Leviticus 14:1-15 (KJV).

[22] Luke 5:13, Luke 17:12-14, Matthew 8:1-8 Matthew 8:3, Mark 1:40-42 (KJV).

[23] Studies done with the archaeological strains of the mycobacterium have helped to give an increasingly detailed understanding of the spread of Hansen’s disease, and suggest that the disease originated from East Africa and transitioned into India possibly during the third millennium B.C.
Taylor, G. Michael et al. “Detection and Strain Typing of Ancient Mycobacterium Leprae from a Medieval Leprosy Hospital." *PloS One* 8, no. 4 (2013): E62406, Mendum, Tom A. et al. "Mycobacterium Leprae Genomes from a British Medieval Leprosy Hospital: Towards Understanding an Ancient Epidemic." *BMC Genomics* 15, no. 1 (2013): 1-8, Robbins et al. “Ancient Skeletal Evidence for Leprosy in India (2000 BC)." *PloS one* 4, no. 5 (2009): 1-8.

[24] Lee, Christina H. "Changing Faces: Leprosy in Anglo-Saxon England." In *Conversion and Colonization in Anglo-Saxon England*, 2006, p. 59-82. To this day, it is difficult to identify Hansen’s disease in its early stages and it is often mistaken for other skin diseases. This is explored further in Section 4.

[25] It is also important to state that all attempts to retrospectively diagnose diseases from historical primary sources should be done with caution. Lee 2006, 59-82.

[26] Brenner 2010, 390, McLeod, Katrina and Robin Yates. "Forms of Ch'in Law: An Annotated Translation of The Feng-chen Shih." *Harvard Journal of Asiatic Studies* 41, no. 1 (1981): 111-163, Rawcliffe 2006, 73.

provide a consistent account of the symptoms, though the first clinical description of the disease is attributed to Aretaeus the Cappadocian from the 1st century AD.[27] He likened many of the symptoms of the disease with the traits of an elephant, where the "thick, rough, insensitive and fissured skin of its victims looked remarkably elephantine", which led to it being described as *elephantiasis*.[28]

It is difficult to pin down exactly where and when the overlap between "leprosy" and "*elephantiasis*" began. Girolamo Fracastoro (AD 1478-1553) suggested that while the ancients wrote about leprosy and *elephantiasis* as two distinct diseases, they should become equated as one illness.[29] Some scholars attribute this connection to John of Damascus (AD 777-857), a Syria-Palestinian monk, who started using *lepra* to refer to a disease that could have corresponded with Hansen's disease.[30] Others suggest that the confusion occurred much earlier with the works of Galen, which contained references to a disease using both the terms "*lepra*" and "*elephantia*".[31] Regardless of when it occurred, the choice of the term *lepra* over *elephantiasis* by medieval European medical writers was solidified during the 11th and 12th centuries, with the translation of Arabic medical texts into Latin.[32] Though it is important to emphasize that during this period, a person diagnosed with leprosy did not necessarily have "Hansen's disease". With the diagnostic capabilities combined with a wider definition of "leprosy" in medieval Europe, a person could have a number of skin diseases that we would now describe as eczema, vitiligo, psoriasis, lupus, scrofula, skin cancers, or ulcers of various kinds.[33]

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[27] McLeod and Yates 1981, 152, Rawcliffe 2006, 74.

[28] Greek physicians also used the terms '*elephas', 'elephancia'* or *elephantiasis Graecorum.* Rawcliffe 2006, 72. Zias 2002, 260.

[29] Brody, Saul Nathaniel. *The Disease of the Soul: Leprosy in Medieval Literature*. Ithaca N.Y.: Cornell University Press, 1974, 45.

[30] Zias 2002, 260.

[31] Brenner 2010, 390.

[32] For example, Brenner describes how "The Viaticum of Constantine the African (d. before 1098–9), a translation of an Arabic work by Ibn al-Jazzar, labelled the disease *lepra*, stating that it took four forms, of which elephancia was merely one." Brenner 2010, 390.

[33] Browne 1975, 487, Douglas, Mary. "Witchcraft and Leprosy: Two Strategies of Exclusion." *Man (London)* 26, no. 4 (1991): 733.

3.2 Leprosy in the Ancient East

India

Based on both historical and archaeological evidence, it seems likely that Hansen's disease has been endemic to India for over four thousand years.[34] It is believed that the disease spread through trade and warfare from India to China and the Middle East, before making its way to Europe and lastly the Americas.[35] It is thought that certain skin diseases referenced in the *Atharawa Veda* (2000 BC) and the *Laws of Manu* (1500 BC) may correspond to leprosy and possibly Hansen's disease,[36] though the first reasonably good account of the clinical features of Hansen's disease comes from the Sushruta Samhida (600 BC).[37]

Described as *kushtha*, meaning "eating away" in Sanskrit, it recommended a treatment with oil derived from the chaulmoogra tree, which remained a mainstay of treatment until the introduction of sulfones in the 20th century (see Section 4 for more details).[38] It is interesting to note that the name "Sushruta Samhita" contains the term, "Samhita", which means an anthology suggesting that the classification of this disease was likely present before the compiling of the work.[39] It is understood individuals contracted this disease because of their sinful nature, and that "they must have committed a most heinous crime in their previous life."[40] They were generally marginalized by ancient Indian society, not just due to the strong association with sin, but also likely because of the disfiguring and contagious nature of the disease.[41]

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[34] The oldest documented skeletal evidence for Lepromatous leprosy has been found in India and dates to 2000 B.C. Robbins et al. 2009.

[35] Jacob, Jeese and Carlos Franco-Paredes. "The Stigmatization of Leprosy in India and its Impact on Future Approaches to Elimination and Control." *PLoS Negl Trop Dis* 2, no. 1 (2008): e113.

[36] Jacob and Franco-Paredes, 2008, e113.

[37] Oommen, Shanthakumar Thomas. "The History of the Treatment of Leprosy and the Use of Hydnocarpus Oil." *BAR International series* 1054 (2002): 201-204.

[38] Jacob and Franco-Paredes, 2008, e113, Oommen, 2002, 201-204.

[39] Ramu, G. "The Indian Classification of Leprosy." *Japanese Journal of leprosy* 50, no. 4 (1981): 226

[40] Oommen, 2002, 202.

[41] Jacob and Franco-Paredes, 2008, e113.

China

One of the earliest written records that provides a description of what seems to be leprosy comes from the 3rd century B.C. in China.[42] The Feng-chen Shih was written between 266 and 246 BC, and consists of laws and public documents.[43] One section of this document involves a situation where the chief of a village describes one of his villagers suffering from a disease called *lail|li* 癘. The list of symptoms include "swelling of the eyebrows, loss of hair, absorption of the nasal cartilage, affliction of knees and elbows, difficult and hoarse respiration, as well as anaesthesia".[44] This is understood as one of the earliest references to "leprosy" though the degree of specificity in the list of symptoms also makes a strong case for this to be a description of Hansen's disease. However, it is still important to emphasize that the identification of modern diseases in ancient texts should be done with appropriate caution.

There is also a folk story from the Tang Dynasty (AD 618-906) that explains the origin of leprosy.[45] The reigning emperor during the period neglected his kingdom because he was too focused on his favourite courtesan, who was a woman of legendary beauty. His guards rebelled against his actions and demanded he execute the courtesan, which the emperor did in order to save his own life. Her body was left lying by the roadside as a sign for the kingdom, but a passing convoy of soldiers found her body and were still charmed by her beauty. They then proceeded to have sexual relations with it, and the legend states that all the soldiers who committed this heinous act developed leprosy as punishment from Heaven.

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[42] It is interesting to note that this text dates from approximately two hundred years before the earliest records of any similar descriptions of *elephantiasis* we have from the ancient Greeks.

[43] McLeod and Yates 1981, 113.

[44] The direct transcript from the text reads: "I suspect leprosy[?] and have come and brought him along. We questioned C. His statement reads: At the age of three, I became sick with sores on the head; my eyebrows swelled up; it could not be ascertained what sickness it was. I have no other liability. We ordered the physician D to examine him. D said: C has no eyebrows; the bridge of the nose is destroyed; his nasal cavity is collapsed; if you prick his nose, he does not sneeze; elbows and knees — down to — the soles of both feet are defective and are suppurating in one place; his hands have no hair; I ordered him to shout and the ch'i 氣; of his voice was hoarse. It is leprosy[?]" McLeod and Yates., 1981, 153.

[45] Skinsnes, Olaf K. "Leprosy in Society. I. 'Leprosy Has Appeared on the Face'." *Leprosy Review* 35, no. 1 (1964): 21-35.

This is possibly one of the reasons for the common misconception that persisted for centuries that leprosy is a venereal disease, and one of the many names still used for leprosy in China is Tien Ying, meaning "Reward from Heaven".[46]

3.3 Leprosy in the Middle East during the Medieval Period

In the Middle East, the term that existed for leprosy was *judhām* (meaning "to mutilate" or "to cut off"), and seems to describe the serious degree of disfigurement experienced by those suffering from advanced cases of Hansen's disease.[47] Throughout the 11th and 12th centuries, there was a large increase in the number of Classical and Middle Eastern sources being translated and transmitted throughout Western Europe.[48] During this period, the term *judhām* was difficult to translate into Latin because the preexisting term used at the time, *elephantiasis*, also corresponded to another disease, *dā'al fīl*.[49] The Western scholars at the time (e.g. Constantine the African and Gerard of Cremona), then chose to translate it as *lepra,* which at that point was still a closer translation of the Hebrew *tsara'ath* (a more generic term for a variety of skin diseases).[50]

One of the most influential medical works during the later medieval period, the *Canon of Avicenna* (Ibn Sīna, d. AD 1037), had an entire section on *judhām* (Latin, *lepra*).[51] However, by the time it became a popular medical text in the West the impact of the alternate translation was too great, and the association between leprosy and biblical sin was already deeply ingrained in medieval society. This association between leprosy and sin can be contrasted somewhat with the experiences of leprosy sufferers in Arabic society at that time, where having *judhām* did not necessitate segregation and stigmatization from society.[52]

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[46] Skinsnes 1964, 23.

[47] Dols, Michael W. "The Leper in Medieval Islamic Society." *Speculum* 58, no. 4 (1983): 891-916, Rawcliffe 2006, 76.

[48] Rawcliffe 2006, 76.

[49] This is more equivalent to the modern disease which is called elephantiasis, which is a parasitic infection which causes fluid to build up in the lower extremities. Rawcliffe 2006, 76.

[50] Rawcliffe 2006, 76.

[51] Rawcliffe 2006, 76.

[52] Dols 1983, 891-916., Douglas 1991, 723-736.

In general, it can be understood that the Islamic tradition did not share the same religious symbolic relationship between sin and disease that is prevalent throughout the Bible.[53] For example, there is a passage from the Qur'an that can be translated as "the blind, the lame, and the sick bear no fault or blame (*haraj)*, and it is permissible for all men to gather and eat together."[54] This is supported by historical and archaeological findings, as there does not appear to be much evidence for the establishment of separate leprosaria (also known as leper hospitals).[55] As well, one of the kings of Jerusalem, Baldwin IV, was considered to have leprosy and was still able to rule the kingdom for over a decade before his condition required him to abdicate the throne.[56] The existence of laws in place that protected the civil rights of people with leprosy during the medieval period in the Kingdom of Jerusalem also seems to support the notion that there was a general lack of stigma associated with the disease.[57]

Overall, it can be understood that the differences in religious discourse between Christianity and Islam during the medieval period greatly shaped how this disease was experienced.

3.4 Leprosy in Western Europe during the Medieval Period

The archaeological evidence appears to be consistent with the historical accounts which suggest that the earliest evidence for leprosy and Hansen's disease in Europe can be traced to the Roman period (1st century BC to 5th century AD), though it did not become prevalent until later in the medieval period.[58] Some of the main sources we have for documentation on those suffering from leprosy during the early medieval period comes from both church and secular documents. One of the earliest examples is from the Council of Orleans (AD 549), which restricted the interaction of people with leprosy from the rest of society.[59]

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[53] An example of this is the concept of *tsara'ath* which was seen as a spiritual uncleanliness that caused a physical manifestation of symptoms.

[54] Dols 1983, 913-914.

[55] Dols, 1983, 894.

[56] Lay, Stephen. "A Leper in Purple: the Coronation of Baldwin IV of Jerusalem." *Journal of Medieval History* 23, no. 4 (1997): 317-334.

[57] Douglas 1991.

[58] Donoghue et al., "A Migration-Driven Model for the Historical Spread of Leprosy in Medieval Eastern and Central Europe." *Infection, Genetics and Evolution* 31 (2015): 250-256.

[59] Lee 2006, 71.

About a hundred years later, the *Edictus Rothari* (AD 643) became the first secular law that banned people with leprosy from being a part of general society.[60]

One of the most widely referenced laws in the historical discourse on medieval leprosy is Canon 23 from the Third Lateran Council of AD 1179.[61] It is often misinterpreted as "a mandate for the exclusion of lepers from society" and many scholars have referenced it to support the idea that those with leprosy were banished from general society.[62] However, the motivation behind the ruling was for the Church to follow its "apostolic mission to the sick" and provide communal spiritual support from those suffering from leprosy.[63] The translation reads as follows:

> Although the Apostles says that we should pay greater honour to our weaker members, certain ecclesiastics, seeking what is their own and not the things of Jesus Christ, do not allow lepers, who cannot dwell with the healthy or come to church with others, to have their own churches and cemeteries or to be helped by the ministry of their own priests. Since it is recognized that this is far from Christian piety, we decree, in accordance with apostolic charity, that wherever so many are gathered together under a common way of life that they are able to establish a church for themselves with a cemetery and rejoice in their own priest, they should be allowed to have them without contradiction. Let them take care, however, not to harm in any way the parochial rights of established churches. For we do not wish that what is granted them on the score of piety should result in harm to others. We also declare that they should not be compelled to pay tithes for their gardens or the pasture of animals.[64]

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[60] Hundeiker, M. "Leprosy in the Middle Ages: Therapeutic Concepts and Fabrications." *Aktuelle Dermatologie* 38, no. 04 (2012): 121-125., Lee 2006, 71.

[61] Brody, 1974, Grigby 2004, Hundeiker 2006, Lee 2006, Rawcliffe 2006.

[62] Rawcliffe 2006, 257.

[63] Rawcliffe 2006, 257.

[64] Tanner, Norman P. *Decrees of the Ecumenical Councils: Nicaea I to Lateran V*. Vol. 1. London: Sheed & Ward, 1990.

The interpretation of this law has been a topic of much debate among scholars, with some using it to support ideas of discrimination and segregation, while others believe it was used as a way to protect the rights of those suffering from leprosy.[65] Based on this translation, it seems that while the law does reinforce ideas of mandatory segregation, it is concerned with guaranteeing spiritual guidance for those with leprosy, as well as encouraging charity towards them by making them exempt from certain taxes. So while individuals suffering from leprosy were forced to be apart from regular medieval society, it is difficult to interpret the degree of stigma and rejection they experienced from this document.

There is both archaeological and historical evidence from all over Europe for the existence of leprosaria before this law was passed, suggesting that the segregation of people with leprosy from the rest of society had been a commonplace practice for many years.[66] In this sense, the establishment of leprosaria can be seen as a physical expression of the social attitudes surrounding leprosy during this period,[67] though the experiences within these places varied greatly depending on the time period and location. Some scholars believe that by counting the number of leprosaria established throughout the medieval period, it is possible to track the relative prevalence of leprosy over time. Section 3.5 examines this concept in more detail with examples from medieval England.

The osteoarchaeological record can also be useful for examining the shifting rates of leprosy over time. Evidence suggests that despite Hansen's disease being present since the Roman period, it did not become prolific in Europe until later in the medieval period.[68] In particular, the period between AD 1050–1350 seems to be when it was most prevalent throughout Europe, which also corresponds with the increased number of leprosaria being established during this period.[69] It is important to emphasize that osteological evidence is only able to identify examples of the physical expression of Hansen's disease in the past, and is

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[65] Rawcliffe 2006, 257.

[66] For example, they existed in Metz, Verdun and Maastricht (AD 636), London (AD 1066), Chatham (AD 1078), Rochester (AD 1084), and Canterbury (AD 1137). Hundeiker 2006, 121.

[67] Dols 1983, 914.

[68] Donoghue et al. 2015, 250-256.

[69] Roffey, Simon. "Medieval Leper Hospitals in England: An Archaeological Perspective." *Medieval Archaeology* 56, no. 1 (2012): 204.

limited in what it can say about the socio-cultural experience of "leprosy". The applicability of archaeological evidence to the study of medieval leprosy will be explored in more detail in Section 6.

3.5 Leprosy in Medieval England

The earliest paleopathological evidence of Hansen's disease in the British Isles dates to the 4th century AD,[70] but despite the presence of this disease within England for hundreds of years, most of the sources referencing leprosy date from around and after the Norman Conquest.[71] This timeline is also mirrored by the creation of leprosaria, as most of them were founded between AD 1150 and 1300, by which date there were at least 496.[72]

The placement of these leprosaria was strategic, usually they were located on the outskirts of towns, on main thoroughfares, or close to town bridges and gates.[73] This served two purposes, the first was to isolate the people suffering from leprosy from the rest of their community, and the second was to facilitate the collections of alms from those travelling through these towns.[74] They also represented a powerful status symbol for the founder of the institutions (usually bishops, kings, or other wealthy patrons), as they were built to be visually impressive representations of the pious and charitable nature of the founder.[75] The experience of the people living within the leprosaria varied greatly depending on the location and time period, though the general rules of most of these establishments followed a strict regime influenced by monasticism that emphasized poverty, obedience, and chastity.[76]

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[70] Taylor et al. 2013, 1.

[71] Manchester, Keith, and Charlotte Roberts. "The Palaeopathology of Leprosy in Britain: A Review." *World Archaeology: The Archaeology of Public Health* 21, no. 2 (1989): 265-272.

[72] Magilton, J. R., Frances Lee, and Anthea Boylston, eds. *"Lepers Outside the Gate": Excavations at the Cemetery of the Hospital of St James and St Mary Magdalene, Chichester, 1986-87 and 1993*. Vol. 158. Council for British Archeology, 2008, 20.

[73] Goose, Nigel, and Leanne Moden. *A History of Doughty's Hospital, Norwich, 1687-2009*. Univ of Hertfordshire Press, 2010, 5, Magilton et al. 2008, 22. This is also supported by the archaeological record. Roffey 2012.

[74] Goose and Moden 2010, 5, Magilton et al. 2008, 22. This is also supported by the archaeological record. Roffey 2012.

[75] Roffey 2012, 222.

[76] Magilton et al. 2008, 21.

The number of these institutions fell off rapidly by the early 14th century, reflecting an overall decline in leprosy, and Hansen's disease.[77] The reason for this decline is not well understood as it likely involves a variety of complex social, demographic, environmental, and bacteriological factors.[78] For example, one theory suggests that the increasing standards of living that occurred after the Black Death meant that people were healthier and more likely to fight off infection.[79] There was still a great deal of poverty and illness during this period, so the surviving leprosaria became adapted for other uses, such as almshouses and generalized hospitals.[80] Most historians agree that by the time of the dissolution of the monasteries in AD 1536-40, the threat of leprosy had ceased to be a matter of public health importance.[81] So it can be understood that England was similar to the rest of Europe, with the peak period for Hansen's disease and textual descriptions of leprosy occurring between the 11th and 14th centuries.[82]

3.6 Leprosy from the Post-Medieval Period to the Present

Based on both the historical and archaeological record, leprosy and Hansen's disease became almost non-existent during the post-medieval period in Europe for a variety of complex socio-cultural and biological factors that are not well understood.[83] One of the leading theories suggests that the decline was due to a cross-immunity developed from tuberculosis (a very similar disease on a bacterial level), which became one of the most prevalent diseases in the post-medieval period (see Section 10).[84] Despite this decline, the idea of leprosy still maintained certain social stigmas and stereotypes from the medieval period.

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[77] Magilton et al. 2008, 10-11.

[78] Magilton et al. 2008, 11.

[79] Magilton et al. 2008, 11.

[80] Goose and Moden 2010, 6, Taylor et al. 2014, Rawcliffe 2006.

[81] Browne 1975, 489, Taylor et al. 2013.

[82] Browne 1975, 485-493, Taylor et al. 2013, 2, Rawcliffe 2006.

[83] Magilton et al. 2008.

[84] Lietman, Tom, Travis Porco, and Sally Blower. "Leprosy and Tuberculosis: the Epidemiological Consequences of Cross-immunity." *American Journal of Public Health* 87, no. 12 (1997): 1923-1927, Manchester, Keith. "Tuberculosis and Leprosy in Antiquity: An Interpretation." *Medical History* 28, no. 2 (1984): 162-173.

During the 17th century, the disease had almost completely disappeared from Europe, yet the association between leprosy and sin persisted.[85] This ultimately meant that most contact people had was with the *ideas* surrounding leprosy, rather than anyone actually suffering from the disease itself (this is explored in greater detail in Section 11).[86]

Leprosy and Hansen's disease continued to be endemic in certain parts of the world, mainly in Asia and Africa, during the post-medieval period.[87] During the 18th and 19th centuries when the period of colonial expansion was at its height, the Western powers (e.g. England, France, Spain, and Portugal) once again came into contact with the disease.[88] Many of the European countries were fearful that the disease would once again become endemic in Europe, and they looked to the past to find the answers. At this time, England was the leading colonial power, and they used the existence of leprosaria in the medieval period as a template for how to treat individuals with leprosy.[89] This set a precedence which lead to the creation of colonies for people with leprosy around the world where they were forcefully segregated because of the disease.[90]

Attitudes towards people suffering from leprosy slowly began to change after 1873, when a Norwegian physician, Gerhard Armauer Hansen, discovered the bacteria that caused leprosy—*Mycobacterium leprae* (see Figure 1 below).[91]

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[85] Oommen 2002, 202.

[86] Brody 1974, 190.

[87] Jacob and Franco-Paredes 2008, e113, Skinsnes 1964, 21-35.

[88] Rawcliffe, 2006, 13-43.

[89] Rawcliffe 2006, 20-25.

[90] Roberts, Charlotte A., Mary E. Lewis, and Keith Manchester. *The Past and Present of Leprosy: Archaeological, Historical, Palaeopathological and Clinical Approaches*: 3rd International Congress on the Evolution and Palaeoepidemiology of the Infectious Diseases, ICEPID, 26-31 July 1999, University of Bradford; Archaeopress, 2002.

[91] Brenner 2010, 389.

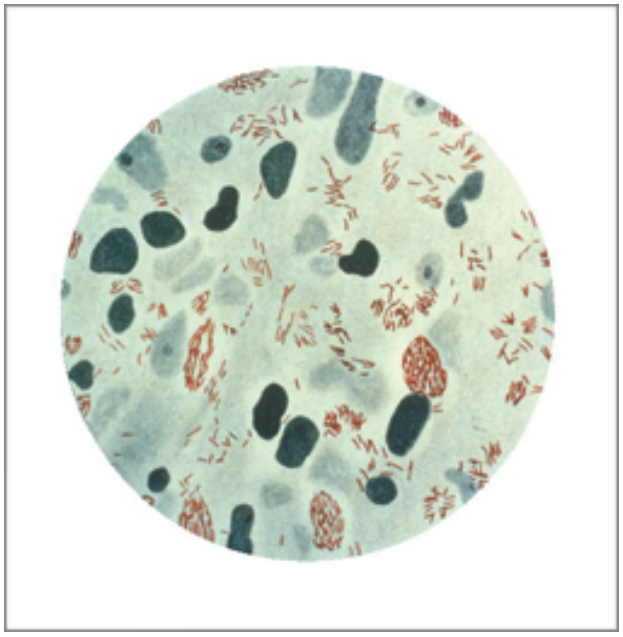

Figure 1. Photomicrograph of Mycobacterium leprae.[92]

This new knowledge allowed for a better understanding of the transmission and infection path of the bacteria, and eventually led to a cure being developed in the mid-20th century. Despite these advancements, even after it started to become known as Hansen's disease, the stigma surrounding "leprosy" continued throughout this period and persists to this day in certain parts of the world. The following section will explain Hansen's disease in more detail, explore the transitionary period between ideas of "leprosy" and "Hansen's disease", and look at some of the modern experiences of individuals who suffered from this disease.

[92] Picture taken from Rinaldi, Andrea. "The Global Campaign to Eliminate Leprosy." *PLoS Med* 2, no. 12 (2005): 1222.

4.0 What is Hansen's Disease?

Before attempting to distinguish between the concepts of "leprosy" and "Hansen's disease", it is first useful to provide a modern biological definition and explanation for Hansen's disease. It is considered one of the oldest human diseases,[93] despite the fact that the mycobacterium causing Hansen's disease was only discovered almost 150 years ago.[94] The bacterium is believed to be transmitted through close contact with an infected individual, though the exact process is still not well understood. The most commonly accepted theory is that the bacilli are expelled from the nose of an infected person which must then be inhaled through the nose of another individual.[95]

Once a human is infected with *Mycobacterium leprae*,[96] it predominantly effects the skin, the peripheral nerves, and the mouth, nose, and eyes.[97] The clinical features of the disease are caused by the proliferation of the bacteria in the body, the body's own immunologic responses to the invasion of the bacilli, and an inflammation of the peripheral nerves (which is a response to the first two features).[98] The disease is not highly infectious, meaning prolonged exposure is considered necessary for infection, with a long incubation period ranging from two years to several decades.[99] The expression of the disease is heavily based on the immune response of the infected individual,[100] and there are two main systems in use to classify the response. The first was recently put forth by the World Health Organization (WHO) and is a simple system that

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[93] Han et al. "Comparative Sequence Analysis of Mycobacterium Leprae and the New Leprosy-Causing Mycobacterium Lepromatosis." *The Journal of Bacteriology* 191, no. 19 (2009): 6067-6074.

[94] Brenner 2010, Taylor et al. 2013, Taylor et al. "Variable Nucleotide Tandem Repeat (VNTR) Typing of Two Palaeopathological Cases of Lepromatous Leprosy from Mediaeval England." *Journal of Archaeological Science* 33, no. 11 (2006): 1569-1579.

[95] Hastings et al. "Leprosy." *Clinical Microbiology Reviews* 1, no. 3 (1988): 330, Roberts, Charlotte. "Applying the 'Index of Care' to a Person Who Experienced Leprosy in Late Medieval Chichester, England." in *New Developments in the Bioarchaeology of Care*, 101-124, Springer, Cham, 2017.

[96] Very recently another strain of the disease was discovered that was genetically divergent enough to be labelled as a new species, *Mycobacterium lepromatosis.* This species is a unique form of leprosy endemic in Mexico and the Caribbean and therefore not useful in the discussion surrounding medieval leprosy in Europe. Han et al. 2009.

[97] Specifically, the disease targets the peripheral nerves of the body which effect the extremities, and any mucous membranes because they allow for a place for the bacterium to enter the body. Hastings et al. 1988, 330.

[98] Hastings et al. 1988.

[99] Spigelman, Mark, and Mauro Rubini. "Paleomicrobiology of leprosy." in *Paleomicrobiology of Humans*, 131–142. Washington, DC, Virginia: ASM Press, 2016, Taylor et al. 2006.

[100] Roffey et al. "Investigation of a Medieval Pilgrim Burial Excavated from the Leprosarium of St Mary Magdalen Winchester, UK." *PLoS Neglected Tropical Diseases* 11, no. 1 (2017): 1-27, Taylor et al. "Leprosy at the Edge of Europe-Biomolecular, Isotopic and Osteoarchaeological Findings from Medieval Ireland." *PLoS ONE* 13, no. 12 (2018): 1-27.

distinguishes the severity of the infection based on the level of bacilli found in the individual.[101] The second, the Ridley-Jopling system, is a five-group classification of leprosy that has been the most widely used and accepted system because it best reflects the complex nature of the immunological status of the patient.[102] Despite this system, it is still only used as a guideline as most presentations of the disease do not fit neatly into one category because "the spectrum of leprosy is a continuous one."[103]

The most severe category, lepromatous leprosy, involves a poor immune response with widespread skin lesions, inflammation, and destruction of bone.[104] The lepromatous skin lesions generally appear on cooler parts of the body, likely due to the preferential growth of *Mycobacterium leprae* at temperatures cooler than core body temperature.[105] This is evident in the patterning of the most common areas of the body affected, specifically, the eyes, nose, and the hands and feet.[106] Tuberculoid leprosy is the other end of the spectrum, involving a strong immune response with a high resistance to the infection and it is the least damaging and the least infectious type.[107] However, tuberculoid leprosy does affect the skin and nerves, with one or, at most, a few skin lesions.[108]

Between the two ends of the spectrum is borderline leprosy, and within this there are two subcategories, borderline lepromatous leprosy and borderline tuberculoid leprosy.[109] These states are characterized by a greater number of skin lesions and more widespread nerve damage than

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[101] This system uses two terms to distinguish the type of leprosy, paucibacillary (small amounts of bacteria) which corresponds closest to tuberculoid leprosy and multibacillary (large amounts of bacteria) which is closest to lepromatous leprosy. Overall the system is not considered to be as useful for studying the disease in the past, as scholars have argued that it does not adequately represent the complexity of symptoms associated with this disease. Taylor et al. 2013.

[102] Singh et al. 2004.

[103] Singh et al. 2004, 388.

[104] Manchester, Keith. "A Leprous Skeleton of the 7th Century from Eccles, Kent, and the Present Evidence of Leprosy in Early Britain." *Journal of Archaeological Science* 8, no. 2 (1981): 205-209, Inskip et al. "Leprosy in Pre-norman Suffolk, UK: Biomolecular and Geochemical Analysis of the Woman from Hoxne." *Journal of Medical Microbiology* 66, no. 11 (2017): 1640-1649.

[105] Hastings et al. 1988, 330-348.

[106] Specifically, it affects the anterior third of the eye, produces rhino-maxillary changes, and damages the peripheral nerve trunks that lead to the arms and legs. Hastings et al. 1988.

[107] Manchester 1984, 162-173, Taylor et al. 2006.

[108] Hastings et al. 1988.

[109] Hastings et al. 1988.

tuberculoid leprosy, but less mucus membrane damage than lepromatous leprosy.[110] Ultimately, borderline leprosy is an unstable state for the disease, and individuals generally end up shifting to the milder tuberculoid form or to the more extreme lepromatous form.[111] To summarize, the list of symptoms experienced can include relatively painless ulcers, skin lesions (consisting of flat, pale areas of skin), bone destruction, secondary infections, and gangrene.[112] In the more severe cases, there can be blotchy and lumpy skin, destruction of the nose, hoarseness of voice, and eye damage that can often lead to blindness.[113]

One of the reasons Hansen's disease holds a prominent place, not just in history but also in archaeology, is due to the fact that it leaves distinct changes on the skeleton. These changes make it one of a very limited number of diseases that are recognizable in the archaeological record. The bone changes generally follow a pattern that is destructive and absorptive, meaning the bone is destroyed and then remodelled giving it a smooth appearance.[114] This process results in distinct skeletal changes that can be separated into cranial changes, affecting the head and face, and post-cranial changes, affecting the rest of the body.[115] The cranial changes, known collectively as *facies leprosa,* are generally localized to the nose area and involve inflammation and erosion of the area.[116] These changes can result in destruction of nose shape, loss of teeth, and perforation of the roof of the mouth.[117] In the post-cranial skeleton, changes include symmetrical inflammation of the leg bones (known as periostitis), and erosion of the bones of the hands and feet giving them a characteristic pencil shape (see Figure 2).[118]

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[110] Hastings et al. 1988.

[111] Hastings et al. 1988.

[112] Spigelman and Mauro 2016, 132.

[113] Spigelman and Mauro 2016, Brenner 2010.

[114] Manchester and Roberts 1989, 265-272.

[115] Manchester 1981.

[116] Spigelman and Mauro 2016.

[117] These changes involve the erosion, inflammation, and atrophy of the nasal spine and alveolar and palatine processes of the maxilla. Keith et al. 1981, Donoghue et al. 2015, Rawcliffe 2006, 3.

[118] Spigelman and Mauro 2016, Keith et al. 1981.

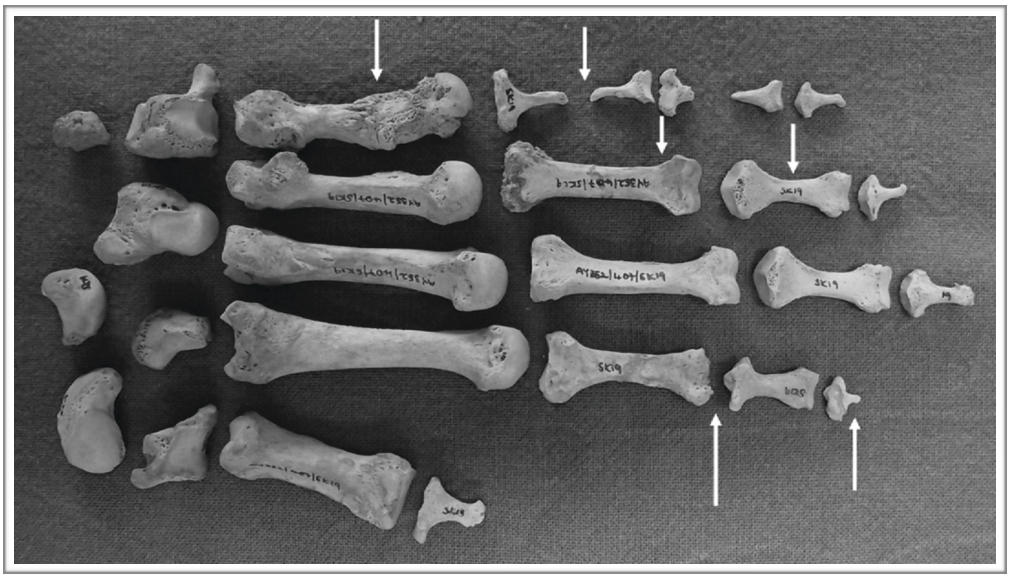

Figure 2. Evidence of the characteristic erosion of hand bones from Hansen's disease.[119]

4.1 Finding a Cure for Hansen's Disease

The picture of Hansen's disease outlined in the previous section shows a debilitating disease that affects both the physical appearance and overall quality of life of those infected. Fortunately on December 9th 1940, Dr. Guy Faget, the Medical Officer-in-Charge at the National Hansen's Disease Center in Carville, Louisiana suggested the use of sulfones,[120] which became the first effective treatment for Hansen's disease.[121] By the 1970s and 1980s, there were an increasing number of drugs that were used to treat Hansen's disease. The current treatment, usually called a multi-drug therapy (MDT), is a combination of these various drugs.[122]

Through the work of multiple agencies (including the WHO), the multiple drug therapy required to cure Hansen's disease is now available completely free of charge to all those worldwide currently suffering from the disease.[123] Despite the existence of an effective

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[119] Picture taken from Inskip et al. 2017, 176.

[120] Developed in the early 20th-century, chemically speaking sulfones are a sulfur atom linking to two carbon atoms. They can be used as both antibacterial and anti-inflammatory agents and are used to treat a range of other dermatologic disorders. Zhu, Y. Isabel, and Matthew J. Stiller. "Dapsone and Sulfones in Dermatology: Overview and Update." *Journal of the American Academy of Dermatology* 45, no. 3 (2001): 420-434.

[121] Oommen 2002, 202.

[122] Oommen 2002, 203.

[123] Law, Anwei Skinsnes, and Oak Hill. "The Last Leprosy Communities and the People Who Call Them Home." *BAR International Series* 1054 (2002): 17.

treatment, one of the main reasons that the disease is still an issue in more isolated areas around the world is due to widespread “structural inadequacies” in local health services that prevent the diagnosis and access to the free MDT drugs.[124] This is summarized by Mehta, “Leprosy is an infectious disease caused by the bacillus *M. leprae*, but there is an additional causative factor in the spread of the disease, poverty, which is anthropogenic.”[125] Consequently, this means that the social discourse surrounding this disease continues to influence how it is physically experienced, in that the social determination of poverty greatly increases the risk of infection, as well as a lack of access to effective treatment.[126]

4.2 The Transition from Leprosy to Hansen’s Disease in the Modern World

> At least some of the beliefs, laws, and practices from medieval times in regard to leprosy were still haunting patients in the nineteenth century and the first half of the twentieth century.[127] – Marcia Gaudet

The discovery of the mycobacterium responsible for Hansen’s disease in the late 19th century was a turning point for how this disease was understood. However, the lasting effects of the history of leprosy continued to haunt those who suffered this disease. The 19th century involved the creation of numerous colonies and hospitals around the world with the main purpose of segregating individuals who were diagnosed with leprosy (or Hansen’s disease if the diagnosis was after 1873). While these institutions usually also allowed for the treatment and care of individuals suffering from the disease, the ever present stigma of “leprosy” continued to negatively affect the experiences of those who were sent to these places. The following section will examine the modern overlap between ideas of “leprosy" and “Hansen’s disease" from three different parts of the world: Polynesia (Philippines and Hawaii), India, and the United States.

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[124] Law and Hill 2002, 18.

[125] Mehta, Jal. "Social reactions in the past and present of leprosy and the socio-economic rehabilitation of leprosy-cured persons." *BAR International Series* 1054 (2002): 22.

[126] This relationship between poverty and infection rates also likely played a factor in how it was experienced during the medieval period as well.

[127] Gaudet, Marcia G. *Carville: Remembering Leprosy in America*. Jackson: University Press of Mississippi, 2004, 5.

It will also examine in more detail the personal anecdotes of some of the patients at the National Hansen's Disease Center in Carville, Louisiana, with the aim of providing a more individualistic and relatable understanding of the social stigmatization attached to idea of "leprosy".

Polynesia

It is understood that leprosy[128] was likely introduced to Polynesia from Chinese immigrants during the early 19th century.[129] In the Philippines in the 1830s, there were three leprosy settlements established with the purpose of housing and caring for over 400 patients, though there was no attempt to isolate or control the disease at this point.[130]

At the turn of the 20th century, the island of Culion was selected to be turned into a colony for people with leprosy. By the 1930s, regional centres were established afterwards and only the most serious cases went to Culion, though those numbers diminished greatly by the end of the century due to improved treatment methods. In 1978, the number of people at the Culion colony was reported to be 739, and according to information from the Philippine consulate in Honolulu, the colony still existed in 2002.[131]

In Hawaii, the presence of leprosy was first reported in the 1830s and 1840s. By 1865, a law was passed that required the reporting of individuals suspected of having leprosy, and a facility was created in Honolulu for the treatment and diagnosis of cases. An "isolation colony" was also created using 800 acres on the Kalawao side of the Kalaupapa peninsula, which continued to be used until the late 20th century.[132] Based on historical sources and first-person interviews, Trembly deduced that the Hawaiians "considered the tearing apart of families, and the shipping of the afflicted off to isolation, as cruel punishment for something they could not help."[133]

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[128] At this point the mycobacterium causing Hansen's disease was not yet discovered, so it would still be considered leprosy at this point. However, it is likely that the majority, if not all, of the cases were caused by the mycobacterium.

[129] Trembly, Diane L. "Perspectives on the History of Leprosy in the Pacific." *BAR International Series* 1054 (2002): 235-236.

[130] Trembly 2002, 234.

[131] Trembly 2002, 235.

[132] Trembly 2002, 236.

[133] Trembly 2002, 236.

This is quite unusual compared with the rest of the world at this time, but despite these beliefs, the first colony for people with leprosy was opened in the mid-1800s. For the first decade of operation, it had a startling high mortality rate of 40%. However, conditions at the colony improved dramatically after the arrival of the Belgian missionary, Father Damien, who brought a compassionate perspective to his treatment of its patients.[134] He was described as "a morale builder… he took no precautions, sharing patients' dishes and utensils, passing his pipe around, sleeping on mats they had slept on, carrying them, and so forth." Sadly, he was one of the few people who was susceptible to the disease, and he died of Hansen's disease in 1889. Unfortunately, his death was widely publicized and used to perpetuate the fear and stigma surrounding the disease.[135]

India

As described in Section 3.2, leprosy and Hansen's disease has been present in India for thousands of years. When the British arrived there during the Colonial period, they focused on leprosy as an "imperial danger", and were terrified that it would spread throughout the empire.[136] The British completed a leprosy census of India in 1872 in order to map out the extent of the disease, and found over 108,000 cases, for a prevalence of 54 cases/10,000 population.[137] Another report commissioned in 1891 found that "the amount of contagion which exists is so small that it may be disregarded", yet despite acknowledging this lack of contagiousness, the popular pressure from England at the time allowed for the passing of the Leprosy Act of 1898.[138] This law mandated the institutionalization and segregation of people with leprosy, and separated them by gender to prevent them from reproducing. Despite challenges with implementing the act, it was only repealed in 1983.[139]

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[134] Trembly 2002, 235.

[135] Jacob and Franco-Paredes 2008, 1-2, Rawcliffe 2006, 24.

[136] One of the examples of this fear mongering can be seen with the publishing of a book titled, *Leprosy an Imperial Danger*, by an Anglican clergymen in 1889. Jacob and Franco-Paredes 2008, 1-2, Rawcliffe 2006, 24.

[137] Jacob and Carlos, 2008, 1.

[138] Jacob and Carlos, 2008, 1.

[139] Jacob and Carlos, 2008, 1-2.

Since the advent of multi-drug therapies, the prevalence in India has dropped, and on January 30, 2005, India reported the elimination of Hansen's disease as a public health problem after achieving the nationwide prevalence of 1 case/10,000 population.[140] However, there continues to be issues in India, where many new cases of the disease are still reported and there is an inconsistency in the availability and types of treatments being provided.[141] As well, individuals who are considered to suffer from "leprosy" continue to be stigmatized by society, which is likely contributed to the fact that Indian society has a deeply ingrained (though legally abolished) caste system.[142]

United States

Leprosy and Hansen's disease was introduced to North America with the European colonial expansion. By the late 19th and early 20th centuries, the highest rates of leprosy were found in southern Louisiana.[143] This led to the establishment of the Louisiana Leper Home[144] in Carville, Louisiana, in 1894. It remained open until 1999 as the only in-patient hospital in the continental United States for the treatment of Hansen's disease. The creation of this institution originated from a fear of leprosy, and patients diagnosed in the United States were legally required to go into quarantine at Carville, which was not changed until the 1960s.[145] One of the few positive outcomes from the creation of this place was that it became "an international medical research centre for leprosy", which led to the eventual discovery of a cure.[146]

However, the experience of the patients at Carville can be considered to be traumatic and played a major role in reinforcing the stigma associated with the diagnosis of Hansen's disease, which was still most often called "leprosy" at this point. They generally lived long lives due to

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[140] Jacob and Carlos, 2008, 2.

[141] Mehta 2002, 21-23.

[142] Jacob and Carlos, 2008, 2.

[143] The stigma of this disease was experienced here as well, and the Cajuns and Creoles in Louisiana described it as "la maladie que tu nommes pas (the disease you do not name)". Gaudet 2004, 4.

[144] The hospital changed names multiple times over the years, and at various times was called: Louisiana Leper Home, United States Marine Hospital #66, National Hansen's Disease Center, Gillis W. Long Hansen's Disease Center. Gaudet 2004, 8-10.

[145] Gaudet 2004, 3.

[146] Gaudet 2004, 16.

advancements in medicine during this century, and “It is easy to forget that most of these individuals were denied their basic human rights simply because they had leprosy.”[147] For patients arriving at Carville during the early 20th century, the experience could be described as “tantamount to imprisonment” and involved a process of losing their former identities.[148] They were often encouraged by the staff working there to hide their true names, which is described in this anecdote from Carville patient Stanley Stein (real name, Maurice Levyson):

> "Morning, Sister Laura.... New patient, I see. What name is he taking?”
>
> — Another name? What was wrong with my own name? Did I have to hide under an alias like a hunted criminal? Could I keep nothing of my old life to clothe my naked ego?
>
> "Have you decided on your new name, young man?" Sister Laura asked sweetly.
>
> — I shook my head. I was too crushed to speak. [149]

After taking new names, most patients had to work hard to reestablish their sense of identity and dignity, and through the use of discursive practices, they were able to create their own customs and traditions that helped to create a sense of community at Carville. Examples of stories like the one above were a way of regaining a personal narrative over their experiences, and they were used to help politicize their fight to regain their human and civil rights.[150] One of the challenges they continually fought was the use of the terms “leper” and “leprosy”, which were used as part of the oppressive discourse surrounding this disease. Betty Martin, not her given name but one a she was forced to choose when admitted to at Carville in 1928. In her autobiography, she describes hearing the words "leper” and "leprosy" applied to her for the first time as a

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[147] Law and Hill 2002, 9.

[148] Gaudet 2004, 16.

[149] This excerpt comes from *Alone No Longer*, an autobiography published in 1936 by Stanley Stein about his time at Carville. Gaudet 2004, 29.

[150] Gaudet 2004, 23.

"soulsearing experience".[151] When she died in 2002, she was buried under her real name with no acknowledgement given of her diagnosis or experiences at Carville.

The deep sense of shame that comes with a diagnosis of "leprosy" continues in many parts of the world to this day, and the introduction of the term "Hansen's disease" was supposed to help eliminate this long-standing stigma. While this notion in theory seems sound, it has not been able to be effectively enacted. Before his death in 2002, one of the patients from Carville, Johnny Harmon, addressed this issue, stating, "They changed the name, but we haven't changed the disease. People are still afraid of us… and I want them to know that it's not contagious, and people are not lepers, they're people."[152] While it is true that the name "Hansen's disease" was introduced into the vocabulary as a substitute for leprosy, the term "leprosy" continues to be widely used in both academic and popular literature. It is possible to somewhat argue with Harmon's statement, as up until now, the people who have shaped the discourse surrounding this disease have not *changed* the name, but only added an alternative term. The continued use of these two terms interchangeably is not only historically, socio-culturally, and biologically inaccurate, it also perpetuates the centuries-old "soulsearing" stigma attached to this disease. The following Section 5, will provide a discussion exploring the inherent issues surrounding this interchanging terminology, and propose a solution that will help to change the discourse surrounding "leprosy" and "Hansen's disease".

[151] Gaudet 2004, 32.

[152] Gaudet 2004, 35.

5.0 Why Medieval Leprosy is Not Equatable to Hansen's Disease

> There were, in fact, many leprosies: of bodies and souls, of saints and sinners, of men and metals, of animals and plants. There were tame lepers and wild lepers, rich and poor, cloistered and vagrant, potential and real.[153] — Carole Rawcliffe

As shown in Section 3, tracing the history of leprosy is a long and complicated journey that includes many different versions of disease experience. By the medieval period in Europe, the understanding of this disease incorporated both a physical and spiritual aspect.[154] The following section explores the understanding of medieval leprosy in England; this overview will not be comprehensive as the discourse surrounding this disease changes depending on what time period, and where in England it is being studied. Rawcliffe touches on this difficulty, stating that the medieval experience of a leprosy sufferer "varied considerably not only with passage of time, but also according to the occupation, status, and of course, the personal repute of the person concerned."[155] Instead, the goal of this section is to show the ways in which the medieval idea of "leprosy" *cannot* be equated to the modern idea of "Hansen's disease". This is done by assessing how the medieval medical system diagnosed and treated "leprosy" and will include primary source examples.

5.1 The Humoral System and the Four Types of Leprosy

Unlike our modern biomedical system, which is based on more rigorous scientific principles codified during the 18th century, the medieval medical system comes from an older medical tradition based on ancient Greek humoral theory.[156] This theory allowed for the incorporation of spiritual and psychological elements as well as physical factors in its understanding of the body. The Greek system was built on the simple, but comprehensive, principle of balance, that within each individual existed the same four elements that made up the universe: earth, water, fire and air.[157]

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[153] Rawcliffe 2006, 43.

[154] Rawcliffe 2006, 44-103.

[155] Rawcliffe 2006, 253.

[156] Brenner 2010, Rawcliffe 2006.

[157] Rawcliffe 2006, 65.

The belief was that each of these elements was represented in the body as four different humours; blood (air), phlegm (water), black bile or melancholic (earth) and yellow bile or choler (fire) (see Figure 3 below).[158]

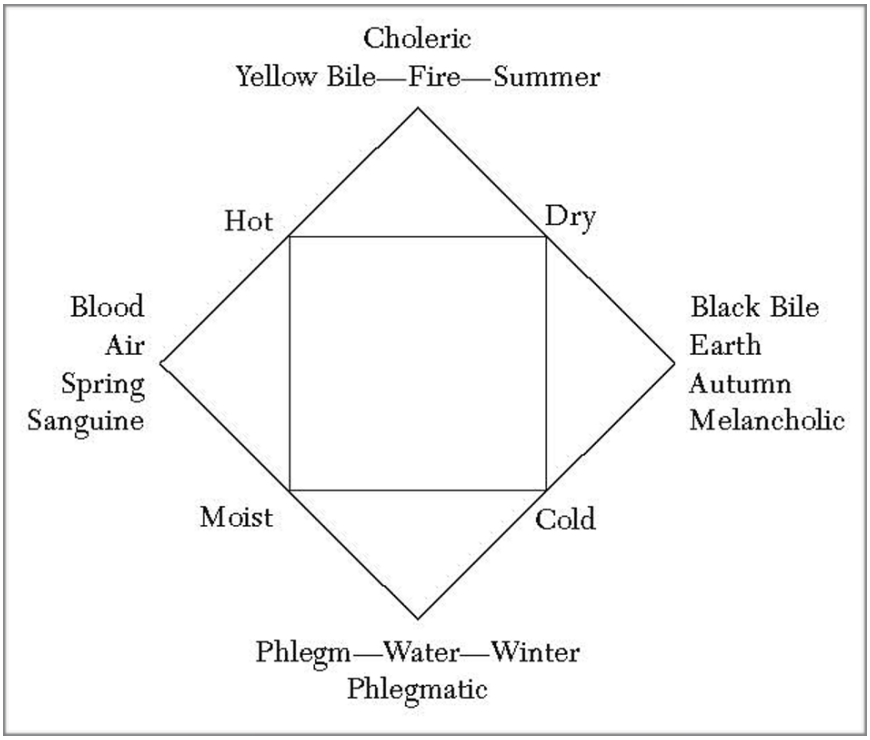

Figure 3. Diagram of the Greek Humoral System.[159]

The understanding was that one became sick when these four components became unbalanced, though even this basic notion was understood differently during Antiquity when compared with the medieval period. Galen understood any departure from balanced humours to be indicative of a pathological condition. Over time and with the introduction of Christianity, the idea shifted so that Christ became the only being with a perfect humoral balance, and all others had individual variations in temperament that influenced their humours.[160] For example, this meant that "Women's damp, timid and fleshy bodies made them inherently phlegmatic, while men naturally veered towards the sanguine or choleric."[161] An imbalance in humours could be caused by a

[158] Brenner 2010, 391.

[159] Picture taken from Galen. *Method of Medicine, Volume I: Books 1-4*. Edited and translated by Ian Johnston, G. H. R. Horsley. Loeb Classical Library 516. Cambridge, MA: Harvard University Press, 2011.

[160] Rawcliffe 2006, 71.

[161] Rawcliffe 2006, 71.

variety of things, though based on the Galic thought, an individual's diet was the most influential aspect, and the rest "fell into the general categories of air, and environment, physical exercise, sleep, evacuation of waste matter, 'accidents of the soul', psychological well-being."[162]

Based on the ancient Greek understanding, there were four types of *lepra*[163] and each corresponded to one of the different humours. One of the influential physicians during the medieval period, Theodoric of Cervia (AD 1205-1298) describes "the four types of lepra: elephantic, which has to be produced from black bile infection the blood; leonine, from bile corrupting the blood; tyrian from phlegm infecting the blood; alopecian from corrupt blood."[164] The different types seemed to correspond to the severity of the disease, and this influenced if, or how, it would be treated, as certain types were considered easier to treat than others. Rawcliffe describes this, "Only a rash — or unscrupulous — healer would undertake to cure full-blown elephantine leprosy (*elephancia*), whereas victims of the vulpine type (*alopecia*) stood a good chance of recovery if it was caught 'atte the bygynnynge' [at the beginning]".[165]

The medieval idea of leprosy described above is caused by an internal imbalance in humours rather than external forces being inflicted upon an individual.[166] This differs greatly from the modern understanding of Hansen's disease where the externally existing *Mycobacterium leprae* invades the body. This difference in understanding does not necessarily mean that medieval cases of leprosy never included cases of what we now recognize to be "Hansen's disease".[167] As well, the variety in types and expressions of symptoms seen with medieval "leprosy" does in fact share some parallels with Hansen's disease, which is known to have a great deal of variation in the presentation of its symptoms.[168] It is not, however, possible to determine how many cases of Hansen's disease occurred during this period and how often

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[162] Rawcliffe 2006, 211.

[163] See Section 3.1 for more details.

[164] Brody 1974, 37.

[165] Rawcliffe 2006, 210.

[166] Brenner 2010, 391.

[167] Based on archaeological evidence, we also are able to confirm the presence of Hansen's disease during that time period in England. Magilton et al. 2008, Roffey 2012.

[168] This is based on the strength of the immune system of the individual infected, see Section 4 for more details.

they overlapped with medieval cases of leprosy. As well, medieval “leprosy” often included cases of other modern diseases like alopecia, psoriasis and lupus.

So while there is certainly a degree of overlap between the past and modern experience of this disease, it is important to emphasize that the way “leprosy" was understood, diagnosed, and treated (as we shall see below) is in no way similar to how we deal with the modern concept of “Hansen’s disease” today.

5.2 Diagnosis of Leprosy

Modern healthcare systems found in much of the world today allow for access to standardized testing and treatment for a variety of diseases and ailments. For example, the same multi-drug treatment is prescribed globally for the treatment of Hansen’s disease. In contrast during the medieval period, the process of diagnosis and treatment varied greatly where the treatment for leprosy could change depending on which person was consulted and the type and degree of medical training he had received. Physicians, healers, surgeons, and priests are a few examples of who might be contacted in order to treat and diagnose a disease like leprosy.[169]

The tradition based on Classical medical training dictated “careful observation of outward signs likely to reveal the delicate humoral balance unique to each individual”, meaning that those trained in the medical profession were encouraged to observe their patients over time in order to find multiple unambiguous symptoms that could confirm a diagnosis.[170] It was understood that “a disease as complex and polymorphous as *lepra* might develop in a variety of ways”, and the diagnosis of leprosy was not a decision made lightly. A misdiagnosis could have psychological consequences for the patient, as well as negatively impact the reputation of the practitioner.

The textual records of methods for diagnosing a patient with leprosy are numerous and vary depending on which source is being examined (see Figure 4 below for an example of a diagram from a 13th century English medical text). Most of the medical sources during the

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[169] Roberts, Charlotte A. *Leprosy: Past and Present*. University Press of Florida, 2020, 106-107.

[170] Rawcliffe 2006, 157.

medieval period in England were translations of ancient Greek or Arabic texts,[171] which had been copied, translated, and passed down for hundreds of years. Brody describes this as the "medieval reverence for authority and tradition" where "the pronouncements of the ancients were passed on from writer to writer, and much that was valuable was preserved in this way, but just as often the transmitted information was faulty, confused or fanciful."[172] It is difficult to know how much the medieval medical practitioner used these sources, and how much was recognized as "faulty" and disregarded. From a current perspective, this might seem like a questionable way to practice medicine. Many scholars, including Rawcliffe, warn against judging "the theory and practice of medieval physicians solely by the standards of modern biomedicine".[173] In this sense, it is important to acknowledge that the discourse of medieval medicine is vastly different than our modern discourse.

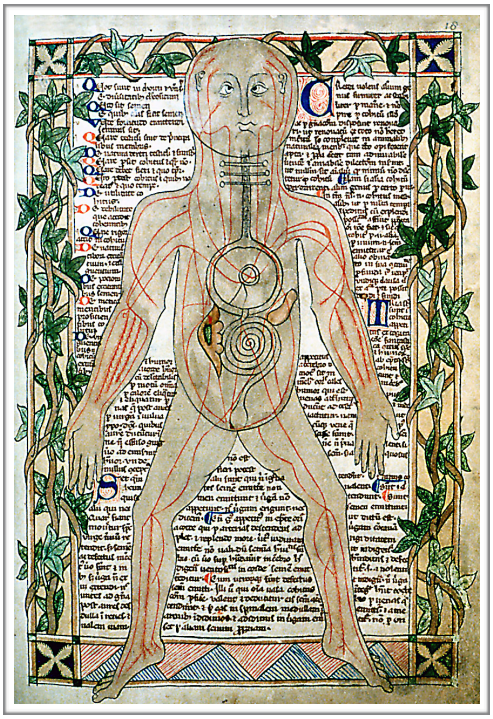

Figure 4. The nervous system from a 13th century English text (Bodleian Library, MS Selden Supra 74, fo. 101v).[174]

[171] Certain sources were more popular than others, a fact that can sometimes be deduced from the surviving number of manuscript copies. The number of references made within other works to certain texts can also be informative as to which texts were more readily accessible.

[172] Brody 1974, 45.

[173] Rawcliffe 2006, 162.

[174] Picture taken from Rawcliffe 2006, 68.

A disease as old as leprosy (*lepra*) had a lot of information written about it, and while some of the descriptions seem quite similar to symptoms of Hansen's disease, other aspects do not align with the current biomedical understanding of this disease. One of the more detailed descriptions of *lepra* comes from *The Surgery of Theodoric* (Theodoric of Cervia), which is based on the writings of Avicenna (AD 980-1087). In his description of the early stages of *lepra*, Theodoric states:

> Some list the general signs of lepra in this fashion; ruddy color of the face, tending towards a much darker color; roundness of the eyes and lividness of their whites; changing of the nails, with spurts of clear blood if the nail is compressed, narrowing of the nares, from which patients seem to talk through the nose, terrible snoring. Likewise, they grow angry very easily, and more easily than was customary. Evil, crafty habits appear; patients suspect everyone of wanting to hurt them. There is corrupt sweating; the face becomes puffy, the hairs of the eyelids and eyebrows thin out, become scarce, and fall out; nodules are felt in the skin; and the personal appearance is foul; the voice wavers, tending to lower, or to thinness, from which it finally grows hoarse and the voice fails completely; outwardly, over the whole body, the hair falls out, especially on the face; hard, stony eminences are felt, on account of the cold black bile. And this is so dispersed outwardly that if patients are pricked in the ankle bone and are unaware, they feel little, and similarly on the leg; and the soft parts of the ears are shrunken. The blood of such patients appears harsh and sour on account of the combustion. Among all signs the surest are the dusky color, lividness of the whites of the eyes and their roundness.[175]

The above description includes an interesting mix of psychological and physical symptoms, with some appearing to match the known symptoms of Hansen's disease (e.g. lower limb anaesthesia, hair loss, and vocal changes), while others are unclear or seem unrelated to any one disease (e.g. sour blood or evil, crafty habits).

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[175] Campbell, Eldridge, and James Colton. *The Surgery of Theodoric Ca. A.D. 1267: Books III and IV. Vol. 2*. New York: Appleton-Century-Crofts, 1960, 170-171.

One of the common diagnostic features that appears in many of the medical sources from this period focuses on the blood of the patient, though this is not altogether unsurprising considering blood is one of the four humours. There are multiple examples in the sources where the quality of the blood of a patient is indicative of leprosy, like the example above where the blood is "harsh and sour", or it is used as part of the diagnostic test. For example, one of the diagnostic tests Theodoric suggests:

> Likewise a common sign is that if three grains of salt are placed upon the blood of the patient they are immediately dissolved. But if the blood is not infected, they are not dissolved. Likewise another common sign is, if blood is taken and rubbed in the palm of the hand and it squeaks or is too greasy, it is a sign of infection and corruption.[176]

The idea of squeaky or greasy blood seems quite strange to us from a modern perspective, however, this was a very common test for leprosy that appears in multiple sources from the period (e.g. Gilbertus Anglicus, John of Gaddesden, Theodoric of Cervia, Avicenna).[177] The belief was that the testing of blood could reveal information that was relevant to determining a physical disorder, including Hansen's disease. Rawcliffe talks about these blood tests, stating "abnormal levels of coagulation and adhesion were, for example, not only based upon clinical experimentation, but may actually have helped to identify cases of Hansen's disease."[178]

While it is very likely that the medieval diagnosis of leprosy did include cases of Hansen's disease, it does not mean that the experience of "Hansen's disease" and "leprosy" were in any way equatable during this period. Rawcliffe eloquently summarizes this notion, "We can be reasonably sure that some - perhaps many - of the individuals… were indeed suffering from Hansen's disease, as we define it today.

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[176] Campbell 1960, 168.

[177] Demaitre, Luke. *Leprosy in Premodern Medicine: A Malady of the Whole Body.* Baltimore: Johns Hopkins University Press, 2007, 200-202, Rawcliffe 2006, 161, Roberts 2020, 108.

[178] Rawcliffe 2006, 161.

Yet such a conviction brings us no nearer to understanding how medieval men and women came to grips with the realities of chronic sickness before the microscope."[179] This is an aspect that has been rarely explored by scholars at this point, and is reflected in the frequent interchangeable usage of the terms "Hansen's disease" and "leprosy" (as discussed in Section 7, 8, and 9).

5.3 Treatment of Leprosy

As previously mentioned, the cure today for Hansen's disease is a multi-drug therapy, but during the medieval period the treatment for leprosy varied greatly from person to person, and in time and place. A treatment had to be tailored to each individual "to embrace the shifting humoral balance and environment of each individual patient", and could include changes to the diet (e.g. fresh milk), the prescription of medicinal plants, minerals, or animal products (e.g. the flesh of vipers), baths (designed to make a patient sweat and eliminate impurities), surgical procedures (e.g. phlebotomy), and attempts to improve the overall mental attitude of the patient (e.g. pleasant recreation and a positive outlook).[180] For example, one of the treatments recommended by Theodoric of Cervia says to make the patient "bathe in cold water…Then on two or three occasions give him snake broth in which the snake has been so cooked that it is all dissolved into the broth."[181]

It is interesting to note the mental aspect of the treatment regime, which is something that is arguably often ignored by modern medical care, which tends to separate the mind from the body. Disturbances of the mind were considered to be a sign of an imbalance of the humours and would be considered a symptom in the same way as a skin rash or fever. An example of this can be seen above where one of the symptoms of leprosy is that patients grow angry very easily. Rawcliffe summarizes this sentiment, "Mind and body thus enjoyed a symbiotic relationship, which depended upon the smooth working of this complex, finely tuned physiological system."[182] Another factor that differs from a modern medical perspective is the place of spirituality, because in medieval society it was understood that the mind, body, and soul were all

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[179] Rawcliffe 2006, 162.

[180] Rawcliffe 2006, 213, 220, 227, 232, 240, Roberts 2020, 116-123.

[181] Campbell 1960, 172-173.

[182] Rawcliffe 2006, 67.

parts of a whole, and the spiritual health of an individual was just as important as their physical health.[183] In this sense, the act of committing a sin had a direct impact on the physical body, where "Hidden sins spread surreptitiously like *lepra*, corrupting first the veins and then the vital organs."[184] Therefore treatment of a disease like leprosy also involved providing care for the soul, and great importance was placed on having regular access to mass and confession.[185]

Medieval treatments may have alleviated some of the symptoms of sufferers but if they were suffering from Hansen's disease, it would not have been possible to provide a long term solution. For example, an herbal bath was a relatively inexpensive treatment at that time and would be effective in cleansing the open sores and ulcers that were common symptoms of leprosy. However, today this would not be considered an effective "cure" for Hansen's disease. It is important to emphasize that our modern medical system is focused on providing a cure for any disease or ailment, but this idea is not transferable to the medieval period. A modern cure eliminates the disease and, in most cases, returns the person back to full health. During the medieval period, a "cure" was something that could provide a "*relative* improvement, a temporary remission of symptoms or the restoration of partial mobility."[186] In this sense, it was possible for the medieval physician to provide a cure for leprosy, as they could prescribe things that would improve the symptoms and overall quality of life of the sufferer. Today, this approach is still taken when treating many diseases that are incurable, such as terminal cancer or AIDS, however these treatments are considered palliative care rather than a "cure".

Aside from receiving medical care from physicians, there are also many textual examples of people suffering from leprosy being cured of their disease by saints, or by making pilgrimages to holy sites.[187] During his life, Thomas Becket, one of England's most famous saints, was said to have cured up to thirty people of leprosy, and it was claimed that God had entrusted him with

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[183] Rawcliffe 2006, 239-240.

[184] Rawcliffe 2006, 242.

[185] This also elucidates why Canon 23 from the Third Lateran Council puts such importance for those suffering from leprosy to still have access to their own church and to be administered to by their own priests (see Section 3.5 for more detail). Rawcliffe, 2006 337-343.

[186] Rawcliffe 2006, 251.

[187] Rawcliffe 2006, 168- 179, Theilmann, John M. "English Peasants and Medieval Miracle Lists." *The Historian* 52, no. 2 (1990): 286-303.

"a special mission to heal the disease."[188] After his death, his shrine became a pilgrimage site for those suffering from leprosy to visit in the hopes of finding a cure. However, it is important to acknowledge that the textual examples of saints curing leprosy was also used to advertise the power of the Church, where "the cure of leprosy…constituted the most dramatic and persuasive proof of sacred power."[189] It is therefore important to exercise a degree of caution before assuming that most medieval people would choose to visit a holy shrine before consulting a physician to treat their leprosy.

[188] Rawcliffe, 2006. 171.

[189] Rawcliffe, 2006, 169.

6.0 The Archaeology of Leprosy and Hansen's Disease

The following section provides a preliminary overview of what the archaeological record can and, more importantly, *cannot* say about medieval leprosy and Hansen's disease. Using the findings from the excavations at the Hospital of St James and St Mary Magdalen, Chichester,[190] it will consider (1) what the presence of paleopathological evidence of Hansen's disease can say about medieval leprosy (2) how the layout of the cemetery can be used to track the development of the hospital (and therefore its inhabitants) over time, and (3) what the location of the hospital says about the place of those suffering from leprosy within medieval society. As well, an in-depth example from Roberts paper, *Applying the 'Index of Care' to a Person Who Experienced Leprosy in Late Medieval Chichester, England*, will be reviewed in order to show what the skeletal remains of an individual with Hansen's disease can (and cannot) say about the experience of "leprosy".[191]

I would like to start with giving a general overview of the osteological signs that archaeologists look for on skeletal remains when attempting to establish the presence of Hansen's disease. One of the first points to address is the reliability of these signs, as much of the academic literature on leprosy does not fully address or comprehend (in the case of historians) the degree of uncertainty involved when diagnosing Hansen's disease from skeletal remains. This is a topic of much discussion among archaeologists, and Magilton et al. summarize this challenge, stating, "The ability to diagnose leprosy in archaeological human skeletal remains ranges from problematic to highly likely."[192] It takes years for the skeleton to show evidence of an infection from *Mycobacterium leprae*, and as previously discussed, the individual's immune response to the infection will influence the expression of the disease. This means that many individuals with Hansen's disease never experience it in a way that will leave its mark upon the skeleton.

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[190] Magilton et al. 2008.

[191] Roberts 2017.

[192] Magilton et al. 2008, 206.

When skeletal evidence of Hansen's disease is present, it follows a predictable pattern which is what allows palaeopathologists to identify cases of the disease in the archaeological record. In general, most archaeologists agree that the distinctive skeletal changes that are located in the face and extremities (detailed in Section 4) and must be found together in order to give a confident diagnosis of Hansen's disease. Roberts addresses this point, "Only when a cranium [skull] with evidence of *facies leprosa* was accompanied by tibiae and fibulae [leg bones] showing periosteal reaction [inflammation], bilaterally and symmetrically, could a firm diagnosis of lepromatous leprosy be considered."[193] I would like to reiterate that despite the use of "leprosy" in the quotations above, the skeletal evidence described is caused by an infection from *Mycobacterium leprae*, meaning it is representative of "Hansen's disease".

The consistent presence of skeletal remains showing evidence of Hansen's disease has been found during the excavation of cemeteries from leprosaria from around Europe,[194] and specifically within England. Roberts addresses the findings within England, "A study of leprosaria in Britain [by Satchell][195] noted that significant numbers of lepers were suffering Hansen's Disease in England between 1100 and 1250."[196] This is supported by the findings from the cemetery at St Mary Magdalen, Chichester, and Magilton et al. state "as excavations of hospital cemeteries in Chichester and elsewhere have shown, the inmates were commonly but not necessarily exclusively sufferers from Hansen's disease."[197] These findings have greater implications for the medieval concept of "leprosy", because it tells us that it often included cases of Hansen's disease. The large numbers of people suffering from Hansen's disease within the cemeteries of leprosaria also suggests that the medieval medical practitioner was able to consistently identify the disease with some accuracy.

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[193] Roberts 2020, 176.

[194] Boldsen, Jesper L. "Epidemiological Approach to the Paleopathological Diagnosis of Leprosy." *American Journal of Physical Anthropology*. 115, no. 4 (2001): 380-387, Roberts 2020.

[195] Satchell, A E M. *The Emergence of Leperhouses in Medieval England* (unpublished DPhil thesis, University of Oxford), 1998.

[196] Roberts 2020, 201.

[197] Magilton et al. 2008, 9.

Within England, the study of medieval leprosaria provides a valuable source of evidence on Hansen's disease *and* leprosy. Modern biases often paints the leprosaria as a harsh prison used for the segregation of those suffering from leprosy, but more recent research has shown that this was not necessarily the case. Unlike monasteries from the same period, the medieval leprosarium did not have a regulated or consistent layout, and the "type and arrangement of buildings was no doubt dependent on various factors including status, location, resources and patronage."[198] Magilton et al. also describe how there were no restrictions, aside from financial, to who could set up a leprosarium, and they were usually financed by the crown, the aristocracy, bishops or other religious orders.[199] It is also important to highlight that "a hospital was not established primarily in the case of public health but as a notable act of piety."[200] This variety in size and resources meant that the lifestyle within the leprosaria was not a universal experience. While some living conditions were certain to be unpleasant, if the hospital had a lot of resources it could be a comfortable place to live. This is supported by historical evidence which has shown that there was often a bias for admittance to these hospitals based on family connections, and that vast sums of money or donations were required in order to secure a place at some of these institutions.[201]

The location of these leprosaria, often determined through archaeological excavation, shows that they were usually placed on the outskirts of towns. There were a variety of reasons for this, including more room for farming and gardening, and importantly, so that they could collect alms and charitable donations from people who were travelling on their way to town. Magilton et al. support this, stating, "Alms gathering from passers-by was a potentially important element in a hospital's income, and main roads, especially road junctions and bridges or river crossings, were favoured sites."[202]

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[198] Roffey 2012, 228.

[199] Magilton et al. 2008, 20.

[200] Magitlon et al. 2008, 69.

[201] Magilton et al. 2008, 20.

[202] Magilton et al. 2008, 69.

One of the other main attractions of life within a leprosaria was that patients were almost certainly guaranteed to have appropriate funeral practices upon their deaths.[203]

One of the largest leprosarium cemetery's excavated in England (and the world) to date is St James and St Mary Magdalen, Chichester, Sussex.[204] The hospital was founded in the early 12th century and was occupied until the mid-17th century, and it provides valuable insight into the period when leprosy was most prevalent in England. As described above, the St James' Chichester site was a classic example of a medieval leprosarium, in that it was reliant on an agricultural-based economy and was located close to two main road junctions.[205] Based on historical documents, the leprosarium was run based off of gifts, alms, and charity, and by the 13th century it was tax exempt.[206] It provided a place for patients to live and it had an associated garden where food and medicines were grown.[207]

Of particular importance to archaeologists, the cemetery attached to the leprosarium yields unique information about how the leprosy patients were treated, and also sheds light on how the hospital developed over time. It is an accepted notion among archaeologists that "the place of burial reflected the status of the deceased," and within the graveyard there were certain locations favoured over others.[208] In the case of St James, Chichester, one example of a "special" burial is with two women who were "privileged" to be buried in the all-male cemetery and "were honoured after death by those who sought to be buried as closely as possible to them."[209] There is one other burial that reflects the status of the individual, a syphilitic person was buried at a distance from everyone else in what appears to be a sign of disrespect.[210] There were many examples of individuals with Hansen's disease buried in the cemetery, but it does not appear that they were treated differently from the other "regular" burials, suggesting that their experience of leprosy did not influence their relative status *within* the hospital.

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[203] Magilton et al. 2008, 20.

[204] Roberts 2020, 206-207.

[205] Magilton et al. 2008, 69, Roberts 2017, 105.

[206] Magilton et al. 2008, 57-68, Roberts 2017, 118.

[207] Roberts 2017, 118.

[208] Magilton et al. 2008, 27.

[209] Magilton et al. 2008, 264.

[210] Magilton et al. 2008, 264.

The burial layout of the cemetery as a whole can also tell us about the chronological development of the hospital. This can be done by tracking the distribution of the burials, for example, at Chichester the burials are split into two time periods. The first period is made up almost exclusively of male burials with many of them having skeletal evidence of Hansen's disease, and the second period shows a decrease in the prevalence of Hansen's disease, and also includes more female burials. Magilton et al. interpret this information, stating "the demographic and pathological profiles confirm a division into two distinct phases, the leprosarium and the almshouse"[211] This is supported by the historical documents for the site, which show that the site was originally made as a leprosarium, but as the number of cases of leprosy decreased by the beginning of the 16th century, it was repurposed to be an almshouse. Figure 5 (below) shows the excavation of the cemetery at St Mary Magdalen, Winchester, which is very similar in size and scope to the St James, Chichester archaeological site.

Unfortunately, at this point there is a decided absence of medical artifacts recovered from medieval leprosaria (including St James, Chichester), and the ones that are found appear no different than artifacts found from comparative monastic sites.[212] Whether this reflects a lack of medical care administered in these hospitals, or an issue of preservation is unknown. It is important to point out that many of the common materials available during this period would not be easily preserved within the archaeological record. For example, one of the popular treatments for leprosy was herbal baths and the type of tub that would have been used in the hospital would likely have been made of wood, and therefore would not survive in an archaeological context.[213] While archaeological evidence from leprosaria can give significant insight into certain aspects of the medieval experience of leprosy, it cannot provide a complete picture. The individuals admitted to leprosaria can still only be counted as a smaller subset of the total number of people suffering from the disease during this period, and unfortunately, the majority of their experiences are lost to the past.

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[211] Magilton et al. 2008, 263.

[212] Roffey 2013, 226.

[213] Rawcliffe 206, 232.

Figure 5. The excavation layout of the cemetery at St Mary Magdalen, Winchester.[214]

6.1 A Discussion of the Analysis of Skeletal Remains from St James, Chichester

The following section gives an overview of a study by Roberts where she applies a unique methodological approach based off the 'Index of Care'[215] to the analysis of a set of skeletal remains excavated from the hospital cemetery of St James and St Mary Magdalen, Chichester. Roberts article explores the idea that it is possible to extrapolate (to a degree) the physical experience of someone living in a medieval leprosarium based on modern information we have about the progression of symptoms of Hansen's disease. She starts by including a description of the archaeological site at Chichester (described in more detail above), and outlines how skeletal remains can be used to discuss a person's biological sex, their gender, age, and status. The skeleton she chose to study was a male, aged 25-35 years at death, and had a variety of issues that indicated various medical problems.

[214] Picture taken from Roffey and Tucker 2012, 206.

[215] A newly developed (2014), more objective method "for assessing the likely provision of care for people whose skeletons bioarchaeologists study". Roberts 2017, 105.

Roberts describes the paleopathological examination: "Lesions caused by bone formation and destruction, and dental destruction (e.g. dental caries, enamel hypoplasia) and accretion (calculus) were recorded, their distribution pattern documented, and differential diagnoses considered."[216]

The following is a summary of these findings and the ways in which they can be interpreted to shed light on the life experiences of a medieval man who lived at St James, Chichester. He had a prevalence of teeth cavities which suggests that he had a diet that was high in starches and sugars, and possibly milk and dairy proteins.[217] Unlike today where it is possible to visit a dentist, this man would not have been able to treat these cavities, meaning they may have been painful and caused problems with eating and overall appetite.[218] His teeth had defects (enamel hypolasia) that indicates periods of stress during development of the teeth, which is interpreted to mean that he experienced some form of dietary deficiencies or childhood disease.[219]

The bones of the face showed signs of inflammation that could be the result of infection of the skin (e.g. the skin lesions from Hansen's disease), and the nasal bones were damaged, meaning he likely would have had a misshapen nose (another sign of Hansen's disease) (see Figure 6).[220] Similar inflammation and other damage was found on the bones of the hands, feet, and lower legs, which follow patterns associated with Hansen's disease. This would have likely led to painful ulcerations of the feet, and the associated nerve damage suggests he might have problems straightening his fingers and using his hands.[221] Signs of inflammation on the ribs and spinal degeneration suggests he may have also been struggling with some form of respiratory disease.

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[216] Roberts 2017, 107.

[217] Roberts 2017, 111-112.

[218] Roberts 2017, 111-112.

[219] Roberts 2017, 112.

[220] Roberts 2017, 113.

[221] Roberts 2017, 115.

Overall, Roberts is comfortable providing a firm diagnosis of "leprosy" (by which she means Hansen's disease) for this set of skeletal remains, and suggests that it was "likely the low resistant form, and it appears that he had it for some time, although it is impossible to say for how long."[222]

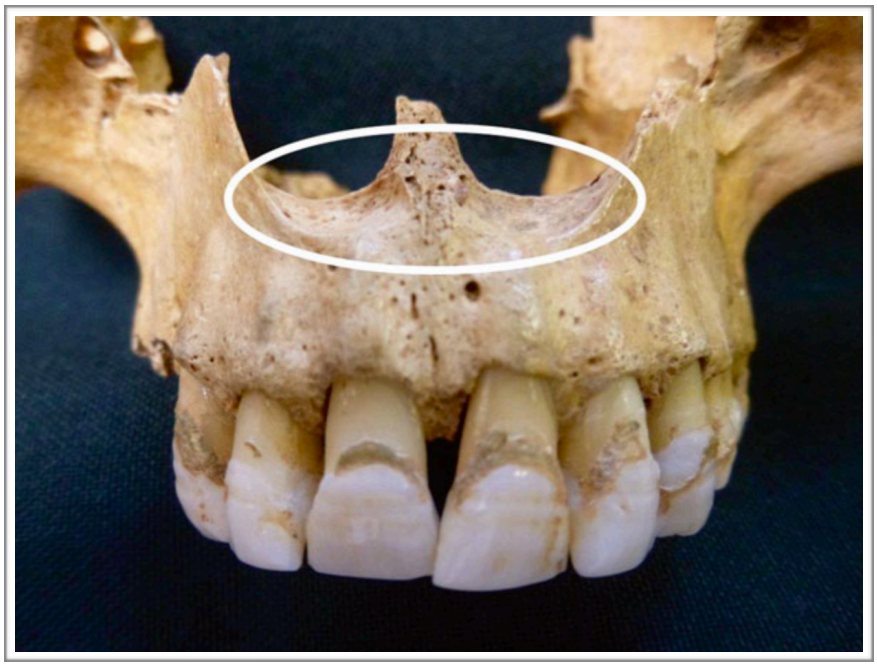

Figure 6. Damaged nasal cavity caused by Hansen's disease, as described by Roberts in her article.[223]

While the above information is enlightening of some of the physical experiences this medieval man may have had to endure, it is also important to discuss what is missing from this interpretation. The study of skeletal remains, while suggestive of physical symptoms, cannot actually confirm whether there were skin lesions, facial nerve damage, blindness or hearing loss, muscle weakness, thinning of eyebrows and eyelashes, the level of difficulty he might have had in walking, using his hands, and breathing.[224] Just as importantly, it is not possible to see how he *felt* about what he was experiencing (e.g. whether he had associated depression), and the extent to which he was stigmatized by his local community.[225]

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[222] Roberts 2017, 114.

[223] Picture taken from Roberts 2017, 109.

[224] Roberts 2017, 116.

[225] Roberts 2017, 117

To this point, while we know he suffered from Hansen's disease and was buried in the cemetery attached to the St James Leper Hospital, we cannot confirm whether he actually resided at the hospital, or instead lived at home and then was buried there after his death.[226]

The study by Roberts is useful in that it provides a starting point for a discussion on what can and cannot be said about the medieval person's life experiences based solely on their skeletal remains. As shown above, it is possible to interpret how the physical evidence of Hansen's disease might have impacted certain aspects of a medieval leprosy sufferer's life (e.g. diet and mobility), which is one of the few areas where there is a direct overlap between the modern idea of "Hansen's disease" and the medieval notion of "leprosy". However, the paleopathological evidence is generally limited to the physical realm, and is not able to say anything about the social experience of the disease. The archaeological record can be used to interpret some of the more social aspects of medieval "leprosy", though it is still not able to provide any great level of detail. For the most part, archaeological and paleopathological evidence can either tell us details about historical cases of Hansen's disease *or* about the treatment of medieval lepers, but usually not both. Many scholars would assume that historical textual references are needed in order to shed light on the experiences of medieval people, and while that certainly continues to be a main source of information, the archaeological and palaeopathologcial record can still provide valuable insight into the experiences of the medieval leprosy sufferer.

[226] Roberts 2017, 117.

7.0 A Clear Definition for Hansen's Disease and Leprosy

Before examining how the different discourses of leprosy in medieval England have made use of terminology, I would first like to clearly explain how I think both "leprosy" and "Hansen's disease" should be used. As I have previously outlined in Sections 5 and 6, it is difficult to clearly define the concepts of leprosy and Hansen's disease, and even harder still to determine how much they overlap. The term "leprosy" has a variety of socio-cultural implications that have changed over the course of its extensive history. It can be applied in historical and archaeological contexts, when referring to the experience of the illness. When studying this disease in the past, it is often difficult to navigate the boundaries between the modern biological understanding of the disease and how it was experienced and understood historically. The term "leprosy" has been used to incorporate many different modern diseases (including Hansen's disease) and the experiences that comprise it have changed over the course of two thousand years. The importance of addressing this issue and clarifying the use of these terms becomes particularly evident when examining examples of multidisciplinary work on this topic. This involves confronting an overlap between Hansen's disease, the modern term for a biological disease, and the lived experience of medieval leprosy.

The written record for this disease starts around two millennia ago, though we know based off of DNA evidence that the mycobacterium causing Hansen's disease has been affecting humans for many thousands of years before this. The historical names that have survived to the present day are many, including, leprosy, *lepra, elephantiasis*, *tsara'ath, lail|li* 癘, *kushtha, judhām,* and now Hansen's disease. The true identity of "leprosy" encompasses all human experiences of this disease over time, most of which are not epistemically accessible to us from the present. So I argue that instead of struggling to find the right terminology to address the *true* identity of this disease, it becomes simpler and more effective to work with the existing discourses surrounding it. Discourses are in a constant process of definition and renegotiation over time, and the current discourse for this disease allows for two separate but overlapping concepts — that of "leprosy" and "Hansen's disease". It is my goal to provide a template for both *why* and *where* these separate terms should be used within the academic literature, which will also have broader implications for the popular discourse of the disease.

While some may state that this is an argument of pure semantics, I would like to clarify that it is addressing the issue of terminology on a pragmatic level. The key difference between semantics and pragmatics is that semantics is context independent whereas pragmatics is context dependent.[227] These concepts can be applied twofold: first, the application of the terminology can be considered a matter of pragmatics because the use of "leprosy" and "Hansen's disease" is dependent on the context in which they are being used (which will be explored in detail in Section 8 and 9). Secondly, these two terms can be split on a basis of a semantic definition (Hansen's disease) versus a pragmatic definition (leprosy).

The Oxford English Dictionary defines leprosy as "a contagious disease that affects the skin, mucous membranes, and nerves, causing discoloration and lumps on the skin and, in severe cases, disfigurement and deformities."[228] This is clearly a description of the modern biological symptoms of the disease, and does not attempt to incorporate its complex history. As I have previously touched on, the concept of "leprosy" has gone through many iterations throughout its lengthy history (see Section 3), and it is very difficult to offer a single definition for this reason. I would like to frame this definition of leprosy from a pragmatic perspective, and emphasize that it should be used to encompass the experiential and subjective (e.g. socio-cultural) aspects of the disease. To provide an example, we would use this term when considering the experiences of a person from the medieval period. While this person may or may not have had the bacterial infection caused by *Mycobacterium leprae*, they believed they were suffering from a condition identified as "leprosy".

To contrast, the term "Hansen's disease" has a very specific biological context in which it should be used, and many would argue that it cannot easily be applied to the past without it creating problems of anachronism. When searching for an exact definition of Hansen's disease, most sources redirect to definitions of leprosy because the two concepts are frequently equated.

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[227] Cruse, Alan. *Glossary of Semantics and Pragmatics*. Edinburgh University Press, 2006.

[228] *Leprosy*, edited by Soanes, Catherine, and Angus Stevenson. 11th ed., rev. ed. Oxford: Oxford University Press, 2008.

The American Center for Disease Control and Prevention (CDC) does provide a definition, stating “Hansen’s disease (also known as leprosy) is an infection caused by slow-growing bacteria called *Mycobacterium leprae*. It can affect the nerves, skin, eyes, and lining of the nose (nasal mucosa).”[229] This is the foundation for my definition of Hansen’s disease, an etiological description that is based on evidence which is biologically determined, and ultimately places this term firmly within the “modern” period. This definition is a matter of semantics because it is an objective definition that does not change depending on the context in which it is being used. For example, a person today who is infected with *Mycobacterium leprae* can be accurately said to have Hansen’s disease, just as the skeletal remains from the medieval period that show DNA evidence of *Mycobacterium leprae* can also be said to have Hansen’s disease. This description is independent of whether either of these individuals considered themselves to have “leprosy" or experienced any stigma related to their disease. The average lay reader is not as familiar with "Hansen’s disease” as compared with “leprosy”. Until “Hansen’s disease” becomes the commonplace term, it will still be necessary to qualify the use of “leprosy” with phrases likes, “historically known as”, in order to better contextualize the substitution of terms. For example, “Hansen’s disease (historically known as leprosy)”.

It is also necessary to address the implications for these definitions for the current medical terminology surrounding Hansen’s disease. As previously mentioned in Section 4, the most popular system for categorizing the symptoms of this disease is by using the Ridley-Jopling scale, which involves a five-group classification system. The system involves using the terms “lepromatous leprosy”, “borderline leprosy”, “tuberculoid leprosy” or a combination of these terms to place the severity of infection on a spectrum.[230] The issue of using “leprosy” for a medical diagnosis has already been addressed by the World Health Organization which created a binary system based on the amount of bacterium present, labelled as either multibacillary (large amounts of bacteria) or paucibacillary (small amounts of bacteria).[231]

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[229] Centers for Disease Control and Prevention. “Hansen’s Disease (Leprosy)”. CDC.gov. https://www.cdc.gov/leprosy/.

[230] Singh et al. 2004.

[231] Taylor et al. 2013.

One of the main critiques of this system is that this simplistic distinction is not particularly useful with a disease that has a wide range of symptoms based on the individual immune response of the patient. I would therefore like to suggest a rewording of the Ridley-Jopling system, where "leprosy" is replaced with "Hansen's disease" and the five groups are relabelled as stages (similar to cancer diagnoses). So the preliminary stage of infection, tuberculoid leprosy, would become Stage 1 Hansen's disease, and this scale would continue up to the most extreme form, lepromatous leprosy, which would become Stage 5 Hansen's disease. The use of this terminology removes the use of the word "leprosy" (and its related stigma) and it is also more consistent with the current medical diagnostic practices for other diseases (e.g. cancer, Parkinson's disease, and chronic kidney disease).

One last topic I would like to briefly address is the use of the term "leper", which at this point in time is considered a derogatory word for someone suffering from Hansen's disease. While many scholars now avoid using the term, it is still often used in the academic discourse on leprosy. This is somewhat problematic still, as many scholars argue that this use helps to perpetuates the stigma surrounding the disease. The depth of this stigma within popular culture can also be seen in the Oxford Dictionary definition of the term "leper". The first definition is "a person suffering from leprosy", and the second is "a person who is shunned by others", which demonstrates the metaphorical and derogatory nature that this term embodies.[232] Skinsnes and Hill bring attention and propose a solution to this issue, stating, "Rather than perpetuate the offensive language of the past under the guise of 'historical accuracy', it is far more humane and appropriate to start referring to individuals diagnosed with this disease by their own names… If their names are unknown, it is far better to say a 'person affected by leprosy' or 'a person affected by Hansen's Disease'"[233] I argue that this solution works in almost all cases, and the only place I see the need for an exception is when quoting directly from historical primary sources that uses the term (e.g. a medieval medical text that uses the term).

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[232] *Leper*, edited by Soanes, Catherine, Angus Stevenson. 11th ed., rev. ed. Oxford: Oxford University Press, 2008.
[233] Law and Hill 2002, 7-16.

8.0 The Historical Discourse of Leprosy in Medieval England

In order to create a strong basis for support for my proposed terminology, I examine the current issues involved with the inconsistent use of "leprosy" and "Hansen's disease" in the historical academic discourse of leprosy in medieval England. This section aims to provide a relatively complete overview of the sources incorporated within this discourse and is organized based on the ways scholars distinguish between the concepts "leprosy" and "Hansen's disease". The aim is to explore how the different approaches taken has impacted the quality of the academic discussion surrounding this disease. I will also provide alternative examples with the terminology usage I propose, in order to demonstrate how it can clarify and improve the efficacy of the academic discussion. The approaches taken by the majority of scholars can be separated into three main categories: the first, in which the two terms are used interchangeably, the second, in which the use of "Hansen's disease" is avoided, and the third, in which the scholars propose their own terminological distinctions, frequently involving Hansen's disease being labelled as "true" leprosy. Within these categories, the academic works will also be examined for their overall contribution to the historical discourse surrounding leprosy in medieval England.

8.1 Interchanging Use of the Terms "Leprosy" and "Hansen's Disease"

Brody's *The Disease of Soul: Leprosy in Medieval Literature*

One of the first historians to tackle the topic of leprosy in the second half of the 20th century was Saul Brody, who published *The Disease of Soul: Leprosy in Medieval Literature* in 1974.[234] It was one of the few authorities on medieval leprosy before the pivotal works by Rawcliffe and Demaitre[235] were published in 2006 and 2007 respectively. It is composed of four in-depth essays on medical leprosy, social leprosy, ecclesiastical tradition, and leprosy in literature.[236] Brody's volume focuses mainly on examples of leprosy from religious and secular literature,

[234] Brody 1974, 78.

[235] This section will not examine Demaitre's response to this issue in any great detail because his book does not fall within the discourse of medieval England. However, I would still like to mention how he addresses the issue of terminology as Demaitre is incredibly cautious and avoids the discussion surrounding the overlap between Hansen's disease and leprosy. He states, "Long before the recognition of HD, a generally corresponding disease differed as a genuine medical entry… I will not pursue the question, of long-standing and great interest, of whether premodern leprosy was identical to Hansen's disease." Demaitre 2007, viii.

[236] Brody 1974.

with the aim of exploring the (often allegorical) association between leprosy and sin. While it is still considered one of the influential works on the topic, Brody's work can be critiqued for having a degree of generalization in its treatment of the experiences of leprosy sufferers from the period. It has, perhaps inadvertently, helped to perpetuate the stereotype of "the stigmatized leper" who was isolated from society, something that continues to persist in the popular discourse and which was not properly addressed in the academic discourse until the publication of Rawcliffe's volume.

Brody starts his volume by making an interesting point about the challenges of tracing a modern disease throughout the past, stating that "without clinical description of it there can be no standard against which to measure the descriptions found in medieval literature."[237] This brings up the issue of overlap between the modern and past understandings of disease. It is certainly possible to examine a disease in the past without trying to find its modern equivalent, and there are diseases in the past that have textual descriptions that do not appear to match up to any known modern illnesses (e.g. sweating sickness).[238] Based on DNA and skeletal evidence, it is also possible to see that certain modern diseases (like Hansen's disease or tuberculosis) did exist in the past, and many scholars consider consider it useful to examine the textual record for information that confirms the archaeological evidence. Brody's point also highlights the fact that the discourse of "leprosy" went through a transformation over time, and this change allowed for the incorporation of a second term, "Hansen's disease".

Overall, Brody does better than most scholars in his treatment of these two terms, as he acknowledges that medieval leprosy does not equate to Hansen's disease. He states, "The picture of leprosy offered by medieval medicinal tracts departs in significant ways from the contemporary representation."[239] The only way I would clarify this statement would be to change the ending to: "the contemporary representation of Hansen's disease", in order to better delineate between the past and present concepts. Brody makes a common choice to sometimes equate the

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[237] Brody 1974, 21.

[238] Described as "a very peculiar case of pre-modern disease, since there has been no agreement among historians as to its identity." Arrizabalaga, Jon. "Problematizing Retrospective Diagnosis in the History of Disease." *Asclepio* 54, no. 1 (2002): 57.

[239] Brody 1974, 24-25.

terms “leprosy” and “Hansen’s disease”, suggesting that he sees the two concepts as somewhat interchangeable. For example, in his description of the symptoms of the modern disease, he states “The first indications of leprosy are usually neurological”, where I would argue that a simple substitution to “The first indications of Hansen’s disease are usually neurological” is a more factual description.[240] The overall treatment of these two concepts by Brody is more effective than those made by other scholars, and the changes to his volume would be very minimal in order to fully incorporate the stricter usage of terms that is argued for in this thesis.

Lee’s *Changing Faces: Leprosy in Anglo-Saxon England*

Christina Lee’s article, “Changing Faces: Leprosy in Anglo-Saxon England”, focuses on evidence for leprosy and Hansen’s disease in the early medieval period of Anglo-Saxon England.[241] Her article is very comprehensive and effectively addresses both the archaeological and historical evidence for the presence of the disease during the pre-Conquest period. Lee, like many scholars, seems to equate leprosy to Hansen’s disease, stating, “Leprosy, or Hansen’s Disease, is an infectious disease caused by the *Mycobacterium leprae.*”[242] She acknowledges that medieval leprosy lacks the modern concept of a unified disease, but she does not try to distinguish between the modern and past understandings of the disease. Somewhat problematically, she also uses the term “leper” which (as previously mentioned) is considered a stigmatizing and unnecessary term in both the modern and historical discourse for this disease.

Despite an initial reference to Hansen’s disease, she maintains the use of “leprosy” throughout the entire article when referencing both the archaeological and textual evidence for the disease. She does not explain how closely overlapping the leprosy described in the textual sources with what is described in her archaeological discussion. It is clear she strongly correlates the two concepts as she attempts to retrospectively diagnose Hansen’s disease from textual examples of leprosy in Anglo-Saxon texts, though she still asserts that the examples she provides are *possible* references to the modern disease.

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[240] Brody 1974, 25.

[241] Lee 2006.

[242] Lee 2006, 26.

Due to the fact that she discusses both archaeological and historical sources, the article would certainly benefit from clearly defined terminology. Her use of “leprosy” works well in her commentary on the textual sources, for example, “it is impossible to draw conclusions about the general treatment of lepers from religious texts, which were taken from a variety of sources and interpret leprosy in an allegorical way”. This statement exemplifies the complex nature of the medieval understanding of leprosy, and I believe that this is an appropriate use of the term. The only criticism of the above statement is the use of the term “leper”, as instead she could have said “the general treatment of leprosy sufferers” or “the general treatment of those suffering from leprosy”. The issue arises in her use of “leprosy” when referencing paleopathological evidence of Hansen’s disease. For example, one of her statements, “Archaeologically, leprosy is very hard to detect”[243] would be more factual if instead she said "Archaeologically, Hansen’s disease is very hard to detect”. Ultimately, “Hansen’s disease” could be used consistently throughout her article in her discussion of the archaeological evidence, and when she switches to discussing the textual references to the disease, then the term “leprosy” can continue to be used. This would help to clarify the difference between the types of evidence she considers, and it would reduce confusion for readers.

8.2 Avoiding the Use of "Hansen’s Disease"

Rawcliffe’s *Leprosy in Medieval England*

As mentioned earlier in this section, there was a perpetuation of misinformation in historical sources which continued until Carole Rawcliffe’s *Leprosy in Medieval England* was published in 2006.[244] This marked a turning point in the discussion around leprosy in medieval England, as the volume corrected much of the misinformation that was being maintained by historians and archeologists surrounding the experiences of people suffering from leprosy in the medieval period. It has been described as "the most comprehensive and accessible history to date”, which is a description that still applies almost fifteen years after being published.[245] In particular,

[243] Lee 2006, 63.

[244] Rawcliffe 2006.

[245] Luke Demaitre. "Leprosy in Medieval England (review)." *Bulletin of the History of Medicine* 82, no. 2 (2008): 439-440.

Rawcliffe's analyses are effective because they address the varying experiences of leprosy throughout the medieval period in England.[246] She is also one of the first to highlight how modern negative stereotypes surrounding medieval leprosy can ultimately be traced back to attitudes formed by the colonial power of 19th century Britain.[247]

Rawcliffe is more aware than many other scholars of the continuing stigmatization experienced by those suffering from Hansen's disease and the potential for confusion involved when using the terms "leprosy" and "Hansen's disease". In her introduction, she states that "to describe medieval lepers as 'sufferers from Hansen's disease' would not only be anachronistic but also inherently misleading."[248] She also addresses the ongoing stigma attached to the disease and how it is influenced by the terminology usage. In the first page of her introduction she notes how leprosy is now known as Hansen's disease "in order to alleviate the sense of stigma experienced by its victims", and later acknowledges how the battle to end this stigma has only been partially successful.[249] It is my hope that this thesis can further contribute to this ongoing battle with this centuries-old stigma.

By acknowledging that there is a modern and a medieval identity for this disease, Rawcliffe is able to mostly avoid issues involved with terminology usage. Her volume focuses on medieval leprosy using historical and primary source evidence, and she does not attempt to bring in an archaeological perspective. Her discussion of archaeological evidence is also generally focused on interpreting the medieval experience of leprosy sufferers, a topic that does not require the use of "Hansen's disease". For example, when she is discussing the excavations made at St. Nicholas's in York, her discussion is focused on what the evidence could show about the diet and general living conditions for the people who lived at the leprosaria there.[250]
For the majority of the volume, Rawcliffe uses only "leprosy" but she is specifically using the term in reference to the medieval understanding and experiences of the disease.

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[246] Touati, François-Olivier. "Leprosy in Medieval England." *Medical History (pre-2012)* 53, no. 1 (2009): 150-151.
[247] Byrne, Joseph P. "Leprosy in Medieval England." American Historical Review 113, no. 2 (2008): 556-557.
[248] Rawcliffe 2006, 12.
[249] Rawcliffe 2006, 1-2.
[250] Rawcliffe 2006, 332.

In a few cases she includes archaeological and osteological evidence of Hansen's disease, and this is where the use of "leprosy" becomes problematic. Despite acknowledging that these two concepts are not analogous, at times she still treats them interchangeably. For example, when Rawcliffe discusses the physical manifestation of symptoms from Hansen's disease, she confusingly switches back and forth between both terms. She finishes one paragraph, "In areas where Hansen's disease has long been established—" and starts the next paragraph with "Leprosy thus adopts a truly protean shape—"[251] In this context, the use of both terms would be acceptable if she were to distinguish between what she meant by "leprosy", and how it differed from her previous references to "Hansen's disease". Overall, Rawcliffe shows much more awareness than other scholars of the distinction between these two terms, though she does not attempt to give any clear guidelines for when they should be used within the literature.

Demaitre's *Leprosy in Premodern Medicine: A Malady of the Whole Body*

Alongside Rawcliffe's text, Demaitre's volume, *Leprosy in Premodern Medicine:A Malady of the Whole Body*, is considered one of the main authorities on medieval leprosy, and for that reason I will also briefly discuss how he addresses the issue of terminology.[252] Demaitre is incredibly cautious and avoids the discussion surrounding the overlap between "Hansen's disease" and "leprosy", stating, "I will not pursue the question, of long-standing and great interest, of whether premodern leprosy was identical to Hansen's disease."[253] He does acknowledge that there are clear examples from the past of people with leprosy who today could be considered as having Hansen's disease. He also importantly states "This, of course, does not mean that the two diseases, or their defining criteria, were the same."[254] He chooses instead to limit his discussion to what he calls the "premodern responses to disease", and does not try to match the written record with archaeological and paleopathological evidence.

For the most part, the historical discourse surrounding leprosy can reasonably avoid terminology issues if the topics studied stay within the realm of the past experiences of the

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[251] Rawcliffe 2006, 3.

[252] Demaitre 2007.

[253] Demaitre 2007, viii.

[254] Demaitre 2007, viii.

disease. Nevertheless, most historians could still benefit from using clearer terminology, especially in their attempts to address the overlap between the past and modern understanding of the disease.

8.3 "True" Leprosy: An Alternative Definition for Hansen's Disease

Browne's *Some Aspects of the History of Leprosy: The Leprosie of Yesterday*

One of the only historical articles of note published contemporarily with Brody's work was Stanley Browne's, "Some Aspects of the History of Leprosy: The Leprosie of Yesterday".[255] This article provides a brief overview of leprosy, including its appearance in Antiquity and the Bible. It then presents evidence for the disease in Britain with a focused section on medieval England, and it looks at the paleopathology of Hansen's disease. I found that the author was a little ambitious in all the topics he tried to cover, as each section could reasonably be its own paper. He does demonstrate appropriate caution in his discussion of the evidence and provides a good general summary of the transformation of "leprosy" over time. His article is also somewhat unusual, in that despite having a historical focus, it also incorporates archaeological and osteological evidence.

Browne attempts to distinguish between the concepts of "leprosy" and "Hansen's disease" by supplying his own terminology. He describes the difference between the historical and biological understanding of the disease by using the terms "true leprosy" or "clinical leprosy" to mean Hansen's disease.[256] The scope of his article and its multidisciplinary nature means that it would benefit from effectively differentiating between the experiential (leprosy) and etiological (Hansen's disease) definitions of the disease. He clearly acknowledges that the two concepts are not totally equatable, though he does so without a clarity of language. He states "The use of the word leprosy is no guarantee that the specific mycobacterial disease called leprosy is intended."[257] This is an instance where I would argue that the use of "Hansen's

[255] Browne 1975.

[256] Browne 1975, 485.

[257] Browne 1975, 486-487.

disease" would serve to further clarify the statement, instead saying "The use of the word leprosy is no guarantee that the specific mycobacterial disease called Hansen's disease is intended."

Browne inadvertently makes a statement that supports the need for differentiation in the terminology of this disease, explaining, "In the face of this verbal uncertainty, it is both helpful and salutary to acknowledge the existence of an objective criterion for the presence of leprosy in any community."[258] In this case, he is referencing the skeletal changes caused by the presence of the mycobacterium causing Hansen's disease. He goes on to discuss the paleopathological evidence of this disease in Britain, however he continues to use the term "leprosy" in his discussion. For example, he states that "Such bony defects, when found in connection with the specific osseous erosion of the above-mentioned cranial bones, are caused by leprosy and only by leprosy." If this statement was changed to "are caused by Hansen's disease" he would not need to specify any further, as the statement immediately becomes clearer. At no point does he actually use the term "Hansen's disease" in his article, despite the fact that he references the discovery of the mycobacterium by Gerhard Armauer Hansen, and is therefore missing out on a useful terminological distinction.

I feel it is important to point out one further issue with Browne's article, which is that he deliberately acknowledges and then disregards the issue of stigma surrounding the term "leper". In the introduction of his paper he gives the disclaimer, "not-withstanding the recommendation of the World Health Organization and the International Leprosy Association, I shall use the word leper from time to time, in context, and without subscribing to the pejorative and stigmatizing connotation that the word commonly evokes."[259] As already mentioned, there are alternatives to using "leper" that are equally as accurate but do not perpetuate this longstanding stigma, and I would argue that the only place where the term "leper" should be used is in a direct quotation of a primary source.

9.0 The Archaeological Discourse of Leprosy in Medieval England

When studying premodern diseases, the field of archaeology provides a unique perspective that involves applying modern scientific methods and concepts to evidence from the past. The mixing

[258] Browne 1975, 487.

[259] Browne 1975, 485.

that occurs of modern and historical understandings of a disease can create a degree of unclarity, especially as many archaeologists also attempt to situate their findings within a broader socio-historical context. Within the discourse surrounding leprosy, I believe it is possible to create a more effective discussion by consciously delineating between the two concepts of “Hansen’s disease" and “leprosy”.

The following section provides a comprehensive overview of sources within the archaeological discourse of leprosy in medieval England, which comprises evidence from three different branches of the discipline, including DNA, osteological, and archaeological evidence. In particular, attention will be given to how the discourse highlights the tension between medieval and modern ideas of disease, and examples will show how the lack of clarity in terminology usage impacts the effectiveness of the discussion on medieval leprosy. Similar to the works in the historical discourse on leprosy, the approach taken in the archaeological discourse can be separated into two main categories.

The first, in which the two terms are used interchangeably, is the most prevalent terminology usage throughout the discourse. The majority of the archaeological works in the discourse on leprosy in medieval England use the terms “leprosy” and “Hansen’s disease” in a way that blurs the lines between these two separate concepts. In many cases, the term “Hansen’s disease” is only mentioned in an introductory sense. The need for the distinction between these two terms is seen most clearly when the osteological evidence of Hansen’s disease is being related to the medieval concept of “leprosy”. Otherwise, in cases where “leprosy” is used to reference the modern understanding of “Hansen’s disease”, it is easy to see where a simple substitution of terms clarifies the discussion.

The second, in which the term “leprosy” is used to reference the modern idea of Hansen’s disease rather than the medieval experience, is seen in the majority of articles that deal almost solely with osteological and DNA evidence of the mycobacterium that causes Hansen’s disease. In these cases, the use of the term “leprosy” can be replaced with “Hansen’s disease” because the medieval understanding of leprosy is not addressed within the discussion. There is also one scholar who makes a similar distinction as Browne (discussed in Section 8.3) to use “true

leprosy", but it is does not appear frequently or consistently in the work, and so I have chosen not to create a separate category in order to discuss this approach.

9.1 Interchanging Use of "Leprosy" and "Hansen's Disease"

Manchester and Robert's *The Palaeopathology of Leprosy in Britain: A Review*

One of the earlier archaeological articles that focuses on the paleopathology of leprosy in England was published in 1989 by Keith Manchester and Charlotte Roberts, titled, "The Palaeopathology of Leprosy in Britain: A Review".[260] The majority of the article does not actually touch on paleopathological evidence, but rather gives historical evidence of leprosy, as well as evidence for its diagnosis and treatment in the medieval period. The authors include information from a number of sources, many of which are not applicable to experiences of leprosy in Britain. For example, there is a description of medieval treatment using "dried scorpions' heads and dead infant's flesh" which was sourced from a volume on "leprosy in oriental antiquity".[261] As a whole, the article is often misleading because it presents primary source information from Antiquity and re-contextualizes it so that it appears to originate from the medieval period. This demonstrates one of the many potential drawbacks when historical sources are used improperly in archaeological papers.

Manchester and Roberts recognize the existence of two terms for the disease, stating "Leprosy, known today as Hansen's Disease", and in many ways it seems that they treat both concepts as the same. They describe the combined forms of evidence for the history of leprosy to include literary, artform, and paleopathological evidence. They describe the first two as part of "the subjective record" (and therefore implying that the skeletal evidence is objective). This is supported by my own interpretation of these concepts, however I argue that these should be treated separately (subjective vs objective), and that this distinction should also be reflected in the terminology used.

While the authors do not use "Hansen's disease" except for the first introductory description, the rest of the article is still relatively separated between "leprosy in an

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[260] Manchester and Roberts 1989, 265-272.

[261] Manchester and Roberts 1989, 270.

archaeological context" and "leprosy in a historical context". For example, the authors start one sentence with "There is evidence today that leprosy is a disease of high rural incidence, clustering in families, a feature largely due to the respiratory mode of transmission".[262] The following sentence continues "It was known, however, that in the post-Norman conquest era in Britain leprosy became a disease of significant prevalence and social importance. The evidence, from this period of rapid urban development and increasing population density, is largely documentary."[263] These two sentences are clearly referencing two separate ideas; the first is a biological understanding of "Hansen's disease" and includes its "mode of transmission", while the second is a reference to medieval leprosy based on documentary evidence. It would be relatively simple to replace the archaeological references of "leprosy" with "Hansen's disease", which would improve the quality of the discussion and create less confusion when the authors reference the medieval experience of leprosy.

Roberts et al.'s *The Past and Present of Leprosy*

Another volume that deserves mention by Roberts et al. is, *The Past and Present of Leprosy: Archaeological, Historical, Palaeopathological and Clinical approaches*, which is a compilation of papers on leprosy and Hansen's disease from the 3rd International Congress on the Evolution and Palaeoepidemiology of the Infectious Diseases.[264] It is one of the few volumes on leprosy that provides a truly multidisciplinary perspective of the disease and combines papers on clinical, DNA, paleaopathological, archaeological, and historical evidence. The majority of the articles in this paper do not focus on leprosy in medieval England and therefore will not be examined in detail in this discussion.

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[262] Manchester and Roberts 1989, 265.

[263] Manchester and Roberts 1989, 266.

[264] Roberts et al. 2002.

However, it useful to acknowledge that the clinical and osteological articles within the volume use the term "leprosy" when instead it would be possible to completely replace the term with "Hansen's disease".[265]

I would also like to commend the creators of the volume for providing a section within the introduction that addresses the impact of terminology on the stigma surrounding this disease. It states, "A final note, and one of great importance that was discussed regularly throughout the conference, are the terms used to describe and refer to people suffering from leprosy. Clinical leprologists emphasise the need to avoid use of the term 'leper', preferring the terms 'person suffering from leprosy', or 'Hansen's Disease' or 'a leprous sufferer'".[266] This statement provides a starting point for a discursive struggle over the terminology usage within the broader "discourse of leprosy" and is one which this thesis hopes to build upon.

One of the main editors of the volume, Charlotte Roberts, contributes an article titled "The Antiquity of Leprosy in Britain: the Skeletal Evidence", which relies on past ideas of leprosy as well as paleopathological evidence of Hansen's disease. In her initial description, Roberts references both the historical and modern conception of the disease, stating "Leprosy is a disease with a long history whose occurrence and character today in some parts of the world indicate that, socially, it is still considered a stigmatising condition that leads to ostracism and isolation."[267] This is not a clear case where "Hansen's disease" can be substituted for "leprosy" because the initial reference is to the historical context. This statement therefore provides a somewhat interesting conundrum for the definitions I propose. It could be argued that this entire definition is still accurate in that it does not necessarily reference "Hansen's disease", but rather the continuing socio-cultural experience of "leprosy".[268]

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[265] For example, in *Leprosy: A Correctable Model of Immunological Perturbation* by Stanford and Stanford, they write "There is little similarity between leprosy and any of the other existent mycobacterial diseases of humans or other animals." This is a statement referencing the mycobacterium causing the disease, and therefore would be improved with the use of "Hansen's disease". Stanford, John Lawson, and Cynthia Ann Stanford. "Leprosy: A Correctable Model of Immunological Perturbation." *BAR International Series* 1054 (2002): 25-38.

[266] Roberts et al. 2002, v.

[267] Roberts, Charlotte A. "The Antiquity of Leprosy in Britain: the Skeletal Evidence." *Archaeopress,* 2002, 213.

[268] This notion will be explored more in Section 9**,** which examines the implications of a shift in terminology usage on the modern stigma surrounding the disease.

While this is a sound line of reasoning, a rebuttal question would be whether continuing to use the term today in an *experiential* context would still contribute unnecessarily to the perpetuation of this ongoing stigma. In this sense, it is difficult to fully reference the modern experience of Hansen's disease without acknowledging its longstanding connections to the "leprosy" stigma. It is possible to reword this sentence to acknowledge both identities attached to the disease, "Leprosy is a disease with a long history whose occurrence and character today under the new name, Hansen's disease, still in some parts of the world is considered a stigmatising condition that leads to ostracism and isolation."[269] This at least recognizes that there has been a shift in the discourse surrounding the disease, and it can be further suggested that the two concepts are not completely interchangeable.

Throughout the rest of the article, the situations where she uses the terms can be separated into the socio-cultural past disease experience of "leprosy" and the modern biological understanding of "Hansen's disease". For example, she states "Leprosy is rarely seen in Britain today"[270], which could be easily substituted for "Hansen's disease". As well, in her discussion of leprosy rates in medieval England, she is referencing the skeletal evidence for Hansen's disease and comparing it with the historical references to leprosy. For example, the statement "results suggest that there was an increase in leprosy through time, which correlates with the historical data" could be changed to the more accurate statement, "results suggest that there was an increase in Hansen's disease through time, which correlates with the historical data that references leprosy".[271] Overall, the paper provides a good summary of the skeletal evidence for Hansen's disease in Britain and has multiple examples of where my proposed terminology could prove to be a useful tool for discussion of this complex disease.

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[269] Roberts 2002, 213.

[270] Roberts 2002, 213.

[271] Roberts 2002, 214-215.

Roffey and Tucker's *A Contextual Study of the Medieval Hospital and Cemetery of St Mary Magdalen, Winchester, England*

A study by Roffey and Tucker, "A Contextual Study of the Medieval Hospital and Cemetery of St Mary Magdalen, Winchester, England", examines the archaeological and paleopathological evidence for leprosy in a medieval hospital and cemetery.[272] The article provides a summary of both the site excavations and the skeletal remains found, and then attempts to situate the results within a historical context. The archaeological results support the updated views outlined in Rawcliffe's volume, namely that the level of exclusion and general living standards for people suffering from leprosy were much better than previously understood. Roffey and Tucker describe how traditional sources support the idea of the "exclusion of those affected with leprosy", but "this position is inconsistent with the archaeological evidence from leper hospitals and their cemeteries."[273] The use of the term "leprosy" here is correct in that it references the textually supported experience of the disease. I would also like to point out that the use of archaeological evidence here does not necessitate the need for the term "Hansen's disease", as they are not talking about any specific biological markers of Hansen's disease. In this context, the archaeological evidence they mention examines where people with Hansen's disease were buried within the cemetery in order to extrapolate how they were treated in the medieval period (this will be explained in more detail in Section 6).

Roffey and Tucker do use the term "leprosy" frequently in reference to skeletal evidence, for example, "Of the 38 burials, 33 showed indications of leprosy (86.8%)".[274] In these instances, I suggest they replace the term with "Hansen's disease". As well, somewhat problematically they make a disclaimer about the use of the term "leper" throughout the article, explaining it is permissible because of its "traditional use in the historical sources and previous scholarly works".[275]

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[272] Roffey, Simon, and Katie Tucker. "A Contextual Study of the Medieval Hospital and Cemetery of St Mary Magdalen, Winchester, England." *International Journal of Paleopathology* 2, no. 4 (2012): 170-180.

[273] Roffey and Tucker 2012, 170.

[274] Roffey and Tucker 2012, 171.

[275] Roffey and Tucker 2012, 170.

I would argue against the use of the term in this context, especially in regards to references from previous scholastic works, because this how the pejorative aspects of the term is perpetuated within the discourses surrounding this disease.

Magilton et al.'s *Lepers Outside the Gate: Excavations at the Cemetery of the Hospital of St James and St Mary Magdalene, Chichester, 1986-87 and 1993*

There are relatively few archaeological books on leprosy in medieval England, and arguably one of the most successful examples is Magilton et al.'s, *Lepers Outside the Gate: Excavations at the Cemetery of the Hospital of St James and St Mary Magdalene, Chichester, 1986-87 and 1993*.[276] The volume provides a combination of archaeological and paleopathological evidence, and also includes a historical background that contextualizes the report. It is a comprehensive report where Magilton et al. demonstrate that it is possible to place archaeological findings in their socio-historical context, in order to create nuanced interpretations from both an archaeological and historical perspective.[277] One of the critiques of the historical section was that it should have benefited from being co-authored by a historian who could have included more primary medieval sources.[278] As well, this section does unfortunately contain some degree of misinformation. This is due to the fact that, despite being published in 2008, it was ready for publishing in 2005, and therefore did not include any information from Rawcliffe's pivotal work. This lack of updated historical information does at times give the volume a slightly dated feel, as it includes certain references that were already discredited at the time of publishing.

Despite being a multidisciplinary volume, Magilton et al. do not adequately address that medieval leprosy cannot be directly equated as Hansen's disease. This is an extremely important clarification to make when attempting to place skeletal evidence of Hansen's disease into the broader context of medieval experiences of leprosy. Magilton et al. recognize that there are two terms to be used when describing leprosy, and that "it would be anachronistic to ask

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[276] Magilton et al. 2008.

[277] An example of this can be seen with the archaeological interpretation of the 400 burials found at the site, which showed that the composition of the cemetery and how it changed over time was mirrored by the changes described in historical documents on the hospital and cemetery. Magilton et al. 2008, 84-132.

[278] Mitchell, Piers D. "Lepers outside the Gate: Excavations at the Cemetery of the Hospital of St. James and St. Mary Magdalene, Chichester, 1986–87 and 1993. J. Magilton, F. Lee, A. Boylston (eds). Council for British Archaeology, York, UK, 2008. *International Journal of Osteoarchaeology* 20, No. 3 (2010): 369.

whether physicians and others were able to distinguish between Hansen's disease and other skin complaints".[279] They also include a footnote where the use of the term "leprosy" is justified in the rest of the volume because it involves the "social as well as medical implications" of the disease.[280] While it is helpful that the authors touch on the complex nature of the terminology surrounding this disease, it is still a very minimal explanation for their decision to *only* use "leprosy". This leads Magilton et al. to contradict themselves, because a huge part their discussion (and the volume as a whole) requires distinguishing between the historical and modern conceptions of the disease. The terminology I propose (which involves using "Hansen's disease" to identify the modern disease) improves the clarity of the discussion and is particularly useful when applied to evidence within the archaeological record.

Similarly to Browne, Magilton et al. also try to make this distinction by calling Hansen's disease "true" leprosy. They state, "The first written records of a disease known as *lepra* in Britain are 10th-century but it was not necessarily the same as Hansen's disease. True leprosy, Hansen's disease, seems not to have become a significant social problem until the 11th century".[281] This complicates their earlier attempt to avoid applying anachronistic definitions of Hansen's disease to the past, and I would argue it is also a problematic description because it inadvertently implies there is a "false" leprosy.

If Magilton et al. were to apply the definitions I am proposing, it would help to clarify both the archaeological and historical areas of their discussion. For example, the authors make a statement that provides an easy example of where the substitution of "Hansen's disease" for "leprosy" both simplifies and creates a more precise statement. "Leprosy is a chronic infectious disease that, fortunately for the archaeologist, commonly leads to bone changes and can be identified from skeletal remains."[282] Instead they could say, "Hansen's disease is a chronic infectious disease".

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[279] He calls it "the infection now sometimes known as Hansen's disease". Magilton et al. 2008, 9.

[280] Magilton et al. 2008, 23.

[281] Magilton et al. 2008, 9.

[282] Magilton et al. 2008, 9.

Another example is when Magilton et al. say, "From a medical and demographic, as opposed to social, point of view, leprosy was relatively unimportant."[283] In this statement, I would argue that the authors want to reference "Hansen's disease" rather than "leprosy", as they goes on to describe rates of transmission from the modern period.

Despite their earlier discussion, they seem to strongly equate the ideas of "Hansen's disease" and "leprosy", and do not appreciate that medieval idea of leprosy could often include other illnesses we would describe today using other labels (e.g. psoriasis or lupus). For example, they reference the paleopathological findings from a Danish cemetery, which showed 70% of the skeletons had characteristic signs of Hansen's disease. The authors then speculate about the remaining number of skeletons that showed no sign of the disease, and assume they were either people who worked at, or contributed financially to, the institution, or they were people who died in the early stages of the disease before they showed skeletal evidence.[284] While these are certainly possible scenarios, it is important to acknowledge that some of the people buried there might have been considered to have leprosy in the Middle Ages, but did not have Hansen's disease.

Magilton et al.'s discussion of the skeletal evidence found at the cemetery also involves the consistent use of the term "leprosy" or "leprous", where it would be possible to replace it with Hansen's disease. For example, they state "The incidence of leprosy in adults is 20.5%, compared with 35% for the latest burials of Area A2."[285] In this context, it would be more factually accurate to describe the skeletal evidence using "Hansen's disease" because they show signs of infection from *Mycobacterium leprae.* By doing so, it would also add more to the authors use of the term "leprosy" in the historical discussion, where it would signal that they are addressing the medieval conception of the disease.

One last example that summarizes Magilton et al.'s problematic approach to the concepts of "Hansen's disease" and "leprosy" is in the discussion portion of the volume, where the authors provide a brief summary of the history of the hospital. They describe the disease, saying

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[283] Magilton et al. 2008, 11.

[284] Magilton et al. 2008, 10.

[285] Magilton et al. 2008, 100.

"Leprosy, in the Middle Ages a spiritual contagion inflicted by God on sinners, manifested itself through symptoms caused by *M. leprae*, but not exclusively so." I argue that this sentence is an unhelpful amalgamation of the past and modern ideas of this disease, and demonstrates an anachronistic and oversimplified definition of complex disease discourses. Overall, I would say that Magilton et al.'s volume is an important work within the archaeological discourse of medieval leprosy and also contributes to the historical discourse of medieval leprosy. However, the volume would benefit from greater consideration given to the terminology usage and how it impacts the accuracy and the broader implications of their discussion.

Robert's *Applying the 'Index of Care' to a Person Who Experienced Leprosy in Late Medieval Chichester, England*

A paper published recently by Roberts, "Applying the 'Index of Care' to a Person Who Experienced Leprosy in Late Medieval Chichester, England", looks for proof of care and treatment using a combination of historical sources and osteological evidence from one set of male skeletal remains from the St Mary Magdalen, Chichester site.[286] Unlike many scholars, she effectively addresses the need for specificity when dealing with disease experiences in the past, in regards to "geographic location, time period, the person affected, the community in which they lived and the agents involved with health care (traditional healer, relatives, surgeon, physician, etc.)."[287] In her own way, Roberts recognizes that the discourse surrounding a disease changes over time and depending on where in the world it was experienced. As well, unlike many historians dealing with paleopathological evidence for leprosy, Roberts also emphasizes the difficulties in interpreting the osteological changes that are associated with Hansen's disease.

This article is unusual in that it provides a detailed examination of one set of male skeletal remains in order to attempt to determine the degree of care the individual was given during their life. This is an area that provides an interesting cross-section of the past and modern understandings of disease, because the skeleton was chosen for the paleopathological evidence of Hansen's disease, but Roberts is also attempting to give information on his life experiences from

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[286] Robert 2017, This site is discussed in greater detail in: Magilton et al. 2008.

[287] Roberts 2017, 104-105.

the medieval period. In her descriptions of the skeletal evidence, she still mostly uses the term "leprosy" and I would suggest she substitutes it with "Hansen's disease". For example, "The type of leprosy this person had was likely the low resistant form" would become "The type of Hansen's disease this person had was likely the low resistant form".[288]

In Robert's descriptions of the possible level of care the man received during his life, she is very cautious, for example, the header of the section is "What *Cannot* Be Said About This Man's Experience?". She states, "In discussing the course of this medieval man's leprosy, it is very difficult to actually say at what point on the spectrum he would have been at any given time in his life."[289] The spectrum she is referring to is the progression of the disease on the Ridley-Jopling spectrum of immune response (meaning lepromatous vs tuberculoid leprosy),[290] which is an area where I recommend the use of "Hansen's disease". While there is a degree of overlap between the modern and past ideas of the disease in this article, Roberts does not attempt to describe the man's experience of medieval leprosy in any great detail. She limits her discussion to suggest that, based on what we know of "Hansen's disease", his physical deformities would have greatly effected his quality of life (this concept is addressed in more detail in Section 6.1). Robert's article provides a unique perspective to explore the cross-section between the *subjective* medieval experience of leprosy and the *objective* modern biological description of Hansen's disease.

9.2 The Use of "Leprosy" to Reference "Hansen's Disease"

Stirland's *Criminals and Paupers: The Graveyard of St Margaret Fyebriggate, Norwich*

The archaeological site report by Ann Stirland, *Criminals and Paupers. The Graveyard of St Margaret Fyebriggate 'in combusto', Norwich* details the analysis of the skeletal remains found at The Graveyard of St Margaret.[291] The report provides a very focused examination of the

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[288] Roberts 2017, 114.

[289] Roberts 2017, 118.

[290] See Section 4 for more detail.

[291] Stirland, Ann. *Criminals and Paupers: the Graveyard of St Margaret Fyebriggate in Combusto, Norwich.* Historic Environment, Norfolk Museums and Archaeology Service, 2009.

osteological evidence found during the excavations of the site, and there is minimal discussion on Hansen's disease within the report. The term "leprosy" is used four times, and in each case it would be beneficial to replace the term with "Hansen's disease". For example, the section on leprosy starts as follows: "Leprosy is a chronic disease caused by *Mycobacterium leprae*..." This would be more precise if instead it went: "Hansen's disease (commonly known as leprosy) is a chronic disease caused by *Mycobacterium leprae*..."[292] The site report involves no historical or archaeological discussion to contextualize the osteological evidence, and so it is a very simple case of substitution of terms.

Taylor et al.'s *Variable Nucleotide Tandem Repeat (VNTR) Typing of Two Palaeopathological Cases of Lepromatous Leprosy from Mediaeval England*

The majority of the papers that deal with DNA evidence for Hansen's disease tend to be heavily technical, and the results focus on confirming the presence and transmission history of *Mycobaterium leprae*.[293] In some cases, these papers touch on the challenges of tracking the past and modern ideas of disease, and they often attempt to trace the strains of the mycobacterium back in time using paleopathological evidence. One of the earlier papers on DNA evidence for Hansen's disease in medieval England by Taylor et al., "Variable Nucleotide Tandem Repeat (VNTR) Typing of Two Palaeopathological Cases of Lepromatous Leprosy from Mediaeval England", focuses entirely on paleopathological evidence and DNA evidence taken from the skeletal remains.[294] Throughout the article, the authors focus almost exclusively on the palaeopathological and DNA evidence of the mycobacterium that is taken from skeletal remains.

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[292] Stirland 2009, 25.

[293] Taylor et al. "A Mediaeval Case of Lepromatous Leprosy from 13–14th century Orkney, Scotland." *Journal of Archaeological Science* 27, no. 12 (2000): 1133-1138, Brown, Terrence, and Keri Brown. Biomolecular Archaeology: An Introduction. Wiley-Blackwell, 2011, Inskip et al. 2017.

[294] Taylor et al. "Variable Nucleotide Tandem Repeat (VNTR) Typing of Two Palaeopathological Cases of Lepromatous Leprosy from Mediaeval England." *Journal of Archaeological Science* 33, no. 11 (2006): 1569-1579.

Their introductory description supports the idea that they are solely concerned with the modern biological concept of the disease, stating “Leprosy is a chronic infectious disease caused by the microorganism *Mycobacterium leprae*, first identified as the cause of leprosy by Armauer Hansen in 1873.”[295] So in this case, and in almost every other instance throughout the rest of the paper, it would make more sense to replace “leprosy” with “Hansen’s disease”.

I would like to mention that Taylor et al. do briefly address the complex history of the disease, "The origins of leprosy are obscure and have been complicated by inaccurate diagnosis, semantics and mistranslation of terminologies which formerly encompassed a number of skin diseases.”[296] In this case, the use of “leprosy” is correct, but they follow up that sentence with references to ancient textual evidence for the disease. It seems that they are describing a form of retrospective diagnosis, and so it would be beneficial to address the fact that they are looking for clinical symptoms of Hansen’s disease in these ancient texts.

Mendum et al.’s *Mycobacterium Leprae Genomes from a British Medieval Leprosy Hospital: Towards Understanding an Ancient Epidemic*

In their paper, “Mycobacterium Leprae Genomes from a British Medieval Leprosy Hospital: Towards Understanding an Ancient Epidemic”, Mendum et al. use DNA evidence taken from skeletal remains from St Mary Magdalen, Winchester in order to trace the strain type of mycobacterium and how it relates globally to other ancient and modern strains.[297] They describe the challenges of tracing this disease over time, "The nature of this ancient endemic leprosy and its relationship to modern strains is only partly understood.”[298] For the most part they do not address the historical socio-cultural concept of “leprosy” aside from mentioning that "Leprosy has been known since the earliest recorded times, with references in ancient texts”.[299]

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[295] Taylor et al. 2006, 1570.

[296] Taylor et al. 2006, 1570.

[297] Mendum et al. 2014. A similar paper was published the previous year by Taylor et al. which also looks at tracing the strain types of mycobacterium from St Mary Magdalen, Winchester. Taylor et al. 2013, 62406.

[298] Mendum et al. 2014, 1.

[299] Mendum et al. 2014, 2.

Due to the fact that they focus and reference mainly the skeletal and DNA evidence of the mycobacterium, the places they use “leprosy” throughout the paper can be substituted accurately for “Hansen’s disease”. Discoveries in this field have the potential to impact the entire discourse of leprosy, as they are able to shed more light on the history of Hansen’s disease and the degree it has overlapped with “leprosy” in different geographies throughout history.

Inskip et al.’s *Leprosy in Pre-Norman Suffolk, UK: Biomolecular and Geochemical Analysis of the Woman from Hoxne*

Published recently by Inskip et al. in 2017, “Leprosy in Pre-Norman Suffolk, UK: Biomolecular and Geochemical Analysis of the Woman from Hoxne", uses DNA evidence to confirm the presence of Hansen’s disease in a set of medieval skeletal remains from England.[300] One of the main aims of the paper was to place the findings from their set of skeletal remains “in context with other British leprosy cases.”[301] In this instance, and with the other references to “leprosy” throughout the rest of the article, a substitution with “Hansen’s disease” would provide a more accurate description of their goal and a more effective discussion of the disease they are studying. At this point, it is relatively easy to make a blanket statement about the terminology usage in the articles discussed here because they deal almost exclusively with evidence of *Mycobacterium leprae,* and I believe that in almost all cases, the use of “leprosy” can be substituted with “Hansen’s disease”.

Through the examination of the historical and archaeological discourses of leprosy in medieval England, it is possible to see that the quality and effectiveness of both academic discourses suffer by having no consistent standard of terminology. Within the historical discourse, the majority of references are to the medieval understanding of leprosy and the use of the term becomes problematic when scholars attempt to bring in modern clinical references or archaeological evidence of Hansen’s disease. In the field of archaeology, where the past is examined with a modern perspective, issues can be seen with the usage of the term “leprosy” in cases where the context is almost exclusively referencing “Hansen’s disease”.

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[300] Inskip et al. 2017, 1640-1649.

[301] Inskip et al. 2017, 1640.

As well, it is often an issue in the archaeological discourse where the scholars refer to the past ideas of "leprosy" in order to retrospectively diagnose "Hansen's disease"**.** Overall, both discourses would greatly benefit from *consciously* choosing between "Hansen's disease" and "leprosy" when talking about this complex disease. I believe it will help to distinguish the degree of overlap between these two terms, as well as help to trace changes in the broader discourse of leprosy.

10.0 Broader Implications for the Study of Past Disease

One of the aims of this thesis is to demonstrate how the conscious choice of terminology can be a useful tool when studying diseases in the past. As shown in Sections 3, 4, and 5, the idea of a disease evolves over time and from place to place, and there are diseases other than leprosy that have a long history worthy of study. The following section briefly explores another disease where the use of terminology may be helpful in navigating the distinction between past and present. Tuberculosis is a disease similar to leprosy in that it leaves archaeological evidence (paleopathological and DNA), and also has a textual history that spans thousands of years. The examination of this disease is done in a very preliminary sense, with the goal of providing constructive comparison for the discussion surrounding leprosy outlined in this thesis.

The processes of examining historical texts for evidence of modern diseases has been a popular pursuit in academia for over a century, and is called retrospective diagnosis. This thesis is arguing in some ways against this type of approach, because it often involves scholars carelessly equating a modern disease with vague or inconclusive textual references from the past.[302] However, the process of retrospective diagnosis can still provide useful information about how the idea of a disease develops over time, and can also be used as support of archaeological evidence that attempts to trace a modern disease back into the past. For example, this thesis highlights that Hansen's disease has been affecting human populations for thousands of years, and by examining textual references it is possible to reaffirm the archaeological findings (e.g. paleopathological and DNA evidence). Overall, the terminological distinction I propose in this thesis could be a valuable tool for historians and archaeologists looking at modern diseases in the past.

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[302] This section will not be addressing all the potential problems involved in retrospective diagnosis as it is too great a topic to tackle. The following sources provide excellent discussion on the pros and cons of this process: Arrizabalaga 2002, 51-70, Karenberg, Axel. "Retrospective Diagnosis: Use and Abuse in Medical Historiography." *Prague Medical Report* 110, no. 2 (2009): 140-145, Mitchell, Piers D. "Retrospective Diagnosis and the Use of Historical Texts for Investigating Disease in the Past." *International Journal of Paleopathology* 1, no. 2 (2011): 81-88.

10.1 What is Tuberculosis?: A Modern Clinical Description

According to the modern clinical definition, tuberculosis is a chronic granulomatous infectious disease caused by the bacteria *Mycobacterium tuberculosis,* which includes two different bacilli, one that is present in humans and the other in bovines.[303] Exposure to the disease does not always result in infection, and in a "healthy, well-nourished person with possibly some genetic immunity, the disease may advance no further."[304] If an individual does not overcome what is termed, the primary infection, it can spread to the internal organs, lymph nodes, brain, and to the bones (which is significant for paleopathological studies).[305] The signs and symptoms of tuberculosis will vary depending on where the infection is first contracted, though the most common form is pulmonary tuberculosis, which causes shortness of breath, cough, chest pain, coughing up infected phlegm or blood, loss of weight, and fever.[306]

The other form of infection is gastrointestinal tuberculosis, which causes abdominal pain and distension of the abdomen, loss of blood from the digestive tract, fever, and weight loss. The most common way to contract gastrointestinal tuberculosis is through the ingestion of the bovine type of *Mycobacterium tuberculosis*, via contaminated meat or milk. Further, primary tuberculosis can be contained within the body for many years with no extra signs, and can be "reactivated" if a person goes through a period of physical stress (e.g. poor diet or other diseases that compromise their immune system).[307] This is important to keep in mind, as it means that individuals in the past could contract the disease without showing effects.

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[303] It is interesting to note that the mycobacterium that causes tuberculosis is closely related to the one that causes Hansen's disease. Manchester 1984, 162.

[304] Manchester 1984, 162.

[305] Manchester 1984, 162.

[306] Roberts 2011, 259.

[307] Roberts 2011, 259.

10.2 Archaeology and Ancient History of Tuberculosis

Like leprosy, tuberculosis is a disease that has been affecting humans for thousands of years.[308] There is substantial archaeological evidence that traces this disease as far back as 10,000 years,[309] and some scholars speculate that it "may have killed more persons than any other microbial pathogen."[310] There are different methods of identifying evidence of tuberculosis in the archaeological record, though arguably the most common is to look for the "typical changes of tuberculous spondylitis"[311] which involves characteristic damage to the spine. Some of the earliest abundant archaeological evidence for tuberculosis is found in Egypt, dating as far back as 5,500 years ago.[312] The unique degree of preservation commonly seen with Egyptian mummies leaves the body relatively intact, meaning that it is possible to find skeletal *and* soft tissue evidence of a tuberculosis infection.[313] There is also visual evidence in the form of Egyptian art that likely shows individuals who are suffering from Pott's lesions,[314] which is depicted as spinal deformations (see Figure 7 below).[315] It is important to emphasize that tuberculosis affects the human skeleton in only a small percentage of cases, meaning that the paleopathological evidence only gives a small insight into the prevalence of this disease.[316]

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[308] There is also DNA research on the tuberculosis bacilli which indicates "that the oldest progenitor species of Mycobacterium tuberculosis originated some 2.6 to 2.8 million years ago in East Africa."
Agarwal et al. "The Tuberculosis Timeline: Of White Plague, a Birthday Present, and Vignettes of Myriad Hues." *Astrocyte* 4, no. 1 (2017): 8.

[309] Agarwal et al. 2017, 9.

[310] Frith, John. "History of Tuberculosis. Part 1- Phthisis, Consumption and the White Plague." *Journal of Military and Veterans Health* 22, no. 2 (2014): 29.

[311] Daniel, Virginia S., and Thomas M. Daniel. "Old Testament Biblical References to Tuberculosis." *Clinical Infectious Diseases* 29, no. 6 (1999): 1557.

[312] Daniel and Daniel 1999, 1557.

[313] Daniel and Daniel 1999, 1557.

[314] These changes involve vertebral collapse and spinal cord paralysis, and are also called Pott's deformities or Pott's disease after Sir Percivall Pott, a British surgeon that was the first to record these changes in 1779.
Barberis, I., N. L. Bragazzi, L. Galluzzo, and M. Martini. "The History of Tuberculosis: From the First Historical Records to the Isolation of Koch's Bacillus." *Journal of preventive medicine and hygiene* 58, no. 1 (2017): 11.

[315] Agarwal et al. 2017, 9, Barberis et al. 2017, 9.

[316] Rawcliffe 2006, 346.

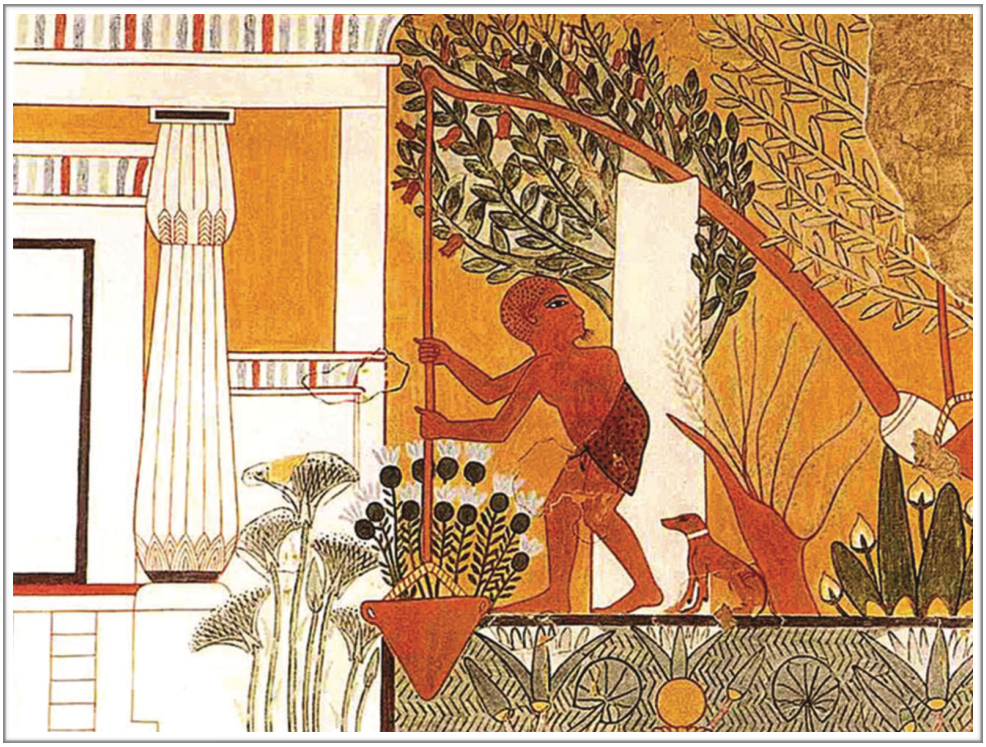

Figure 7. An ancient Egyptian painting that possibly depicts a man afflicted with Pott's disease, which causes deformation of the spinal cord.[317]

The earliest textual records that likely reference the disease date back 3,300 years ago in India, and 2,300 years ago in China.[318] For example, one reference found in the Rig Veda (1500 BC) called the disease *yaksma*.[319] Another possible reference to the disease comes from the ancient Hebrews, where the word *schachepheth*[320] appears in the Biblical books of Deuteronomy and Leviticus to describe symptoms similar to those seen in tuberculosis.[321] The term *schachepheth* was originally translated by the classical scholars of Antiquity as "*consumptio*", a noun that means "wasting", and by the medieval period this disease was described as "consumption".[322]

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[317] Picture taken from Agarwal et al. 2017, 9.

[318] Barberis et al. 2017, 9.

[319] Agarwal et al. 2017, 9.

[320] It is interesting to note that the term persists today with the modern word for tuberculosis in Hebrew, *schachefet.* Daniel and Daniel 1999, 1557.

[321] Barberis et al. 2017, 9.

[322] Daniel and Daniel describe how the plague referenced in these sections of the bible (Leviticus 26:16 and Deuteronomy 28:22) are called "consumption" in both the King James (dating to 1611) and the Revised Standard Versions (dating to 1901) of the Bible, and "were made at times when consumption was a word commonly used to refer to tuberculosis." Daniel and Daniel 1999, 1557.

It is definitely possible that the a "wasting" disease is a reference to tuberculosis, because there is archaeological evidence from that time period that confirms it existed in the region where this was written.[323] However, I would still suggest a strong degree of caution when equating the ancient illness with its modern equivalent, as the description provided is still quite vague.

More detailed descriptions of the disease are found in ancient Greece, where it was a well-known disease called *phthisis*.[324] Hippocrates in his book, *Of the Epidemics* (410-400 BC), accurately defines the symptoms including the characteristic tubercular lung lesions and describes *phthisis* as a common disease that was usually fatal, especially for young adults.[325] The Greek physician, Aretaeus of Cappadocia,[326] also wrote about the disease in his work, *De Causis et Signis Diuturnorum Morborum*, where he states, "If from an abscess in the lung or a settled cough or spitting of blood, pus should develop within and the patient should spit it out, the disease is called pyë and phthisis."[327] Another famous classical physician, Galen (129-216 AD), described the symptoms of the disease as producing a fever, sweating, coughing, and blood stained sputum, and "he recommended fresh air, milk and sea voyages as successful treatments for the disease."[328] The understanding of the disease at this time was based on the respiratory symptoms alone, and other manifestations of the disease, like scrofula(affecting the cervical lymph nodes in the neck)[329] or Pott's lesions (spinal deformities) were considered as separate illnesses.[330]

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[323] Daniel and Daniel 1999, 1557.

[324] The origin comes from the Greek *phthiein*, meaning to waste away, and variations of the spelling include phtisis or ptisis. Barberis et al., 2017, 9, Frith, 2014, 29, Rawcliffe, 2006, 345.

[325] Barberis et al. 2017, 9, Frith 2014, 29.

[326] He is also mentioned in Section 3.1 for his description of *lepra*.

[327] Frith 2014, 30.

[328] Barberis et al. 2017, 10.

[329] Aristotle (384-322 BCE) and Cassius Felix (447 CE) were possibly some of the first scholars to describe scrofula. Frith 2014, 30

[330] Barberis et al. 2017, 10.

10.3 Tuberculosis in Medieval Europe

Tuberculosis continued to be a prevalent disease during the medieval period, which is supported by both the textual and archaeological record. The disease, still called *phthisis,* also gained the name, 'consumpcioun'[331] during this period, and it held a prominent place in medieval remedy books and medical treatises.[332] Unlike much of modern medicine which is heavily centred around providing a diagnosis for specific diseases, during the medieval period there was more of a focus on treating symptoms. In this sense, infections from tuberculosis were not always (or even often) labelled as *phthisis,* scrofula, or consumption*,* but instead treated based on its common symptoms, such as fever, cough, or spitting up blood. In order to better demonstrate this, I provide primary source examples taken from the *Old English Herbarium*,[333] which include three different symptoms that may be attributed to tuberculosis: coughing blood, lung disease, and glandular swelling. Below I have listed an example of a treatment for each symptom:

> 134.1 The *action* plant, which is Burdock "If one coughs up blood and phlegm together, take four pennies' weight of the seeds of this plant and nuts from the cones of pine trees, and pound them together just as you make an apple dumpling. Give this to the patient, and it will cure him."[334]
>
> 5.7 The *symphoniaca* plant, which is Henbane "For lung disease, take the juice of the same plant and give it to drink; the person will be remarkably cured."[335]
>
> 169.1 The *psillios* plant, which is Fleawort or Fleaseed "For glandular swellings and all bad swellings, take the seeds of this plant pounded in one oil jar plus two cups of water, and mix them together. Give this to drink. Take some of the same seeds, make them into a plaster, put them on the sore, and it will be healed."[336]

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[331] The term "consumption" continued to be used to reference tuberculosis up to the 19th century.

[332] Rawcliffe 2006, 345.

[333] The translation used below is by Van Arsdall, and is based primarily on De Vriend's 1984 edition of the work, which uses Cotton Vitellius C. iii as the main text. Van Arsdall, Anne. Medieval Herbal Remedies: The Old English Herbarium and Anglo-Saxon Medicine. New York: Routledge, 2002.

[334] Van Arsdall 2002, 207.

[335] Van Arsdall 2002, 149.

[336] Van Arsdall 2002, 222.

While it is not possible to say for certain that these treatments were used for infections of tuberculosis, it does seem at likely that it would have been applied in some cases.
It is also possible to see how there is a focus on the symptoms, for example, coughing up blood or glandular swellings, and in the case of "lung disease" it is still a general concept rather than a specific diagnosis.

The glandular swellings of scrofula[337] were of particular interest during the medieval period in France and England, where it gained the name *morbus regius* or "King's Evil".[338] In his article, "The King's Evil", Frank Barlow gives a detailed overview of the history of the use in medieval English texts.[339] During this period, the belief was that a touch from the king was considered to heal the "king's evil", as it was thought that God was working divine healing with the king as a conduit.[340] As with many medieval references to disease, the term "King's Evil", did not correspond to just one disease, as over time it appears to have also referenced jaundice and leprosy.[341] It was not until the middle of the 13th century that the term *morbus regius* came to include scrofulas or strumas, and these names "covered not only tubercular infection of the lymph nodes (lymphatic glands), which caused a swelling and often suppuration of the neck, but also other glandular disorders, such as goitre, a morbid enlargement of the thyroid gland, and mumps, inflammation and swelling of the parotid and salivary glands."[342] Despite the variety of illnesses that are categorized under the term "King's Evil", it is important to acknowledge that at least some of the cases in the historical sources were likely secondary infections of tuberculosis.

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[337] This is understood today as a secondary infection of tuberculosis in the lymphatic system. Manchester 1984.
[338] Barberis et al. 2017, 10.
[339] Barlow, Frank. "The King's Evil." *The English Historical Review* 95, no. 374 (1980): 3-27.
[340] Barlow 1980, 8.
[341] Barlow 1980, 5.
[342] Barlow 1980, 7.

10.4 Modern History of Tuberculosis

From the medieval period onward, tuberculosis (still called *phthisis*) continued to be a problem and reached epidemic levels by the 18th century. There has been much speculation as to why it increased in prevalence during this period, and it is likely due to an overall rise in the global population. In particular, the period during the Industrial Revolution saw a great increase in the global numbers of the disease, which has been attributed to rising levels of poverty, malnutrition, and overcrowding.[343] To this day, tuberculosis remains a dangerous disease that currently infects around 2 billion people globally, and there are around 10.4 million new cases each year.[344]

The terminology for the disease changed from the 17th until the mid-19th century, and while *phthisis* was still in use during this period, the term "consumption" became the popular or layman's term for the disease.[345] For example, during the early 18th century the "infectious origin of TB was conjectured by the English physician Benjamin Marten, in his publication 'A new theory of Consumption'".[346] The term "tuberculosis" was first used by Johann Lukas Schönlein, a German physician, in 1834 as a descriptive term for general tubercles.[347] It wasn't until 1853, when the description "tuberculosis of the lungs" was used by a medical graduate of the University of Berlin, Hermann Brehmer, that it gained popularity in the years following.[348] It was still almost thirty years before the biological cause of tuberculosis, *Mycobacterium tuberculosis*, would be discovered by the famous German scientist, Robert Koch, in 1882.[349]

During the 18th and 19th centuries when the disease was at its peak, it began to take on a somewhat mythical status, representing spiritual purity, holiness, and temporal wealth.[350] By the early 19th century, tuberculosis was considered a fashionable disease which lead to many

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[343] Frith 2014, 32.

[344] Barberis et al. 2017, 9.

[345] Daniel and Daniel 1999, 1557, Frith 2014, 30.

[346] Barberis et al. 2017, 10.

[347] Barberis et al. 2017, 10, Frith, 2014, 30.

[348] Frith 2014, 30.

[349] Barberis et al. 2017, 11.

[350] Agarwal et al. 2017, 14.

"young, upper−class women to purposefully pale their skin to achieve the consumptive appearance."[351] This popularity also led to the disease gaining many different nicknames, including: the white death, the white plague, the robber of youth, the graveyard cough, and the Captain of all these men of Death.[352]

As the previous sections have shown, tuberculosis has a long and complex history, and the discourse surrounding the disease has evolved over time. One of the main reasons I believe this disease would greatly benefit from the application of structured terminology is that it will help to distinguish between the archaeological evidence (which focuses on the modern notion of the disease) and the historical evidence (which is centred on the conception of the disease in a specific time and place). This is also a disease with many names, meaning the use of a standardized terminology will help to organize and improve the quality of the academic discussion. For example, if there is a study focusing on the disease in the classical period, the term "*phthisis*" would potentially be more appropriate than tuberculosis. If the focus is on the 18th century experience of the disease, then the term "consumption" may be a better term to use. It is my hope that the idea of a standardized terminology will be incorporated into future research on tuberculosis, a disease with many names.

[351] Agarwal et al. 2017, 14.

[352] Barberis et al. 2017, 10, Frith 2014, 29.

11.0 Broader Implications for the Stigma of Leprosy

> Anytime anyone is diagnosed with this disease, they are traumatized because they are burdened with 3,000 years of stigma, fear and rejection. Your belief is your reality and all too often, your beliefs about the disease stem from what you've heard about the stigma, fear and rejection. We can no longer sit by and watch people's identities and people's lives be destroyed by the stigma associated with this disease. We are your sons, daughters, fathers, mothers, brothers, sisters, grandparents. We are truck drivers, poets, teachers, politicians, musicians, artists and so much more. We refuse to allow people to define ourselves, our humanity, by a disease.[353] — Bernard K. Punikai'a

One of the main arguments in this thesis concerns the impact of terminology usage in addressing the constantly shifting discourse surrounding diseases, and how specific terms can be used to shape the understanding and experience of the disease. In the case of the term "leprosy", the identity of the disease incorporates a centuries-old stigma that is continuing to be felt around the world today. This section looks at the implications of the use of the term "leprosy" and how it influences the current experience of those with Hansen's disease. In order to address the modern discourse of leprosy in a more nuanced way, I focus mostly on sources from outside academia, because they provide a more humanistic approach in how to address this stigma.

As previously touched on in Section 4.2, for many people suffering from Hansen's disease the social side-effects (e.g. stigma and societal rejection) are in some ways worse than the medical ramifications of the disease, because the emotional consequences often persist long after the physical symptoms have been treated. In her article, *The Global Campaign to Eliminate Leprosy*, Andrea Rinaldi addresses this, stating "Stigma, community rejection, loss of employment, and sometimes forced isolation are still prevalent in both endemic and non-endemic countries."[354] In today's world (and to some extent, historically) this disease has usually been associated with poverty,[355] which is likely due to the fact that the poor nutrition associated with poverty also leads to a weakened immune system and higher rates of susceptibly to infection.

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[353] International Leprosy Association. "A Quest for Dignity". leprosyhistory.org. https://leprosyhistory.org/testimonies/a-quest-for-dignity.

[354] Rinaldi 2005.

[355] Lee 2006, 80.

However, despite knowing that there is a link between Hansen's disease and poverty, it is difficult to see at national, community, or even individual levels.[356] Studies have been done worldwide, but the experience differs from place to place, and so it is difficult to determine any universal results that can be applied on a more global scale. One study in a highly endemic area of leprosy in Brazil showed that the level of economic inequality, population growth, and presence of a railroad were associated with higher levels of leprosy.[357]

Another study of a community in north Bangladesh looked at the impact of socio-economic factors on the degree of stigma and disability experienced by those suffering from Hansen's disease. The conclusions of the study were that "an increased focus by leprosy services on the socio-economic factors associated with poorer physical and social outcomes is recommended. Where adequate finances and trained staff are available, efforts could be made to identify those at higher risk of poor outcomes, and to provide or to mobilize appropriately targeted socio-economic interventions."[358] This suggests that by addressing some of the socio-economic factors that negatively impact people suffering from Hansen's disease, it may also improve the associated issues of stigma experienced.

One of the reasons that the experience of Hansen's disease differs greatly from other medical conditions is because the concept of "leprosy" is applied to people as a label, with the suggestion that it somehow becomes a part of their individualistic identity. There are many terms used to refer to a person with the disease, including "leper", "person affected with leprosy" (PAL), and "Hansenite". All of these labels share a similar aspect, in that they label the person who is experiencing the disease, and in many ways it can become incorporated into their self-identity. The impact of this disease on an individual's identity cannot be understated, either through the process of labelling a person as a "leper", or in more extreme cases like at Carville, where the patients were encouraged to forget their old names and reinvent themselves with new names (see Section 4.2 for more details).

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[356] Lockwood, Diana NJ. "Commentary: Leprosy and Poverty." *International Journal of Epidemiology* 33, no. 2 (2004): 269.

[357] Lockwood 2004, 269-270.

[358] Withington, S G, Joha, S, Baird, D, Brink, M, and Brink, J. "Assessing Socio-economic Factors in Relation to Stigmatization, Impairment Status, and Selection for Socio-economic Rehabilitation: A 1-year Cohort of New Leprosy Cases in North Bangladesh." *Leprosy Review* 74, no. 2 (2003): 120.

The degrading, and arguably dehumanizing, experience of being assigned a derogatory label due to an infection from a specific type of mycobacterium is not an experience shared with many other diseases.[359] For example, a person who becomes infected with tuberculosis (caused by a mycobacterium closely related to the one causing Hansen's disease) does not become labelled as a "tuberculonite" or a PAT (person affected with tuberculosis). When faced with these examples, it is much easier to see how absurd it is to attach an identity label to someone who is in a temporary state of sickness. This is arguably one of the more damaging aspects of this disease, and one of the ways to counteract this issue it to acknowledge that "it affects millions of *individuals* with unique personalities and real names who were denied family, community and personal identity because they had a disease that was feared and misunderstood."[360] The importance of educating and challenging these aspects of "leprosy" has been an issue that many have undertaken, and one the most successful examples has been with the Quest for Dignity.

The Quest for Dignity was a phrase originally coined by Bernard K. Punikai'a, and has subsequently come to symbolize the global efforts that have been taken to counteract the stigma of "leprosy" and to reaffirm "the human rights and humanity of all those who have had leprosy."[361] Bernard was born in Honolulu, Hawaii, and was diagnosed with leprosy at the age of six, and his personal experience involved being forcibly separated from his family and isolated at the colony at Kalaupapa peninsula.[362] His personal experiences of the disease, and the serious degree of stigmatization and abuse he received because of it, spurred him to become a voice for those with Hansen's disease and an advocate for education. He describes how he has "always been concerned about fairness, rights, civil rights, human rights, how people treat other human beings" and the importance of speaking out because "To be silent is to be part of the oppression."[363]

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[359] However, it is important to acknowledge that there are certain diseases that do involve experiences of stigma, for example, HIV/AIDS or other sexually transmitted diseases.
Van Brakel, Wim H. "Measuring Leprosy Stigma-a Preliminary Peview of the Leprosy Literature." *International Journal of Leprosy and Other Mycobacterial Diseases* 71, no. 3 (2003): 190-197.

[360] Law and Hill 2002, 7.

[361] International Leprosy Association. "A Quest for Dignity". leprosyhistory.org.

[362] Also briefly discussed in the section on Hansen's disease in Polynesia in Section 4.2.

[363] International Leprosy Association. "A Quest for Dignity". leprosyhistory.org. https://leprosyhistory.org/testimonies/a-quest-for-dignity.

This is one of the concepts I am trying to reinforce with this thesis, specifically that in order for effective changes to be implemented within the discourse of leprosy, it is first necessary to identify and speak out about the problem.

In 2000, Bernard was elected as IDEA's (Integration Dignity and Economic Advancement) President for International Advocacy, which is one of the main organizations that is fighting to combat the enduring stigma associated with leprosy. It is described as an "international advocacy organization whose leadership is primarily made up of individuals who have personally faced the challenges of leprosy, also called Hansen's disease."[364] They acknowledge and advocate for the importance of terminology use and its effects on the experience of stigma, and promote using "dignified terminology" and reject using "hurtful words, stereotypes, and labels like "leper", "Hansenite", "PAL" (People Affected with Leprosy). In this way, the terminology usage I am proposing is in line with this sentiment, and will hopefully contribute to one of the main mission goals of IDEA. Specifically, by highlighting the need for awareness with terminology usage, this thesis is contributing to the fourth goal: 4. Transform the Social Image of Leprosy by Promoting a Positive Image and Emphasizing the Legacy of Creativity and Inspiration.[365] In this sense, I am supporting the idea that the experience of a disease should not necessitate the loss of human rights and dignity.

The continued use of the pejorative words "leper" and "leprosy" is a persisting problem in the popular discourse surrounding leprosy and Hansen's disease. As previously mentioned in section 3.6, there was a general drop in the disease during the 18th to 20th centuries, meaning that most people were familiar with the *idea* of leprosy rather than the *reality* of Hansen's disease. To this day in the West, most people have an understanding of the terms "leprosy" and "leper", though they mostly encounter them being used metaphorically in a derogatory context.

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[364] Integration Dignity and Economic Advancement. "About IDEA" idealeprosydignity.org.

[365] The full list goes as follows: 1. Acknowledge that Stigma Can be Eliminated., 2. Continue to Expand IDEA's National and International Network of Support., 3. Ensure Adequate Support and Counseling to Enable Individuals to Resolve the Deep Emotional Issues that Continue to Accompany a Diagnosis of Leprosy., 4. Transform the Social Image of Leprosy by Promoting a Positive Image and Emphasizing the Legacy of Creativity and Inspiration., 5. Promote Opportunities for Education and Economic Independence., 6. Promote the Restoration of Family Ties., 7. Respect and Promote the Dignity of the Older Generation of Individuals Affected by Leprosy by Using Their Lif Experiences to Effect Social Change., 8. Ensure that Individuals Affected by Leprosy are Accorded Their Rightful Place in Their Own History., 9. Build Bridges Towards Universal Human Rights and Peace through the IDEA Center for the Voices of Humanity. Integration Dignity and Economic Advancement. "IDEA's Global Campaign to Eliminate Stigma". idealeprosydignity.org.

There is an infamous example from the 1960s where a reporter described a British Tory politician, Peter Griffiths, as a ‘parliamentary leper’, though he was subsequently criticized for his offensive language.[366] Even as recently as 2018, the United Nations wrote an article drawing attention to the continued degrading use of these terms in politics. In the article, both the Portuguese Prime Minister, António Costa, and Bangladesh’s Minister of Shipping, Shajahan Khan, were found to have used the word “leprosy" when referring to opposition parties.[367] The persisting use of “leper” and “leprosy” in the popular discourse is one of the main ways that the historical stigma surrounding this disease is being perpetuated.

[366] Rawcliffe 2006, 11.

[367] UN News. "Using ‘Leprosy’ Metaphors in Political Rhetoric ‘Fuels Public Stigma’ and Discrimination: UN Rights Expert”. news.un.org.

12.0 Conclusion

> Leprosy not only stigmatized, it transformed basic identity. Unlike any other illness, this disease branded its victims with its name. One became a "leper" with all the judgment-laden associations from the Bible, from literature, and popular culture.[368] — Marcia Gaudet

This thesis looks at the impact of terminology usage on the study of disease in the past using the historical and academic discourses of leprosy in medieval England. Using discourse analysis as a methodological framework, it was possible to trace the changes in the discourse surrounding this disease over time (Section 3 and 4). The multidisciplinary boundaries between history and archaeology were also briefly explored, in order to determine what each discipline can contribute to the study of this disease in the past (Section 5 and 6). The main contribution of this thesis was the proposal of a new form of terminology usage in which to better navigate the boundaries between the past and present ideas of leprosy and Hansen's disease (Section 7). The term "leprosy" should be used in a socio-cultural context to reference the experiential nature of the disease. The term "Hansen's disease" is understood from an etiological perspective and it should be applied to the modern biological understanding of the disease.

By giving an overview of the main works from both the historical and archaeological discourses surrounding leprosy, I was able to explore the current limitations of the terminology usage in the current scholarship. It was then possible to use specific case examples from the academic sources from both disciplines to demonstrate where my proposed terminology helps to clarify the discussion and understanding of leprosy within the academic literature (Section 8 and 9). The thesis also looked at the broader implications for other disease terminology usage within academia, using tuberculosis as an example (Section 10). Finally, it explored the impact that terminology change could have on the popular discourse which continues to influence those still experiencing Hansen's disease today (Section 11).

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[368] Gaudet, Marcia G. *Carville : Remembering Leprosy in America*. Jackson: University Press of Mississippi, 2004, 24.

Ultimately, this thesis is proposing that the term "leprosy" should be relegated to the past (used to discuss the lived experiences and stigma of this disease), and that the understanding of "Hansen's disease" should only carry a medical meaning rather than a lasting stigma. A person should be able to become infected and subsequently cured of Hansen's disease without the labels of "leper" or "leprosy" becoming attached to their personal identity. In his discussion on the modern sufferers of Hansen's disease, Anwei Skinsnes Law describes how "authors, historians, archaeologists, palaeontologists and the general public have an opportunity to be a part of the global "Quest for Dignity",[369] and I applaud him for recognizing the important role of these groups in shaping the broader discourse of this disease. It is my hope that this thesis can contribute to the "Quest" by highlighting the need for a critical and conscious review of the terminology usage within the academic discourse surrounding leprosy and Hansen's disease.

[369] Law and Hill 2002, 7.

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