LEPROSY AND A COLONIAL LEGACY

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Introduction

Leprosy is a disease surrounded with an air of mystery. Its very mention evokes images of medieval times and biblical scenes. Over the years, persistent misunderstanding and unrelenting prejudice, have led to an unwavering stigmatization of leprosy and discrimination of those who suffer from it. In today's day and age, intolerance is still an important part of the suffering of people affected by leprosy. They still endure social isolation, discriminatory laws and human rights violations. Social prejudices have become an essential part of the treatment of leprosy affected persons. Thus, it is important to understand all dimensions of their suffering. It can be useful to understand where the prejudice and injustice originate, whether in religion, the unknown, simple scorn or fear of contagion and the perceived risk of physical harm and pain.[1]

In 2010, the United Nations Human Rights Council adopted a resolution on elimination of discrimination against persons affected by leprosy and their family members. In 2017, they appointed Alice Cruz as the UN Special Rapporteur on this specific resolution. The stigma and discrimination around leprosy is all but uncontested by academics. Literature on the subject is abundant. However, the source of this hostile attitude and the reason for its endurance is rarely the main topic of debate. It is important to consider the historical development that led to the human rights violations of today. In *Leprosy, Racism and Public Health*, Zachary Gussow argues that the neglect of academics to make comparative studies of a leprosy stigma has created the misgiving, that hostility towards the disease is universal and historically continuous when it's not. He believes that the stigma around leprosy is shaped by racism of Europeans in the 19th century.[2] Gussow's argument lacks some nuance, but he makes an important point and his view on 19th century Europeans can be made to fit into a broader theory. Many scholars, perhaps most notably, Roy MacLeod, have argued that medicine was a tool for empire. Medical practices were often politicized and became a way to convert, suppress and civilize the empire's newfound subjects.[3] It can be valuable to analyse European colonial practices. Their medical policies were shaped by their norms and values and the politicization of medicine contributed to discriminatory legislation and human rights violations against persons affected by leprosy.

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[1] Bart van den Borne, 'Dimensions and Process of Stigmatization in Leprosy', 2014, 348.

[2] A. M. Brandt, 'A Disease and Its Specter: Leprosy, Racism, and Public Health.', *Science* 246, no. 4930 (3 November 1989): 679.

[3] Roy M. MacLeod and Milton James Lewis, eds., *Disease, Medicine, and Empire: Perspectives on Western Medicine and the Experience of European Expansion* (London ; New York: Routledge, 1988), x.

In many previously colonized countries discriminatory treatment still endures and government legislation lags miles behind scientific and medical breakthroughs.[4] This phenomenon can be explained by looking at the reaction of European colonizers to leprosy. To many Europeans, the discovery of leprosy in the colonies, confirmed racist as well as Christian ideas.[5] Many religious groups ventured to control the disease using leprosaria[6], but in doing so had a drastic impact on how leprosy was perceived and treated. This paper will answer the question; how did the Europeans, in the age of imperialism, contribute to current-day human rights violations against persons affected by leprosy?

Important is, to first establish the extent and the gravity of discrimination against leprosy patients. The first part of the paper will discuss the different dimensions of the human rights violation that persons affected by leprosy face in today's day and age. The following part of the paper will discuss norms and values of European colonialists that inspired discriminatory treatment. The stigma surrounding leprosy is often presumed to be primarily grounded in a fear of contagion. However, religious ideas as well as 19th century racism have also been very important in cultivating hostility towards leprosy patients. The final part will analyse how these norms and values came to influence official legislation. Throughout the paper I will consult some primary sources. I will include reports by the United Nations, reports and articles by NGO's, newspaper articles and legislation.

First, it is important to give a short explanation of the cause and the symptoms of leprosy as there are many misunderstandings about the contagion of the disease and the impairments it causes. Leprosy is an infectious disease caused by, *Mycobacterium leprae*. The bacterium mainly affects the skin, eyes and peripheral nerves. Damaged nerves result in loss of feeling, dryness of the skin and paralysis.[7] The disease has a long incubation period in which there are no signs or symptoms, but transmission of the disease to others is already taking place.[8] On average, the incubation period lasts between three to five years. When left untreated, leprosy can lead to impairments like shortened fingers and limbs. More damage is often done by careless use of numb extremities due to a lack of awareness. Medical research has shown that the disease is only mildly communicable and most people have enough immunity and are therefore unlikely to get sick. Thus, quarantine is not necessary or even

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[4] Omobolanle Kazeem and Temitayo Adegun, 'Leprosy Stigma: Ironing out the Creases.', *Leprosy Review* 82, no. 2 (2011): 104.

[5] Rod Edmond, '"Without the Camp": Leprosy and Nineteenth-Century Writing', *Victorian Literature and Culture* 29, no. 2 (September 2001): 511.

[6] Leprosaria are places for quarantine where patients, and sometimes members of their family, live in segregated societies.

[7] Borne, 'Dimensions and Process of Stigmatization in Leprosy', 342.

[8] Liora Navon, 'Beggars, Metaphors, and Stigma: A Missing Link in the Social History of Leprosy', *Social History of Medicine* 11, no. 1 (1998): 89.

effective. However, forced segregation in leprosy colonies or leprosaria, is still common in many endemic countries.

Violations of Human Rights

Leprosy is a heavily stigmatised disease and discrimination is an important part of the suffering of leprosy patients. Even today, patients regularly face human rights violations. Forced segregation is one of the many forms of discriminatory treatment that leprosy patients experience. While effective medical treatment of leprosy has been available since the 1940's, forced segregation of leprosy patients still happens in many countries. For example, the International Federation of Anti-Leprosy Associations (ILEP) states, in a 2018 report on the social stigma, that there are 119 discriminatory laws in place in India. Many of these laws concern the segregation of leprosy patients from their communities. This legislation and the forced segregation of leprosy patients constitute violations of human right as they are in conflict with several articles of the 1948 Universal Declaration of Human Rights.[9] Forced segregation, for example, is not in line with Article 13 of the declaration which states that everyone has the rights to freedom of movement. Neither is such legislation in line with Article 9 of the same declaration by which no one shall be subjected to arbitrary arrest, detention or exile. Moreover, discriminatory legislation also negatively affects patients' access to public services; their right to work; and their equality in marriage, violating articles 21, 32 and 16 respectively.[10] An example of such legislation can be found in India, where Leprosy was still a grounds for divorce until 2019.[11] In 2010, violations of human rights against persons affected by leprosy were fully recognized by the United Nations Human Rights Council when they adopted a resolution on elimination of discrimination against persons affected by leprosy and their family members.

It should be mentioned that this resolution is surrounded by some debate and controversy. Some academics have said that the specific and separate mention of leprosy only perpetuates the narrative that has long surrounded leprosy. Again, leprosy is portrayed as a disease apart, while health should naturally be pursued for all people, including people affected by leprosy.[12] Nonetheless, the adoption of this resolution is testimony to the gravity of the problem.

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[9] 'ILEP-PUBLICATION_EN', 7, accessed 22 January 2020, https://indd.adobe.com/view/794531c5-0b0f-4b1b-bf24-5bf13bf15854.

[10] Shigeki Sakamoto, 'Elimination of Discrimination against Persons Affected by Leprosy and Their Family Members' (Human Rights Council Advisory Committee, 2009), 2.

[11] 'Eliminating Discrimination Against Persons Affected by Leprosy', D.O. No.6(3)/273/2015-LC(LS) (Law Commission of India, 2015), 18.

[12] Douglas Soutar, 'Leprosy and Human Rights.', *Leprosy Review* 79, no. 3 (2008): 239.

The resolution was adopted not long after a 2009 report by Shigeki Sakamoto, a member of the advisory committee of the Human Rights Council. In this report, information is collected from several NGO's as well as governments, regarding the measures that governments have taken to eliminate discrimination against persons affected by leprosy and their family members.[13] The report makes abundantly clear that, at the time it was written, discriminatory measures against people affected by leprosy were still taken by many countries, with patients still forcibly quarantined under law.[14] Other countries had only recently repealed discriminatory laws.[15] Myanmar, for example, only abolished its discriminatory legislation concerning leprosy in 1992.[16] Since this report of 2009, the world has seen some improvement as countries have taken proactive steps to repeal discriminatory legislation. However, on their website, The International Federation of Anti-Leprosy Associations states that as of today, 132 laws that discriminate against people affected by leprosy are still in place.[17] The majority of these laws concern forced segregation. Others relate to employment, immigration, marriage, voting and access to public transport.[18]

It is often believed that quarantine is justified due to the contagious nature of leprosy. However, it has long been well known, in medical circles, that quarantining patients is not effective due to the long incubation period during which contagion is already possible, but symptoms not yet apparent.[19] Neither is there any scientific evidence for the necessity of quarantine as the disease is only mildly communicable and most people have sufficient immunity to resist it.[20] Furthermore, the disease has been curable since 1982 when multidrug therapy was introduced. Even in the 1940's leprosy could already be affectively treated using the antibiotic, Dapsone.[21]

The Origins of Discrimination

Having established that, even today, the human rights of persons affected by leprosy are continuously and unjustifiably violated, this section of the paper will discuss the different norms and values that inspired such treatment. According to the aforementioned, 2018 report by ILEP, much of the discriminatory legislation of today has its origin in the 19th century. The historical development

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[13] Sakamoto, 'Elimination of Discrimination against Persons Affected by Leprosy and Their Family Members', 2.
[14] Sakamoto, 2.
[15] Sakamoto, 2.
[16] Sakamoto, 4.
[17] 'Zero Discrimination', International Federation of Anti-Leprosy Associations, accessed 30 January 2020, https://www.ilepfederation.org/what-we-do/zero-discrimination.
[18] 'ILEP's Research into Discriminatory Laws: Legislation' (The International Federation of Anti-Leprosy Associations, 2019), 18.
[19] Navon, 'Beggars, Metaphors, and Stigma: A Missing Link in the Social History of Leprosy', 89.
[20] Sakamoto, 'Elimination of Discrimination against Persons Affected by Leprosy and Their Family Members', 2.
[21] Navon, 'Beggars, Metaphors, and Stigma: A Missing Link in the Social History of Leprosy', 89.

that led to the hostile treatment of leprosy patients is complex and the role of European colonialists is important. Missionaries were especially instrumental in the stigmatisation of leprosy. They were active in treatment and the use of forced segregation to control the disease. Contagion was not the only, or even the most important reason for the perceived necessity of these leprosy colonies. Religion and racism are two other important informants of hostile treatment by missionaries and other European settlers. They had both a religious and a civilizing motive. It is worth taking a look at the foundations laid by these colonialists.

An important place to look when studying the perception of leprosy, is the Church. Religion has long shaped people's opinions, perceptions, norms and values. The Bible often makes explicit mention of leprosy, but it is now well known that what they called 'leprosy' in the Bible actually refers to different diseases and not to the leprosy that we know (and medically define) today.[22] The symptoms of 'leprosy' in the Bible can refer to many skin diseases and, in some cases, even exclude leprosy as a possibility. Nevertheless, the association and the presumed connection with the Bible was important. It is crucial to consider both the disease and the concept, as these have not always been one and the same. The name, though attributed to a changing concept, kept many of its connotations. Biblical notions were long cultivated by priest, missionaries and artists. It is important to take a close look at the 'leprosy' of the Bible as it will have inspired many of the prejudices of European colonialists.

The Leviticus, the third book of the Hebrew Bible, discusses Leprosy in some detail. The 13th chapter instructs priests on how they would be able to diagnose leprosy in a person. The 14th chapter discusses its treatment. According to Leviticus, leprosy can be recognized by blisters, ulcers, scabs and discoloration of the skin. If a person is diagnosed with leprosy, they are declared unclean and banished from the community until the leprosy disappears. When the discolorations are either gone or they have spread to fully cover the person from head to toe, they will be declared clean and they will be allowed back to church and to the community in which they lived.[23] The Leviticus expresses, in no uncertain terms, the need for segregation of leprosy patients. Leprosy is portrayed as a sinner's disease and little pity or compassion is shown to those who suffer from it. Because exile was used in the Bible, it was not far-fetched for missionaries to use similar tactics.

The New Testament has a slightly different tone. Throughout it, the focus is on healing leprosy patients. A good example is Luke 17:19. After healing a leprosy patient, Jesus tells him "Rise and go; your faith has made you well.". Again, there is a parallel to be drawn with missionaries in the 19th century. Medically trained missionaries were tasked with the continuation of the work of Christ the

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[22] Mary Douglas, *Leviticus as Literature* (Oxford University Press, 2001), 183.

[23] 'Leviticus. 13', in *Bijbel* (Amsterdam: De Nederlandsche Bijble-Compagnie, 1986).

healer, in order to display the superiority of Western culture and civilisation.[24] It is summarized well by the medical missionary, Robert G. Cochrane:

> *'The evangelisation of the world depends on the indigenous people of each nation, and what better missionary could be found than the leper[25] cured of his disease, going back to his people telling them out of the fullness of his heart, the twofold gospel of spiritual and physical healing.'*[26]

The missionary's perception of leprosy was determined by their beliefs and it is clear that the Bible was a solid foundation for discriminatory treatment.

Unfortunately, the Europeans did not only export religious ideas to the colonies, they also brought a significant amount of racism. Social Darwinism and a civilising mission constituted another step towards human rights violations. Finding leprosy among the 'coloured and black races' was, to them, conformation that they were dealing with an underdeveloped people. An 1862 article in The Times speaks to this sentiment.

> *'Most of the countries in the East continue to be infested with* [leprosy] *to a greater or less extent, generally speaking to the physical and moral degradation of their people.'*[27]

Leprosy became associated with the 'underdeveloped' coloured races. As Zachary Gussow points out, leprosy in the endemic Norway of the late 19th century, never excited the same prejudices or frenzy among the European public.[28] This is a testament to the racism underlying this fearful perception of the disease. Outside of Norway, Leprosy had all but disappeared from Europe and it was therefore thought that fighting the disease required European knowledge and techniques. [29]

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[24] Michael Worboys, 'The Colonial World as Mission and Mandate: Leprosy and Empire, 1900-1940', *Osiris* 15 (2000): 209.

[25] The term 'leper' was historically used to refer to people affected by leprosy. However, it is now considered to be an offensive term that has often been used to justify hostile treatment and discriminatory legislation. For that reason, I will not use the term throughout the rest of this paper unless it is part of a quote.

[26] Worboys, 'The Colonial World as Mission and Mandate', 210.

[27] 'Leprosy In The East Indies', *The Times*, 26 November 1862, The Times Digital Archive.

[28] Shubhada S. Pandya, 'The First International Leprosy Conference, Berlin, 1897: The Politics of Segregation', *História, Ciências, Saúde-Manguinhos* 10, no. suppl 1 (2003): 163.

[29] Worboys, 'The Colonial World as Mission and Mandate', 208.

Discriminatory treatment by colonialists made leprosy more than just a biblical affliction; it became a danger to empire and a threat to western civilization. Their use of leprosaria and forced segregation reinforced the stigma and created further misunderstandings.[30]

While this section of the paper has attempted to establish clear and important connection between 19th century, European ideals and discriminatory treatment of persons affected by leprosy, it is essential not to understate the relative autonomy of many features of indigenous culture, even under colonial rule.[31] Contemporary perceptions of leprosy are embedded in a conglomeration of colonial ideas and local (religious) notions of purity and karma as well as personal experiences and encounters with the disease. For an example of pre-colonial discrimination towards leprosy patients one can turn to ancient, Indian texts. Mentions of skin diseases translated to 'leprosy' can be found in *Atharava Veda* (circa 2000 BC) and the *Laws of Manu* (circa 1500 BC). These laws ostracized people affected by the disease by prohibiting contact with them and punishing those who married into their families.[32] In ancient Indian society, leprosy patients were marginalized because of the disease's association with sin as well as a fear of contagion resulting in physical harm.[33]

I do not wish to suggest that all aspects of local culture were wiped out under colonial rule. However, it is important to acknowledge the role of European settlers. Though segregation of leprosy patients has its roots in Ancient times, the practice only truly gained currency with European expansionism. As part of their mission to civilize, convert and control native populations in the colonies, Europeans politicized medical practices.[34] What makes their role so instrumental, is the impression they left on local politics and legislation.

The legacy of colonial legislation

Having established that the human rights of leprosy patients are continuously violated, and, having acknowledged the different prejudices of European settlers, it is important to take a look at the politics behind the discrimination. Much of the discriminatory legislation of today has its origin in 19th century global policy of compulsory internment.[35] This legislation followed Dr. Gerhard Hansen's discovery of *Mycobacterium leprae* in 1873. His discovery strengthened people's belief that

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[30] Michelle Therese Moran, *Colonizing Leprosy: Imperialism and the Politics of Public Health in the United States*, Studies in Social Medicine (Chapel Hill, NC: University of North Carolina Press, 2007), 204.

[31] Worboys, 'The Colonial World as Mission and Mandate', 209.

[32] Jesse T. Jacob and Carlos Franco-Paredes, 'The Stigmatization of Leprosy in India and Its Impact on Future Approaches to Elimination and Control', *PLoS Neglected Tropical Diseases* 2, no. 1 (30 January 2008).

[33] Jacob and Franco-Paredes.

[34] MacLeod and Lewis, *Disease, Medicine, and Empire*, x.

[35] 'ILEP-PUBLICATION_EN', 7.

leprosy was a highly contagious disease, despite a lack of sufficient evidence.[36] There was still no way to explain how the disease was transmitted.[37] Among scholars of the time, a debate around the contagious nature of leprosy continued to exist, with some academics believing in an important hereditary component.[38] In 1893, the Leprosy Commission in India published a report stating the following:

> *'The amount of contagion which exists is so small that it may be disregarded, and no legislation is called for on the lines either of segregation, or of interdiction of marriage with lepers'.39*

This knowledge did not immediately affect the policies of leprosy experts and lawmakers, neither did it have a noticeable impact on public opinion. Colonialists continued to blow the threat of leprosy out of proportion and with the help of Hansen's discovery, anxiety in Europe flourished. In the late 1800's leprosy grew beyond the bounds of medical attention. Its mention was common in literature, newspapers and periodicals.[40] The disease was believed to be spreading across the imperial world and a growing number of leprosy cases in Europe was being reported in the 1880's. Arguments for forced segregation became widely supported among the European public.[41] Racism, religion and the discovery of the bacterium caused a frenzy in Europe which further justified settlers in their use of leprosaria in the treatment and control of leprosy in the colonies. Treatment of leprosy had political value as it was a means to assert professional dominance over the native populations.[42] What people presumed to be advanced medical know-how, cultivated a narrative of superiority and authority.

In the late 19th century, leprosy was a topic of debate for the European public as well as missionaries, medical experts and political figures. 1897 saw the first International Leprosy Conference. Here, medical experts as well as government representatives came together to discuss the perceived threat they were facing. The objective of the conference was clearly expressed by Albert Ashmead, one of two of its initiators.[43] He wrote a letter titled 'The Object of the Berlin Leprosy Conference' to the Journal of the American Medical Association, in which he made the following statement:

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[36] Alice Cruz, 'Report of the Special Rapporteur on the Elimination of Discrimination against Persons Affected by Leprosy and Their Family Members*' (Human Rights Council, 2018), 7.

[37] Rod Edmond, *Leprosy and Empire a Medical and Cultural History* (Cambridge: Cambridge University Press, 2007), 80.

[38] Edmond, 80.

[39] *Leprosy in India: Report of the Leprosy Commission in India 1890–1891* (Calcutta: Superintendent of Government Printing, 1892), pp. 289–90.

[40] Edmond, *Leprosy and Empire a Medical and Cultural History*, 81.

[41] Edmond, 82.

[42] J Buckingham, *Leprosy in Colonial South India: Medicine and Confinement.* (Place of publication not identified: Palgrave Macmillan, 2014), 135.

[43] Pandya, 'The First International Leprosy Conference, Berlin, 1897', 165.

> *'We declare at once that we are contagionists, and that we do not believe that anything but absolute isolation can destroy a disease which affects nearly a million of human beings. Such a committee can not but be for isolation. In this respect we are intolerant.'*[44]

Dr. Hansen, being a leading expert and leprologist, had an important voice at the conference. He agreed with Ashmead and campaigned for segregation and compulsory registration of persons affected by leprosy.[45] Though the resolutions emerging from the first, as well as following conferences, were not binding, it did set the tone for politicians and lawmakers.[46] Endorsement of compulsory internment remained the official policy until it was abandoned at the International Leprosy conference in 1948. Even then, many established national policies and legislations continued to exist.[47]

Conclusion

Leprosy is a heavily stigmatised disease. This paper has established that this stigmatization has led to discriminatory treatment and human rights violations. The origins of this stigma are important to consider. Understanding all dimensions of discrimination might be valuable in the search for, and application of, solutions. This paper has argued that European expansionism and colonial policy have played an instrumental role in the discriminatory treatment of persons affected by leprosy. It has also tried to establish and explain the influence of European norms and values on current day human rights violations.

On encountering cases of leprosy in the colonies, European settlers took it upon themselves to endeavour treatment and control of leprosy patients. Both their religious believes and their racist ideals informed their practices. These ideals, together with the discovery of *Mycobacterium Leprae* and ample media coverage of the disease, resulted in a panic among the European public and a wide support for forced segregation. Discourse on leprosy also entered politics as medical treatment was an important concern for many colonial rulers. Medicine was a way to assert superiority and control, civilize and convert local populations in the colonies. After the first International Leprosy conference, Europeans started to secure their treatment and policies concerning leprosy in official legislation.

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[44] Albert S. Ashmead, 'The Object of the Berlin Leprosy Conference.', *JAMA: The Journal of the American Medical Association* XXVIII, no. 9 (27 February 1897): 425.

[45] Pandya, 'The First International Leprosy Conference, Berlin, 1897', 172.

[46] Pandya, 175.

[47] Cruz, 'Report of the Special Rapporteur on the Elimination of Discrimination against Persons Affected by Leprosy and Their Family Members*', 8.

Much of today’s discriminatory treatment has its roots in these 19th century laws. Consequently, colonial practices, informed as they were by racism, Christianity, and a misguided fear of contagion, are some of the foundations of today’s human rights violations against persons affected by leprosy.

It cannot be stressed enough that stigmatization is very complex and is informed by more than only European settlers. This paper has focussed on the influence of colonial rule, but it should be considered as part of a bigger story, an important chapter in the historical development of the leprosy stigma. It is important to be weary of oversimplification and generalization.

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