

Leprosy - The Name and the Stigma

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The stigma associated with leprosy, which has prevailed in virtually every culture, has resulted in discrimination, stereotypes, labelling, and ultimately the social exclusion of individuals affected by leprosy from equal participation in society. This paper traces back the religious worldview of the disease and the term '*leprosy*' and its impact on stigma and attitudes. Stigma is multifactorial and is related not only to the nomenclature of the disease but to other factors like availability of effective treatment, ability to control the transmission of the disease and disability. It has been observed that a society's response to leprosy is determined by a combination of religious, medical, legal, and social ideas. The milestones in the semantics of the term leprosy and the proposals to change to less stigmatising eponyms, including Hansen's disease point to these influences. In recent times, there has been increased advocacy in various fora on the replacement of the word '*leprosy*' with other more acceptable terms. This paper examines the pros and cons of this name change proposal in different cultural contexts of India, Brazil and other parts of the world and the practicality of abandoning the use of the word '*leprosy*' from all reference to the disease. The need for a new outlook on leprosy by the public, the patient and the doctor cannot be over emphasised; and similarly, the need to rid society and patients from the shackles of negative narratives and traditions. Key approaches that could positively reduce stigma related to the disease and to the term leprosy are to clear the misconceptions about the disease through awareness and educational campaigns, and strengthen the efforts to diagnose the disease early to prevent disability. The endeavour should be to remove the stigma wrongly attached to the word "*leprosy*" rather than to abandon the name.

Keywords : Leprosy, Eponym, Stigma, Scriptures, Semantics

Introduction

Stigma and discrimination against people affected by leprosy and their families are almost as old as recorded history. Stigma in leprosy leads to different types of discrimination (community, religious, social, education, economic and health related), amounting to violation of constitutional as well as human rights (Dongre 2017). Much of the stigma in the past was linked to the fear that it

caused unsightly disfigurement of the hands, feet and face, that it was contagious, and that it was not treatable. This attitude of dread existed in virtually every culture resulting in discrimination and social exclusion of persons and families affected by leprosy from equal participation in the society. Hence, the term '*leprosy*' itself evoked fear and several other emotions in people affected by the disease, their families and people

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around them. Leprosy finds mention in various religious scriptures and texts. It has often been a point of discussion in sermons and discourses, more frequently in a negative connotation, even after the discovery of effective treatments for the disease. The scientific medical community has discussed the term 'leprosy' for well over a century. In the mid 20th century, this led to a lot of debate, especially in western countries, to promote action/legislation to replace the name '*leprosy*' with a less stigmatized name.

Throughout history, the word leprosy has been a perennial target for popular prejudice. In some countries, discriminatory laws enacted decades or even centuries ago continue to be practised. Concerted efforts are on to build alliances and sensitise administrators and lawmakers of national governments to repeal them. It is important to note that stigma is not a fixed entity and can change over time or in different environments (Kaseem & Adegun 2011). Fortunately, recent decades have seen remarkable progress in addressing the psychosocial impacts of this disease (Kuipers et al 2013, Rao 2015). However, during the same time, there has been renewed discussion in leprosy e-groups, conferences presentations, in advocacy approaches and in medical journals on replacement of the name 'leprosy' by other more acceptable terms (Deps & Cruz 2020, Burlin & Lockwood 2020, Barve 2020, Almeida 2020). At the same time, there are others who feel that such moves imply that we are giving indirect approval to the concept that having leprosy is indeed stigmatising (Cochrane 1970, Ajit 2020). While the programme is working actively to repeal these discriminatory laws related to leprosy the world over, it will be an excellent exercise to examine the argument put forward to legally exclude the word 'leprosy' itself. This paper examines the need for such a change

and its relevance to India, which has the greatest number of the world's leprosy patients and possibly to other countries endemic for leprosy.

Impact of a religious worldview of leprosy

Writings in religious scriptures and a spiritual worldview have significantly impacted societal attitudes to leprosy. But the fact remains that leprosy described in historical and religious texts was not the same as modern leprosy but included a variety of skin conditions from rashes and patchy skin to swellings (CDC 2021 website). Trying to identify diseases retrospectively based on historical scriptures is a tricky business but what is obvious is that much of the stigma of leprosy in Western societies are based on how leprosy has been portrayed in the Bible (Pierre 2012). In the Old Testament of the Bible, the term 'Zaraath' was used to describe various diseases affecting the skin and not necessarily leprosy as described today. The description included discolouration of the skin and physical disfigurement of the body but was associated with divine retribution, disgrace, spiritual and physical defilement that distanced a person from God, the temple and from society. From its earliest descriptions in the Bible, exclusion from society has been a feature of leprosy, and the person with leprosy was referred to as a 'leper'. The exclusion was not just a social phenomenon but a divine institution intended to serve as a public health measure to contain a disease that could spread to others in the community. A provision for re-entry into society also existed if the person was healed of their condition (Dharmendra 1947). In Brazil, a predominantly Christian country and where leprosy is endemic, the disease is still viewed as a shameful and spiritually polluting condition. This is perpetuated in sermons of even evangelical churches, which are popular among the working classes, frequently suggesting that the diseases may be the result of sin and demon possession

and that faith healing, rather than medical treatment, is the only effective cure (White 2008).

Despite advances in knowledge about the disease, it is surprising how many Western countries considered leprosy much less of a medical problem and more of a disease associated with sin and uncleanness, with the person needing pity and prayer for cleansing and healing (van Brakel et al 2021). Some researchers argue that, in the West, the medical community overreacted to leprosy because of the knowledge that the disease was caused by a bacillus, combined with the biblical concept of contagion (Sinha et al 2010).

Potentially stigmatising references to leprosy can similarly be found in Hindu and Muslim religious texts (van Brakel et al 2021). Sushruta-Samhita, an ancient Hindu medical manual, mentions that sometimes a man is cursed with this dreadful disease '*Kushtha*' (whose description befits leprosy), by way of divine retribution. '*Manu Smriti*', (Laws of Manu), a book of great antiquity, forbids marriages into families whose members are subject to certain diseases and defects and *Kushtha* is one of these (Dharmendra 1947). In the Quran, the two terms '*Baras*' and '*Judham*' are used to describe leprosy. There is also a saying in Islamic religious texts advising people to keep away from the leprosy person as they keep away from a lion (Sinha et al 2010). At the same time Islamic sacred texts have also promoted destigmatisation, and even inclusion of people living with leprosy into society (Hasnain et al 2020).

Several reviews relating to leprosy and religion have been published, including those which suggest that religion is certainly one of the several contributing factors to stigma (Raju et al 2020, McEwen & Earnest 2021, Grzybowski & Nita 2016, Hanumanthayya et al 2017). At the same time, almost all religions have had some points of discussion on leprosy relating to its cure in their

ancient texts, which also support the idea of not discriminating against leprosy sufferers (Sinha et al 2010, Hasnain et al 2020). There is a need to channelise the positives from these scriptures to create an atmosphere in the society, free from feelings of discrimination against leprosy.

Leprosy semantics: Replacing leprosy with 'Hansensiasis' and Hansen's Disease

At National Leprosarium, Carville, Louisiana, a leprosy patient named Sidney Maurice Levysen, who became famous with this assumed name 'Stanley Stein' given at that institute to prevent stigmatizing of his family, was instrumental in printing an in-house patient newspaper *The Star* in 1941 with the mission to spread the light of truth about leprosy. He was the first to advocate change the name leprosy to Hansen's disease, to mitigate stigma and honour the Norwegian scientist who discovered *Mycobacterium leprae* (Trautman 1968). One of the early attempts to address the leprosy nomenclature by the medical fraternity was at the 5th International Congress of leprosy held in Havana in April 1948, which supported the campaign to get rid of the odious word 'leper' and passed a resolution to abandon it in favour of the term 'leprosy patient'. However, simultaneously it also passed a recommendation that the name leprosy should be retained as the scientific designation for the disease, and active steps should be taken to fully explain its real nature to the general public. It also recommended that if the regional popular less specific term in substitution for the scientific name "leprosy" may be used, but it would be unwise to adopt such terms to conceal the true nature of the disease. This resolution was once again ratified at the 6th International Congress of leprosy held in Madrid, Spain, in 1953 (STAR 1973). However, the efforts to have a less stigmatising eponym for leprosy continued. The modification of the word "

leprosy" was recommended by a significant group of the 'Pan-American Health Organization's Seminar on Administrative Methods for Leprosy Control Programmes' held at Guadalajara, Mexico in the year 1968. Brazil is the largest country of American continents where the word "leprosy" affects patients and contacts emotionally, so much so that it blocks their education and hinders prophylactic programmes (Rotberg 1972). The 18th Brazilian Congress of Hygiene, held at Sao Paulo, Brazil in 1970 considered that changing the term 'leprosy and its derivatives would be a constructive psychological step towards promoting health education, facilitating leprosy control and eliminating the social stigma experienced by patients and their families (Rotberg 1972). In 1976, through a ministry of health ordinance, Brazil replaced the term 'lepra' (leprosy) with *Hanseniasis* or Hansen's disease after Gerhard Hansen, thus introducing his name into the semantics of the disease (Oliveira et al 2003). The idea behind this change was that it would not only reduce self-stigmatisation and stigmatisation of patients by others but would also avoid confusing leprosy with other diseases with which the word *lepra* was associated in Portuguese, such as dog mange, scabies and a variety of other common skin ailments. Lobbying efforts on physicians and the non-governmental organizations by the MORHAN (Movement for the Reintegration of People Affected by Hansen's Disease) played a great part in sustaining these efforts although the terms did not disappear totally from popular discourse. The decision of whether to use Hansen's disease or leprosy in writing about the disease was and is a difficult one, but in general, Hansen's disease and *Hanseniasis* are presently in common use in Brazil (White 2008).

The prejudice and regulations against leprosy patients were rife in the United States of America as well, and they are well documented (Doull

1950, Gould 2005). In the United States, the national leprosy programme was named National Hansen's Disease Program (NHDP), credit to the efforts of Stanley Stein, a person affected by leprosy, who first advocated such a change. NHDP states that it 'coordinates care, research, and information about *Hansen's disease (also known as leprosy)*'. Note that the term leprosy is still mentioned in parenthesis (NHDP website).

The use of Gerhard Hansen's name appeared non-controversial until recently when attention was drawn to the fact that Hansen as he was found guilty of unethical human experiments with *M leprae* bacillus during his lifetime (Gould 2005, Ghosh & Choudhuri 2015). Citing it, there was also a suggestion to use an alternate term '*mycobacterial neurodermatosis*' as an eponym reflecting the cause and clinical features of the disease (Butlin & Lockwood 2020). This name was originally suggested 50 years ago by Cochrane in his seminal article titled 'In defense of name leprosy'. However, in the same article, he opined that although descriptive, this name is clumsy because of its length and therefore would not be generally acceptable (Cochrane 1970).

Stigma of word leprosy in other parts of the world

By and large, Asia, Africa and the Western Pacific areas are free from the complex 'leprosy; the word and the disease' as the Graeco-Latin root *lepra* and its derivatives are not part of their languages (Cochrane 1970). For example, in Russia, the word 'leprosy' is used occasionally and does not carry stigma; whereas the regional stigmatising and ostracising word '*prokaza*' is never used in scientific writings (Rotberg 1972). On the other hand, in Botswana, leprosy is referred to as 'lepero', implying an association with 'bad blood' and in Ethiopia as 'qumtina', denoting the 'state of amputation or mutilation' (Brown 2006).

To be fair, stigma to the English word 'leprosy' is foreign to India as English is not a native language, although read and spoken widely. India has twenty-two scheduled regional languages and leprosy is known by many different names across the country. As previously mentioned, it was referred to as *Kushta* or '*aruna kushta*' in ancient Vedic scriptures written in Sanskrit before the common era (CE). In the Hindi heartland it is still known in its shorter version '*Kusth*' while in other parts of India it is known by a variety of other names; as *Pedda rogam* (big disease) in Telugu, and as '*Periya Viadi*' (great disease) in Tamil. Hence the use of the name *leprosy* by academicians and medical personnel does not matter to these populations. While those educated in English in India do understand the word leprosy, it surprisingly does not carry the kind of stigma discussed or observed in western countries.

Although societal stigma is known to affect treatment-seeking behavior, adherence to treatment and overall patient experience influencing public health policies, it is the individual cultural and regional differences that will determine whether or not certain aspects of the medical diagnosis of disease leprosy will result in stigma (Doull 1950). Identifying and understanding culture-specific forms of the stigma associated with leprosy is vital for improving patients' acceptance and compliance for circumventing stigma and eliminating the disease in a region. However, it is debatable if a change of name by itself will serve the intended purpose well.

The difficulty in understanding the concepts of a disease can be one of the causes of the stigma. Some of the fear and stigma associated with leprosy was linked to the view that it was untreatable. That changed with the advent of drugs like dapson, rifampicin which were effective in curing leprosy. As a result, the name 'leprosy' no longer had the same connotation

with which it was invested in the centuries before adequate treatments were available (Ghosh & Chaudhuri 2015). Multidrug therapy has revolutionised the treatment of leprosy world over during last few decades and has shown that leprosy is completely curable. This has resulted understandably in the decline of stigma towards persons and families affected by leprosy, as the curability of leprosy became widely known.

How has the substitution of the term 'leprosy' worked over the last 40 years?

For any health education intervention to succeed, the people's perception of the disease, their beliefs and cultural practices are of utmost importance (Chen & Sim 1986). In an attempt to combat stigma, non discriminatory terms are sometimes used, once such intervention is calling leprosy Hansen's disease. However, in Brazil the use of the eponymous term *Hanseniasis* was also found to be problematic, as some patients who knew that the *Hanseniasis* and lepra were the same, felt that physicians were using the term as a means of withholding information from them about their illness (Wheatley 1985). Overtime, *Hanseniasis* has gradually come to be associated by with same stigmatising words and phrases often associated with lepra/leprosy (Oliviera et al 2003, Brown 2006).

After analysing 50 interviews of people affected by leprosy, 30 years after outlawing the term, a study from Brazil concluded that the terminology change did not eradicate the circulation of the term 'lepra' and did little to reduce prejudice against the disease (Femina et al 2007). The study points out that the change of the term lepra failed to eliminate stigma and prejudice.

The change in terminology for socio-cultural reasons might sound acceptable and be even 'politically correct', nonetheless, to use it as a single measure for reducing stigma is questionable. In a three-year study on the identification of

psychosocial factors related to the rehabilitation of leprosy patients, potential employers were given written descriptions of seven different employees with histories of illness and/or disabilities (Rolson & Chesteen 1970). It was observed that those with leprosy were rejected significantly more often, regardless of whether the illness was identified as leprosy, Hansen's disease or bacterial neurodermatitis. Dispelling misbeliefs and misconceptions, unfounded fears and prejudices are factors important in leprosy control. Less sensationalism, more real progress in research and selecting the right priorities constitute the road to demystification of leprosy (Keto 1990).

Addressing Stigma rather than dropping the word leprosy

Stigma is a multidimensional phenomenon that includes labelling, interpersonal exchanges, health practices, cultural values and shared knowledge about the disease (Link and Phelan 2001). It, therefore, takes multi-level and multi-dimensional interventions to bring about the desired change (Heijinders & Van Der Meiz 2006). In leprosy too the stigma is multi-dimensional and is influenced by a prior concept or misconception about the disease rooted in religious beliefs, hearsay, societal views, stories carried down and cultural constructs. Even with its sanitized name Hansen's disease, the disease can still confer pariah status on the victim (Lerner 2003). A complete understanding of the disease, including the efficacy of treatment interventions, its spread and the possibility of its complete cure, can break many of the misconceptions mentioned above. The onus is on the treating medical team to ensure that the patient and family are counselled, and awareness is created on all these aspects of the disease.

An argument was put forward that many specialists of Asia, Africa, the Western Pacific and

Eastern Europe are not insisting on retaining the word leprosy, a stigmatising word which in any case does not belong to their native languages (Rotberg 1972). However, the fact remains that in all world communications, the word leprosy has come to stay. In most global and national health parlance, the word leprosy denotes the disease it is. Moreover, even in non-English speaking countries of Asia endemic to leprosy, the medical education is mostly in English medium, and the word leprosy is used widely. Importantly, even the general public who have a working knowledge of English understand the term leprosy. The word leprosy is a medical term and a part of the English language, just as are plague or cancer. It is easier for medical professionals to switch terminology than for the English language to be changed as language is determined by common usage rather than central diktat (Almeida 2019). In addition, the word leprosy is an integral part of many national health programs e.g. National Leprosy Eradication Programme (NLEP); associations, e.g. International Leprosy Association (ILA), Indian Association of Leprologists (IAL); and titles of scientific journals, e.g. Indian Journal of Leprosy (IJL), Leprosy Review, Indian Journal of Dermatology, Venereology and Leprosy (IJDVL); and conferences e.g. International Leprosy Congress (ILC). In addition, phrases like lepra reactions, leprosy disability, leprosy nodule, lepromatous spectrum and lepra bacillus are too familiar and practical to be discarded for some new eponymous terminology. And where is the need!

Effective ways to reduce stigma

Our efforts should be to remove the stigma wrongly attached to the word "leprosy" rather than to abandon the name (Cochrane 1970). The suffering caused by leprosy is real; reactions, neuritis, disabilities, disfigurement, among others. The psycho-social issues are just one facet

of it. As there is a sustained reduction in global leprosy numbers, the fear and stigma are also on the wane. Even in a country like India, which has the largest number of leprosy patients, it is not uncommon to meet medical personnel not working in fields related to leprosy, who often wonder if leprosy is still prevalent in this country! Such has been the reduction in obvious deformities which define leprosy and its stigma due to the successful implementation of MDT programme over the last four decades. While it is laudable to address the psycho-social issues effectively, it is imperative that the focus of the programme should firmly be on advances and methods to alleviate the distress and cure the disease. World Health Organization (WHO) is advocating a global 'zero leprosy' strategy for the years 2021-2030, with one of the goals being to remove stigma (WHO 2020). If leprosy workers themselves say that the term *leprosy* should be avoided because of stigma, then in a way it is an indirect approval of the concept that leprosy is indeed stigmatising (Ajit 2020). And there are other issues to consider while renaming a known disease with the name of a scientist. According to WHO document on best practices for naming new human infectious diseases, the disease names may not include people's names (WHO 2015). It further states that, given that long names are likely to be shortened into an acronym, potential acronyms should be evaluated to ensure they also comply with these best practices. It is already happening with the commonly known eponym for leprosy, as the term Hansen's disease is often shortened to HD in print and practice.

Conclusion

Even the most fair-minded of us will at times harbour irrational stereotypes of people who are in some way different. And even the victims of prejudice may themselves stigmatise other

people (Frist 2003). Leprosy has for centuries been a symbol of all that is outcast and feared, which was a difficult social burden to bear for so long. Fortunately, today the societal approaches to leprosy have changed, and stigma and discrimination towards persons and families affected by leprosy are reducing. Hence, leprosy is breaking up fewer families than before, partly because of increased understanding of the disease and partly because of the shift away from institutional care towards local outpatient treatment. Attitudes are now increasingly inclusive as a number of new leprosy cases have fallen dramatically over the decades (WHO-News 2016). More importantly, leprosy is now more seen as a skin disease which can be easily cured (Almeida 2020).

As already stated, colleagues in Eastern Europe, Asia, Africa and the Western Pacific areas are mostly untouched by the negative connotations of the word leprosy. It being so, the word leprosy has no stigmatising effect in these parts of the world. Views also vary with geography, culture and over time and many terms that some people view as offensive are not viewed as offensive by others. Fund-raisers and fieldworkers also look at leprosy in a different light. We must therefore be aware of these non-uniform points of view and the reasons why they differ (Frist 2003). While measures are already taken to substitute the name leprosy by the eponym Hansen's disease in countries such as Brazil and USA, where the word leprosy is a psycho-social disease, more feared than the physical ailment itself due to the pervasive and entrenched spiritual beliefs, is understandable. Nevertheless, advocating similar change globally is neither justifiable nor has a relevance. On the other hand, it is incumbent on us to develop further the concept and spread the message that leprosy is not a feared or dreaded disease but a disease of relatively low communi-

cability that can be managed and cured, while steadfastly working towards the goal of 'Zero leprosy'. It is important to project a positive image of leprosy, as it is no longer the scourge it was once thought to be. Education with prudent use of communication ushering in the brightness of reason can alone clear up the darkness of ignorance and prejudice.

References

- Ajit P (2020). Leprosy Eponym: need for a medical name. Leprosy Mailing List, January 22, 2020. (LML) http://leprosymailinglist.blogspot.com/2020/01/fw-lml-leprosy-eponym-need-for-medical_43.html, accessed 4 April 2021.
- Almeida J (2019). Is the use of an eponym for leprosy inappropriate? http://leprosymailinglist.blogspot.com/2019/11/fw-lml-is-use-of-eponym-for-leprosy_18.html, accessed 5 April 2021.
- Almeida J (2020). Leprosy Eponym: need for a medical name. Leprosy Mailing List – January 26, 2020 (LML) http://leprosymailinglist.blogspot.com/2020/01/fw-lml-leprosy-eponym-need-for-medical_26.html, accessed 5 April 2021.
- Barve A (2020). Why we should stop using the word leprosy. *Lancet Infect Dis.* **20(11)**: 1236-1237.
- Brown W (2006). Can social marketing approaches change community attitudes towards leprosy? *Lepr Rev.* **77(2)**: 89-98.
- Butlin CR, Lockwood DNJ (2020). Why we should stop using the word leprosy. *Lancet Infect Dis.* **20(8)**: 900-901.
- CDC Hansen's disease (Leprosy) (2021); World leprosy day: Burst the myths and learn the facts. <https://www.cdc.gov/leprosy/world-leprosy-day/> accessed 5 April 2021.
- Chen PC, Sim HC (1986). The development of culture-specific health education packages to increase case-finding of leprosy in Sarawak. *Southeast Asian J Trop Med Public Health.* **17(3)**: 427-32.
- Cochrane RG (1970). In defence of the name "leprosy". *Int J Lepr Other Mycobact Dis.* **38(2)**: 207-9.
- Deps P, Cruz A (2020). Why we should stop using the word leprosy. *Lancet Infect Dis.* **20(4)**: 75-78.
- Dharmendra (1947). Leprosy in ancient Indian medicine. *Int J Lepr.* **15(4)**: 424-30.
- Dongre VV (2017). Human rights and stigma in leprosy. In : IAL Textbook of Leprosy (Kumar B, Kar HK eds), Chapter 46, 2nd edition. Jaypee The Health Sciences Publisher, pp646-651.
- Doull JA (1950). Laws and regulations relating to leprosy in the United States of America. *Int J Lepr.* **18(2)**: 145-54.
- Ghosh S, Chaudhuri S (2015). Chronicles of Gerhard-Henrik Armauer Hansen's life and work. *Indian J Dermatol.* **60**: 219-21.
- Femina LL, Soler ACP, Nardi SMT et al (2007). Lepra para hanseníase: a visão do portador sobre a mudança de terminologia. *Hansen.* **32(1)**: 37-48.
- Frist T (2003). Don't treat me like I have leprosy. Published by ILEP, 234 Blythe Road, London. <http://tomfrist.com/publications/wp-content/uploads/2011/11/Dont-treat-me-like-I-have-leprosy.pdf> accessed on 25 oct 2020.
- Gould T (2005). Stanley Stein and miracle at Carville. In: The disease apart; Leprosy in the modern world. 1st edn. St. Martin press, New York, pp237-272.
- Grzybowski A, Nita M (2016). Leprosy in the Bible. *Clin Dermatol.* **34(1)**: 3-7.
- Hanumanthayya K, Manjunath KG, Yadav J et al (2017). Leprosy Discovered Through Religious Books. *RGUHS J Med Sci.* **7(3)**: 122-125.
- Hasnain R, Queijo J, Laher S et al (2020). Islam, Leprosy, and Disability: How Religion, History, Art, and Storytelling Can Yield New Insights and Acceptance. *Societies.* **10(1)**: 6. <https://doi.org/10.3390/soc10010006>.
- Heijnders ML, Van der Meij S (2006). The fight against stigma: an overview of stigma-reduction strategies and interventions. *Psychol Health Med.* **11**: 353-363.
- Kato L (1990). The demystification of leprosy: a multifactorial problem. *Acta Leprol.* **7(2)**: 199-204.
- Kazeem O, Adegun T (2011). Leprosy stigma: ironing out the creases. *Lepr Rev.* **82**: 103-108.

24. Kuipers P, Rao PS, Raju MS et al (2013). A conceptual protocol for translational research in the complex reality of leprosy. *Lepr Rev.* **84**: 166–174.
25. Lerner S (2003). "Leprosy, a Synonym for a Stigma, Returns," New York Times, February 18, 2003. <http://www.nytimes.com/2003/02/18/health/leprosy-a-synonym-for-a-stigma-returns.html>, accessed 23 March 2021.
26. Link BG, Phelan JC (2001). Conceptualizing stigma. *Annu Rev Sociol.* **27**: 363–385.
27. McEwen, Ernest L (1911). The Leprosy of the Bible: Its Religious Aspect. *The Biblical World.* **38**(4): 255–261. *JSTOR*, www.jstor.org/stable/3141642, accessed 24 March 2021.
28. National Hansen's Disease (Leprosy) Program (NHDP), Health resources and services administration, United States. <https://www.hrsa.gov/hansens-disease/index.html>, accessed 6 June 2021.
29. Oliveira ML, Mendes CM, Tardin RT et al (2003). Social representation of Hansen's disease thirty years after the term "leprosy" was replaced in Brazil. *Hist Cienc Saude Manguinhos.* **10**(Suppl 1): 41-48.
30. Pierre VL (2012). Living with Leprosy: Carville Patients in the Early Twentieth Century, Thesis submitted to the University of Minnesota, USA. https://conservancy.umn.edu/bitstream/handle/11299/132418/1/Pierre_Vicki_June2012.pdf, accessed 5 April 2021.
31. Raju S, Rao PSS, Karthikeyan G (2020). Socio-medical perspectives on leprosy in Indian religions. *Lepr Rev.* **91**: 190-199.
32. Rao PSS (2015). Perspectives on the impact of stigma in leprosy: strategies to improve access to health care. *Res Rep Trop Med.* **6**: 49-57.
33. Rolson RH, Chesteen HE (1970). The Identification of Psychosocial Factors Related to the Rehabilitation of Leprosy Patients: A Final Report: Louisiana State University and Agricultural and Mechanical College. School of Social Welfare. <https://play.google.com/books/reader?id=jV9YA AAAMAAJ&hl=en&pg=GBS.PA1>
34. Rotberg A (1972). Leprosy: the word, the disease. *Lepr Rev.* **43**: 96-105.
35. Sinha AK, Banerjee BG, Singh S (2010). Leprosy and its socio-cultural perception in Indian religions and ancient texts. *Indian J Lepr.* **82**: 1-21.
36. STAR (1973). Radiating the Light of Truth on Hansen's Disease | 100th anniversary Celebration. May-June; Vol **32**: No.5.
37. Trautman JR (1968). Stanley Stein. 1899-1967. *Int J Lepr Other Mycobact Dis.* **36**(2): 234-5.
38. van Brakel WH, Peters R, Pereira ZB (2021). Stigma Related to Leprosy – A Scientific View. In: International text book of leprosy. (Scollard DM, Gillis TB, eds) <https://internationaltextbookofleprosy.org/chapter/stigma-quantitative>, accessed 5 April 2021.
39. Wheatley MA (1985). Leprosy a disease apart, A hand cross-cultural analysis of stigma. ProQuest (firm), Thesis and dissertations, Sociology, Carleton University. https://conservancy.umn.edu/bitstream/handle/11299/132418/1/Pierre_Vicki_June2012.pdf, accessed 7 April 2021.
40. White C (2008). Iatrogenic stigma in outpatient treatment for Hansen's disease (leprosy) in Brazil. *Health Educ Res.* **23**(1): 25-39.
41. WHO (2015). World Health Organization best practices for the naming of new human infectious diseases. https://www.who.int/topics/infectious_diseases/naming-new-diseases/en/, accessed 8 February, 2021.
42. WHO (2020). Global consultation of National Leprosy Programme managers, partners and affected persons on Global Leprosy Strategy 2021–2030. Report of the virtual meeting 26–30 Oct 2020.
43. WHO-News (2016): Religious communities unite to address leprosy-associated stigmatization and discrimination 26 June 2016. https://www.who.int/neglected_diseases/news/religious_communities_unite_to_address_leprosy/en/, accessed 5 April 2021.

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