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LEPROSY: A FORGOTTEN DISEASE

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DISCUSSION PAPER

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ABSTRACT

In 2005, the Government of India declared that India had eliminated leprosy as a public health issue. However, according to the WHO, 1,25,000 new cases of leprosy continue to be reported in India every year, with 60% of the world's total new leprosy cases being in India. This paper seeks to bring leprosy back into the discourse around diseases and public health in India.

INTRODUCTION

In 2005, the Government of India declared that leprosy has been eliminated from the country (Anand 2019). According to the World Health Organisation (WHO), elimination of a disease as a public health concern entails a prevalence rate of less than one case in a population of 10,000, whereas eradication denotes zero new cases. In 2018, while the incidence of leprosy cases came down from 1 case per 10,000 population to 0.67 per 10,000, WHO reports 1,25,000 new cases of leprosy in India every year (National Leprosy Eradication Programme 2018). 60% of all new cases reported globally are from India.

Leprosy, also referred to as Hansen's disease, is among the oldest known diseases. Yet, its 'etiology, causation, means of transmission and curability' remains misunderstood (Report 256 2015: ii). Leprosy is caused due to a chronic bacterial infection caused by *Mycobacterium leprae*, which attacks the skin and peripheral nerves. The early symptoms of leprosy include discoloration of the skin (pale and red skin patches) and numb patches, which if untreated can lead to severe deformities.

GRADE 0	GRADE 1	GRADE 2
<ul style="list-style-type: none">• Normal Sensation• No Visible Impairments	<ul style="list-style-type: none">• Impaired Sensation• No Visible Impairments	<ul style="list-style-type: none">• Visible Impairments• Deformity

As opposed to popular belief, leprosy is not hereditary. *Mycobacterium leprae* is among the least contagious pathogens. It produces symptoms in less than 10% of the human population, primarily due to prolonged exposure to the bacteria, over a long incubation period. Leprosy is transmitted mainly through the moisture expelled from the respiratory tract of an untreated leprosy patient. Leprosy, once diagnosed, can be easily cured by MDT (multidrug therapy). Moreover, a patient taking MDT most often becomes non-infectious within the first week of treatment (The Leprosy Mission Trust India n.d.).

Beyond its biomedical understanding, leprosy is imbued in a deep-rooted social stigma driven by myths surrounding curability (the idea that leprosy cannot be cured), cause (that leprosy is the result of a curse or bad karma), transmission (that leprosy is hereditary) and more importantly, the myth of eradication (that leprosy is a disease of the past and stands completely eradicated). Thus, leprosy becomes an interesting vantage point to understand the public health discourse in India, which is shaped by the operational definitions of elimination and eradication.

UNDERSTANDING ELIMINATION AND ERADICATION OF LEPROSY IN THE INDIAN CONTEXT



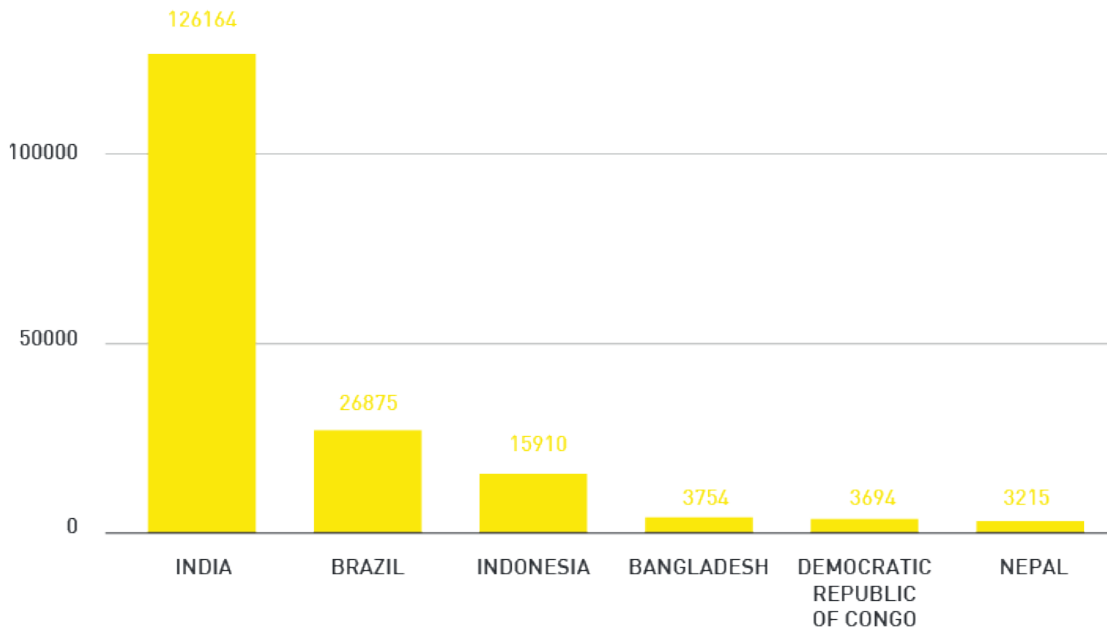
In 1991, the World Health Organisation laid down the elimination of leprosy by 2005 as a global public health goal. In 2005, the Government of India declared that India had eliminated leprosy. However, India had only eliminated leprosy as a public health concern¹ and not eliminated or eradicated it as a disease affecting the Indian population. Additionally, little has been said about the methodology that was used to achieve the status of statistical elimination of leprosy.

Due to the one dimensional focus on elimination of leprosy as a public health concern, as opposed to its complete eradication, it may be argued that leprosy has lost its significance as a matter of health policy concern. Several leprosy programs were merged with the National Health Mission. The allocation of funds for leprosy was reduced, as the focus shifted to other public health concerns such as HIV/AIDS and tuberculosis (Mohta 2019)

¹ According to WHO, if the prevalence level of disease is less than 1 in 10,000 population, it is a marker for elimination of a disease as a public health concern.

PRESENT-DAY STATUS OF LEPROSY IN INDIA

According to Report 256 of the Law Commission, in 2014, India had the largest number of new leprosy cases globally, followed by Brazil and Indonesia (2015). Under The National Leprosy Eradication Programme of Ministry of Health and Family Welfare, 1,35,485 new leprosy cases were detected in India during 2016-17 (National Leprosy Eradication Programme 2017). WHO data suggests a total of 2,10,671 new leprosy cases reported in 2017 in 150 countries (The Leprosy Mission Trust India n.d.). This suggests that cases of leprosy in India constitutes approximately 60% of the world total.



SOURCE: LEPROSY MISSION TRUST INDIA

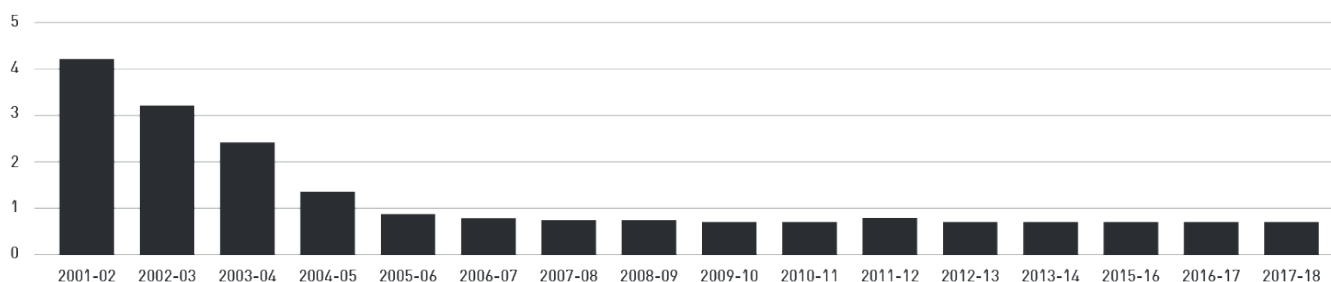
The number of newly reported cases of leprosy in India are over 8000 more in 2016 (1,35,485) than 2015 (1,27,326) (National Leprosy Eradication Programme 2016). Such an increase in the reportage of leprosy cases has been credited to the three-pronged strategy adopted by the National Leprosy Eradication Programme - leprosy case detection campaign, focused leprosy campaign, and special plan for hard-to-reach areas (ibid.)

Despite these campaigns, India's leprosy situation continues to be dismal. Due to the contestation between the operational definition of elimination and eradication of leprosy in the wider public discourse, with elimination gaining paramount importance, there has been a significant push back on its eradication.

1. Stagnation of Prevalence Rate and Annual New Case Detection Rate

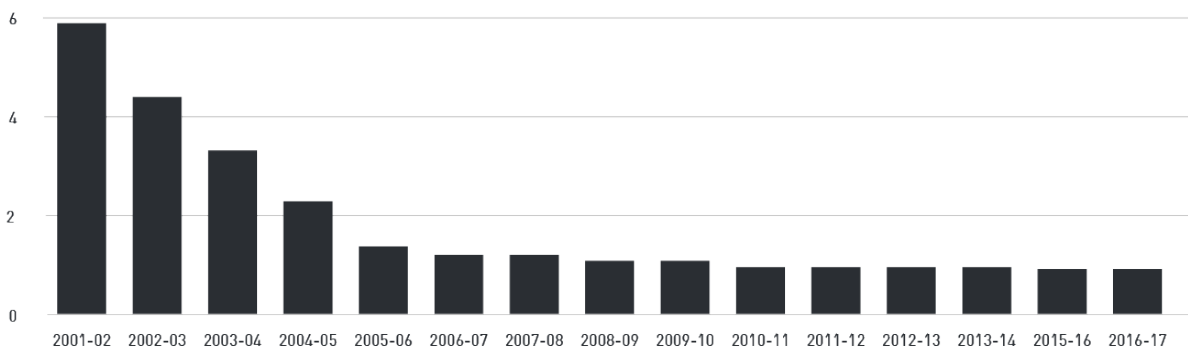
Prior to declaring leprosy as an eliminated public health concern, there was a strong focus by the government on building and implementing an effective programme through leprosy detection campaigns and national programmes. This is evident through the staggering decline in trends for both the prevalence and detection of new cases of leprosy between 2001 and 2005,. However, post-2005, for over a decade, there has been stagnation in leprosy cases – both PR and ANCDR. This poses serious concerns and questions about the wider project of eradicating leprosy. Is the stagnation of PR and ANCDR¹ due to cutting down of budgetary allocation for leprosy?

TRENDS OF PREVELANCE RATE OF LEPROSY PER 10,000 POPULATION



SOURCE: ANNUAL REPORT NLEP 2017-18

ANNUAL NEW CASE DETECTION (ANCDR) (PER 10,000 POPULATION)



SOURCE: ANNUAL REPORT NLEP 2017-18

2. Methodological concerns about PR and ANCDR

As per the Annual NLEP Report 2017-18, the national PR for leprosy is 0.67. However, a closer glance at the state-wise PR reveals a methodological loophole - the national average of the annual PR undermines the higher PR trends in some states and UTs. The elimination of a disease as a public health concern is calculated by the prevalence of less than 1 case per 10,000 population. However, Bihar, Chhattisgarh, and Jharkhand, among others have a prevalence rate >1. Therefore, it is significant to point out the structural drawback in achieving a target of elimination as it does not identify the state-wise prevalence of leprosy, further undermined by the national average.

¹ PR and ANCDR stand for Prevalence Rate and Annual New Case Detection Rate respectively.

STATE/UT	PREVALENCE RATE (PR 1/10,000 POPULATION)
Bihar	1.18
Chhattisgarh	2.25
Jharkhand	1.05
Odisha	1.38
Dadra And Nagar Haveli	4.85
Lakshadweep	2.23

Source - Annual Report NLEP 2017-2018

3. Plunge in awareness and delay in diagnosis

The declaration of statistical elimination of leprosy, with lack of clarity regarding the difference between its elimination as a public health concern and its complete eradication, leads to a decline in awareness about the disease among the general public. It is often assumed that India has eradicated leprosy from the grassroots. However, *Mycobacterium leprae* has an incubation period of 5-6 years. A possible consequence of the lack of clarity between elimination and eradication of leprosy could be the underreporting of leprosy cases due to the majority of the early symptoms being passed off as dermatological issues, till the time a visible deformity takes place. Post achievement of the status of elimination, inadequate monitoring of new cases of leprosy pose an important question: was underreporting, steered by lack of awareness and diagnostic skills, a significant cause for the supposed decline in the number of new cases of leprosy, encompassed under the misconception of 'eradication'?

4. Biocultural dynamics of social stigma

Historically, leprosy has been embedded in deep social stigma, which further leads to underreporting of cases. Leprosy, unlike many other diseases, needs to be viewed through a complex lens of social discrimination and physical disfigurement. Barrett (2005) traces three such processes through which the social stigma attached to leprosy is physically expressed:

1. Strategies of concealment which further the spread of leprosy due to late detection and delay in treatment.
2. Bodily dissociation due to self-neglect.

3. Self-mortification under conditions of severe poverty.

The biomedical and social understanding of leprosy cannot be viewed as mutually exclusive strands. The medical diagnosis of leprosy gets impacted by the myths and stigma which surrounds it. As opposed to popular belief, leprosy is very rarely an infectious disease, and if diagnosed on time, completely curable.

MYTH	FACT
Leprosy is a hereditary disease. It is also the result of past sins or 'karma'.	Leprosy is not a hereditary disease. Leprosy does not pass from a parent to a child. It is an infectious disease caused by a bacterium, <i>Mycobacterium leprae</i> .
Leprosy is a disease of the past, completely eradicated.	Leprosy is still prevalent in 125 countries where 2,08,619 new cases were detected in 2018. Over 345 people are diagnosed with leprosy in India every day.
Leprosy is very contagious and is transmitted through touch.	Leprosy is not transmitted through casual contact such as shaking hands or playing together. Leprosy is transmitted by air through droplets of the nose and mouth during close and frequent contacts with untreated cases. Leprosy is one of the least infectious diseases with over 95% of the population being naturally immune to it.
Leprosy only affects the skin.	Leprosy mainly affects the skin, peripheral nerves, mucosa of the upper respiratory tract and also the eyes. Untreated, leprosy can cause progressive and permanent damage to the skin, nerves, limbs and eyes.
Leprosy is not curable.	Leprosy is curable with multidrug therapy (MDT) within 6-12 months of treatment.
Leprosy causes the fingers and toes to fall off.	Fingers and toes do not 'fall off' due to leprosy. In advanced stages, the bacteria that cause leprosy attacks the nerves of the fingers and toes and causes them to become numb. Injuries and infection of numb areas can cause the bones to shorten. The tissues around them shrink, making them short.
Persons affected by leprosy cannot lead a normal life and need to be isolated.	Persons affected by leprosy can lead normal and dignified lives like any other person. Patients with leprosy, taking multidrug therapy (MDT) do not spread the disease. A patient becomes non-infectious within one week, after the very first dose of treatment.

| CONCLUSION

In 2018, Health Minister Jagat Prakash Nadda declared that India would achieve the goal of eliminating leprosy that year (Kurian 2019). However, this target was later pushed to 2019. It is important to note that despite fulfilling the official WHO guidelines of eliminating leprosy as a public health concern, there is still a need to address the methodological concerns surrounding the operational definition of elimination, in light of the stagnant trend in the detection of new cases of leprosy and consequently the reduction of elimination and eradication to mere official and operational categories.

A crucial question thus arises: What does it mean to eliminate a disease as a public health concern? Indeed, elimination of leprosy as a public health concern is an achievement for India. However, the methodological loopholes and the stagnating trends render the status of 'elimination' as being devoid of any steps towards the target of eradication - driven by a shift in resources away from the programme itself (Kurian 2019). Interestingly, according to the National Health Profile¹ (Central Bureau of Health Intelligence 2018), leprosy has 'nearly' been eliminated. Despite the public declaration of elimination by the Indian government in 2005, the immediate challenge for India is to strive towards the elimination of leprosy as a disease affecting over 1 lakh people in India, across several states and districts. This can only be achieved by removing the stigma, identifying hidden cases, achieving a timely diagnosis, repealing/amending discriminatory laws, building an effective healthcare system, and most importantly reopening the conversation around building a stronger policy concern towards the eradication of leprosy - a forgotten disease.

¹ National Health Profile is an annual report published by Central Bureau of Health Intelligence (CBHI).

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