

# Leprosy—A raging persistent enigma

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## ABSTRACT

Leprosy or Hansen's disease despite having achieved the elimination target across the world, the decrease in detection of new cases has almost stagnated for the last 10 years. Southeast Asia is having the highest prevalence of leprosy among all regions in the world. The review focuses on the programmatic laggards' post-achievement of elimination target in India, the most significant contributors to leprosy caseload in the world, and a way forward.

**Keywords:** ANCDR (Annual New Case Detection Rate), communicable disease, grade 2 disability (G2 D), leprosy, MDT (Multi Drug Therapy), Re-emergence

## Introduction

Leprosy or Hansen's disease, a chronic granulomatous condition caused by *Mycobacterium leprae*, is one of the most prevalent re-emerging neuromuscular disorders.<sup>[1]</sup> It is a slow-growing obligate parasite. Untreated leprosy patients are the only source of the disease. Leprosy is transmitted via droplets, from the nose and mouth, during close and frequent contacts with untreated cases, and only a small proportion of the people suffering from leprosy can transmit it.<sup>[2]</sup>

It can occur at any age, but most commonly manifests in the 20 – 30 year age group in high-burden communities, where active disease transmission persists. As the burden in community decreases, it is seen more in older age groups. It affects both the genders, with a slightly higher preponderance for males.<sup>[2]</sup>

The earliest clinical presentation of the disease is mostly vague; presenting as a small hypo-pigmented macule with diminished sensation, described as indeterminate leprosy, 70% of which heal spontaneously. When the bacillary growth outstrips body defense mechanism, the condition progresses to leprosy. The

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incubation period can range between 2 and 12 years.<sup>[3]</sup> The average incubation period is 5 – 7 years (tuberculoid leprosy 2 – 5 years and 8 – 12 years in case of lepromatous leprosy).<sup>[2,4]</sup>

Leprosy, one of the Neglected tropical diseases, is generally associated with poverty, overcrowding, thereby affecting the most underserved population of the country.<sup>[2]</sup> The visible deformities of hand and foot and the accompanying sensory loss contribute significantly to the stigma faced by leprosy patients.<sup>[5-7]</sup> This stigma and ostracization of patients severely affects social existence of the patients (affecting marriage, employment, etc.) and contributes to the spread of disease away from public glare by reducing health-seeking behavior among the community for leprosy.<sup>[5]</sup>

## Burden of the disease

The global prevalence of leprosy according to Global leprosy Update 2017 is 0.25 per 10,000 population (Total 1,92,713 cases); an increase of 20,765 cases as compared to 2016. The increase in cases was observed in all WHO regions (42.8% in AFR, 19.5% in AMR, 42% in EMR, 3.4% in South East Asia Region (SEAR)). The highest prevalence was seen in SEAR, i.e. 0.6 per 10,000 population. The trend of new cases has shown almost stagnation over the last 10 years. SEAR contributes about 73% of the global leprosy burden (India and Indonesia contribute 67.4% of new cases globally and 92.3% regionally). Cases with G2 D

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decreased from 2008 (2.5 per million) to 2017 (1.6 per million), but it remains above the global target for achieving G2D 1 per million population.<sup>[8]</sup> Detection of G2D reflects a delay in the diagnosis of leprosy, which results in persistent neuritis leading to disability. There is also a possibility that there might be hidden cases in the population.<sup>[9]</sup>

India contributes the highest number of leprosy patients to the burden of leprosy all over the world. A total number of new cases diagnosed in 2017 were 1,26,164 (approximately 60% of the world's new leprosy cases). The number of G2D diagnosed cases was 4,552 (equivalent to about 40% of the world's total grade 2 disability in 2017). The ANCDR was 9.27 per 1,00,000 population, and PR was 0.67/10,000 population. Percentage of G2D among new cases was 3.61.<sup>[10]</sup>

While the detection of new cases was almost stationary for the period 2008 – 2017, grade 2 disability showed a constant decrease over the period 2013 – 2017.<sup>[11]</sup> The worrying part is huge interstate disparity over the burden of disease. From 2012 to 2017, there was an increase in the number of districts having a prevalence of more than 5 per 10,000 population (1 district in 2012 increased to 4 districts in 2017). In total, 53 districts in 11 states reported a prevalence of more than 2 per 10,000, which is considerably higher as compared to 2012 (27 districts had a prevalence of >2 per 10,000). The number of districts having ANCDR more than 20/1,00,000 also increased from 2012 (74 districts) to 2017 (101 districts). Among the states in 2018, the highest number of leprosy cases were reported from Bihar (14,338 cases) followed by UP (12,583), Maharashtra (9,836 cases), and West Bengal (9,175 cases). The highest prevalence of leprosy was seen in Chhattisgarh (2.25/10,000 population) followed by Odisha (1.38/10,000 population). Highest Grade 2 D was seen in Meghalaya (31.25%) followed by Daman and Diu (26.32%). In total, 10 states and union territories had Grade 2 disability more than 10% in 2017 – 2018 as compared to 11 states in 2016 – 2017.<sup>[10,12]</sup>

### Persisting problem

India continues to account for approximately 60% of new cases reported each year globally. This scenario is especially worrisome even after 14 years of attaining the elimination status<sup>[13]</sup> of a PR of <1/10,000 population in the year 2005, and this indicates a continued transmission of leprosy in the community. There has been an increase in the detection of cases from 2012 onwards. Naturally, one ponders about the reasons for this continued transmission/persistent problem. And the reason that we are still talking about ways to tackle this problem.

We delve into the reasons for this raging persistent enigma; some which might be:

1. In the year 2000, WHO announced that leprosy had been eliminated as a public health issue, with the global prevalence below 1 case per 10,000 population. It was assumed that at this prevalence the disease will disappear from the community. The term 'Elimination' leads to confusion with 'Eradication' among the general public and even in the medical profession. The leprosy eradication from community appears to have been equated with the reaching of the WHO-defined target of elimination as a public health problem (prevalence of <1 per 10,000 population), which India reached by the end of 2005.<sup>[14]</sup>
2. The elimination of leprosy was used as an interim goal to create interest in the neglected disease and raise funds globally. The experts suggest that the meaning of this milestone was not clearly communicated to political leaders. Even today, both Indian and international media often cover the issue while using "leprosy free" as a synonym for "elimination."<sup>[15]</sup>
3. The epidemiological definition that is used for the programme purpose is different from the clinical definition. Relapse cannot be considered a new case by epidemiological definition because the patient has been treated before, or cases that have been treated before if reregistered for treatment as a new case.<sup>[16]</sup>
4. Disability rates in new cases are high. The probable reasons for the rise in disability maybe a delay in the diagnosis of leprosy and lepra reactions that lead to persistent neuritis and ultimately to disability.<sup>[17]</sup>
5. After the attainment of the elimination status of <1/10,000 in 2005, the vertical NLEP program was integrated with the general health services. The focus of the programme got diverted. No proper post-elimination policy was envisaged and implemented. A surveillance system should have been in place under the program for quick detection and treatment of new cases to halt transmission of infection in the community. Leprosy being a chronic disease, having a long and unpredictable incubation period; it is expected to have many individuals in the population who will be incubating the disease for many years before they become clinical cases.<sup>[18]</sup>
6. False sense of security among the health care workers/and the public regarding the elimination of the disease. This has created a perception that the disease has been eliminated, and this disease is neither kept as a probable diagnosis nor reported. The skilled manpower, which was instrumental in the 2005 declaration, is non-existent/declining and no refresher training of MPHWS or even doctors exists as of today.
7. Research on leprosy, especially the enigma of its mechanism of transmission, its incubation period, and the effectiveness of MDT among the children is hardly emphasized upon.
8. Leprosy affects the most underserved population; thereby the emerging spread is away from public gaze and governments' attention. Unofficial colonies/Social banishment adds to the stigma and various heresies regarding the disfigurement and forces patients to seek care in the alternative systems of medicine.
9. Leprosy is primarily a disease of the skin and nerves. Generally, the first lesion to appear is a skin patch and patients often seek help or are referred to dermatologists who are very few in India.
10. Political and financial commitment is declining, and not much proactive steps have been taken in the past few years.

11. Though drug resistance in leprosy is slowly but worryingly emerging,<sup>[19]</sup> there is no evidence-based alternative regimen to tackle the problem of drug resistance or for the patients suffering adverse effects of the MDT drugs; on the other hand, WHO has advised conditional recommendation for rifampicin and ofloxacin resistance due to the lack of evidence. There have been several drugs, such as rifapentin, moxifloxacin, etc., which have shown a considerable amount of efficacy, but conclusive evidence is missing.<sup>[13,18]</sup>

### The way forwards

Leprosy is a silent emergency; the real burden of which is underestimated; affecting the most underserved population of the country. The next steps which need to be emphasised upon are:

1. To accord high priority to leprosy control/eradication/elimination programs. There should be a country-specific elimination target, which is epidemiologically feasible.
2. The focus should be on highly endemic geographical areas (Adivasi, Tribal), as these areas continue to foster community transmission of leprosy due to a lack of awareness among the population.
3. Innovative approaches for timely detection and management of the disease through evidence-based practices. For evidence to be generated, adequate economic and human resource investment needs to be made in the field of leprosy in India, because of the sheer numbers of the cases.
4. Community participation through improving felt need by reducing the stigma through mass awareness with the involvement of peer educators and local private sector NGOs should be emphasized upon.
5. Social inequities in health need to be addressed especially in tribal and hard to reach areas through strengthening health system, creating and maintaining health expertise regarding leprosy. Strengthening health and wellness centres will be a critical step in implementing a sustainable model for early diagnosis and management of leprosy.
6. There should be conscious efforts to promote voluntary reporting through incentivisation along with active case detection through the health system. Improvement in reporting of cases is not possible until the private medical practitioners are roped in through sensitisation and training. The GOI has started NIKUSHTH portal for improvement in private health system reporting of leprosy, which needs to be promoted and maintained.<sup>[13]</sup>
7. To obtain higher reporting rate through active and passive surveillance primary care, physicians and peripheral health workers need to be trained through CMEs, refresher training, or workshops regarding early detection of leprosy through its signs and symptoms. For leprosy patients, the primary care physicians should also be trained in recently recommended guidelines of a treatment protocol by WHO [Table 1], so that the earliest possible treatment can be started preventing further infection. There is a need for sensitisation among the healthcare personnel also to promote a positive attitude towards the disease and the patients.<sup>[20]</sup> This is essential as the

**Table 1: Treatment protocol for leprosy patients<sup>[20]</sup>**

Age group	Drug	Drug dosage & frequency	Duration	
			MB	PB
Adult	Rifampicin	600 mg once a month	12 months	6 months
	Clofazimin	300 mg once a month and 50 mg daily		
	Dapson	100 mg daily		
Children (10-14 years)	Rifampicin	450 mg once a month	12 months	6 months
	Clofazimin	150 mg once a month and 50 mg daily		
	Dapson	50 mg daily		
Children (< 10 years old or less than 40 kg)	Rifampicin	10 mg/kg once a month	12 months	6 months
	Clofazimin	6 mg/kg once a month and 1 mg/kg daily		
	Dapson	2 mg/kg daily		

primary care physicians are usually the first level of contact; and if they are attuned to these signs and symptoms, it will result in a quicker diagnosis and early treatment initiation.

8. New modalities of combined post-exposure prophylaxis, e.g. MIP vaccine by ICMR has shown moderate benefit, the protective efficacy of prevention was up to 68% in the first year, up to 60% in the second year, and up to 38% in the third year after 2 doses of vaccine. It is being evaluated by ICMR as a part of double intervention post-exposure prophylaxis along with a single dose rifampicin.<sup>[21]</sup> Innovations like these need to be promoted through organisational research for newer modalities of diagnosis, treatment, or program implementation.
9. Finally, there is a need to reaffirm the political commitment through active advocacy. This will not only bring the much-needed focus on interruption of transmission in the community but will also sustain the programmatic improvements.

### Conclusion

There is a common misconception that it is a disease of the past in public despite the data available show the increase in new cases. There is a need for a clear cut strategy and an implementation plan to address the problem. Leprosy control requires a multipronged approach towards addressing all aspects (social, environmental, nutritional, etc.). Until these aspects are addressed, leprosy remains a raging persistent enigma and is a reminder of social inequity in health, and yet the country is a long way from eliminating leprosy.

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