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Review Article



Epidemiological scenario of leprosy in marginalized communities of India: Focus on scheduled tribes

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The Scheduled Tribes (STs) are designated among the most disadvantaged social groups in India. Until the year 2005 (pre-elimination era of leprosy in India), several leprosy-specific control field programmes were implemented, which have been discontinued subsequently. Since then, leprosy diagnosis and treatment have been integrated with General Health Services. Thereafter, specialized expertise for the early diagnosis of leprosy has been gradually diminishing, especially at the peripheral clinics in remote areas. Hence, leprosy cases usually remain undetected for a long time and persist as endemic reservoirs. The tribal population of India accounts for just 8.6 per cent of the overall population. However, 18.5 per cent of the new leprosy cases were detected within the tribal community in the year 2020, indicating a disproportionately high burden of leprosy among the tribal population. Recent data suggest that these health disparities can be mainly related to the increased marginalization of STs as compared to other communities. This shows the need to further explore the current situation of leprosy in STs so that suitable interventions can address the contributing factors, leading to health inequalities in disadvantaged socio-economic groups. Therefore, this review aims to present the current distribution of leprosy in marginalized communities with a special emphasis on STs. Further, this review discusses how resources might be mobilized for such communities to find and treat undetected leprosy patients in STs to enable effective control of leprosy through early detection and timely treatment.

Key words Burden - elimination - evaluation - leprosy - tribal

Leprosy or Hansen's disease is one of the world's oldest diseases. It is caused by uncultivated mycobacterial pathogens, *Mycobacterium leprae* and *M. lepromatosis*. Leprosy usually presents as patches/lesions on the skin. Leprosy bacilli affect peripheral nerves, eyes and the mucosa of the upper respiratory tract^{1,2}. The physical symptoms include having patches on pale and reddish skin (usually flat, that may be numb and look faded),

numbness in limbs (hands and feet), loss of sensation in the affected patch of skin, accompanied by loss of eyebrows and eyelashes in some cases^{3,4}. The routes of *M. leprae* transmission are still not entirely known^{5,6}. Although there is compelling evidence of increased risk of infection due to close and prolonged contact with an index case through aerosols generated during coughing and sneezing, there is also a possibility of direct and indirect exposure from the environment, or via direct contact. However, it is generally emphasized that leprosy cannot simply be acquired by casual contact with an uninfected person⁷. The incubation period of *M. leprae* might last anywhere from a few weeks to more than two decades8. Only a small fraction of infected people contract leprosy, the majority (>80%) of the population can resist leprosy owing to genetic factors^{9,10}. Leprosy occurs in many regions of the world, but over three quarters of all the cases are reported from Brazil, India and Indonesia^{9,11}. The likelihood of leprosy infection is also correlated with socio-economic conditions and poverty^{12,13}. A mix of variables such as crowded settings and poor hygiene may also result in increased chances of transmission. Malnutrition, as well as other comorbidities, may be the factors associated with leprosy to consider it as a disease of poverty^{14,15}. While leprosy treatment is free in India as also around the world, the cost of travel and the associated loss of wages, failure of surveillance mechanisms in endemic areas and a lack of information about the availability of treatment are significant barriers to treatment^{16,17}. Discontinuation of specialized leprosy hospitals and stopping the treatment follow up and surveillance activities can contribute to poor adherence to treatment.

Many individuals having leprosy or leprosy-like symptoms might avoid or postpone looking for care, conceal the condition of the disease or stop the ongoing treatments^{18,19}. The social stigma associated with leprosy is also a major deterrent for people while seeking treatment^{18,20}. Even nowadays, a sizeable number of cases have been identified within Schedule Caste (SC) and Scheduled Tribe (ST) communities with a prevalence rate of leprosy as high as 4.5/10,000 in contrast to the national level figures of 0.6/10,000 population, which demonstrates a high burden of leprosy in certain pockets of India^{21,22}.

Despite this, little is known about the current situation of leprosy in the ST population as the information about social group or caste (whether SC/ST/OBC, *etc.*) is not recorded during the documentation of cases.

Search strategy: Leprosy prevalence rate provides insight into disease transmission patterns as well as serves as an indicator of the efficacy of public health schemes in different geographical regions and communities. After attaining the leprosy elimination goal in 2005, there is still no comprehensive data regarding the prevalence of leprosy among SCs and

STs. Most of the epidemiological studies demonstrate that NLEP contributed by sustaining the control efforts in all sections of the society, including tribal populations; however, there is a need to improve the surveillance efforts in hyperendemic areas and populations with higher prevalence of disease, such as in tribal populations in difficult terrain. To provide a comprehensive guide for future studies and policies, research articles from MEDLINE were identified using the following keywords: "Leprosy", "Tribal", "Leprosy" India Tribal, "Adivasi leprosy" and "Indian tribal leprosy". Papers were selected if they included epidemiological aspects of leprosy in the tribal regions of India. However, most studies were related to traditional knowledge about the usage of medicinal plants for treating leprosy and leprosy-like presentations. The extended Google search was done again using the same keywords to get the reports from NGOs and news articles that shed light on leprosy in tribals. Many studies/reports have focussed on determining the societal perceptions of leprosy, however, only a few publications are available on the epidemiological situation of leprosy among tribals²³⁻²⁵. Compiling these studies will be useful to obtain a broad overview of the situation. Hence, this literature review aimed to consolidate this knowledge on the present situation of leprosy in tribal areas based on various sources of information.

Current scenario

With over 1.14 lakh new leprosy cases detected in 2020, India accounts for >55 per cent of the total cases reported globally, indicating an active transmission, especially in certain pockets of hyperendemicity¹¹. By bringing down the prevalence rate <1/10,000 at the national level, India had officially reached the leprosy elimination goal, as a public health issue (Prevalence rate <1 per 10,000 population as defined by the WHO) in 2005²⁶. However, leprosy remains endemic in several States and Union Territories of India, where prevalence was > 1/10,000, such as Jharkhand, Chhattisgarh, the UT of Chandigarh, Dadra and Nagar Haveli, Maharashtra, Odisha and Bihar. In the post-elimination era of leprosy, major structural changes were made by the National Leprosy Eradication Programme (NLEP) and the Global Leprosy Plan²⁷. These changes were aimed at reducing disability and improving the detection of new cases, especially among children below 15 yr of age. However, the pace did not go as planned and deficiencies in attaining these targets continue to persist to this day. As per the latest available data for 2019-2020, the Grade 2 Disability (G2D) is identified in 2.41 per cent of leprosy cases, with a G2D rate of 1.96 per million population. A recent five-year retrospective analysis reported the G2D in children as high as 14 per cent, suggesting a diagnostic delay²⁸. Moreover, around 77 per cent of the total districts in the country have ANCDR <10 per 100,000 population (NLEP report)²⁹. However, in the remaining 23 per cent districts, it is important to investigate the underlying epidemiological/demographic factors so that a revised optimal strategy can be implemented there.

Scheduled castes (SCs) and scheduled tribes (STs)

Caste system is commonly practised in India. Scheduled Castes (SCs) and STs are economically deprived communities with a greater chance of living in unfavourable circumstances³⁰⁻³². SCs and STs are the most neglected communities of India that have often experienced a higher level of poverty and discrimination^{33,34}. STs face more marginalization in Indian society as compared to SCs35. Several independent studies also revealed the disproportionate burden of leprosy cases in these communities^{17, 23-25,36-38}. The ST is the collective word for Indian subcontinent tribes that are considered indigenous to places in India where they live. As per the census report 2011^{39} , they account for 8.6 per cent of the total population of India and comprise 705 tribes. Similarly, the population of the SC or Dalits represents 16.6 per cent of the Indian population. Together, SCs and STs comprise roughly 25 per cent of the total population, but these account for 37.6 per cent of all new leprosy cases detected in the country, and therefore, leprosy is starting to become a disease mostly in the marginalized and neglected communities^{39,40}. A further breakdown of these figures revealed that while the proportion of new leprosy cases among the SC population has remained almost constant over the years, there has been a continuous increase in the proportion of new cases belonging to the ST population. The proportion of SC cases of leprosy remains between 18 and 19 per cent in the past decade. However, the proportion of new cases of leprosy among STs grew from 13.3 per cent in 2009 to 18.8 per cent in 2017 (Fig. 1). This is a matter of concern that may highlight a possibility of inadequate efficacy and/or access to leprosy control programmes among the ST population⁴⁰.

State-level data present an even more dismal picture. For example, in 2017, 'three out of every four new leprosy patients belonged to either SC or



Fig. 1. Proportion of STs among new leprosy cases in India until 2017. An increasing trend has been shown. Data beyond 2017 are not yet available (*Source*: ORF report 2019⁴⁰). ST, scheduled tribe

ST community in Tripura while their combined share in the population is around 50 per cent. In Gujarat, two out of every three new leprosy patients belonged to either *Adivasi* or *Dalit* communities, and in States such as Odisha, Madhya Pradesh, Maharashtra, West Bengal and Jharkhand, every second new case of leprosy belonged to these communities^{'40}. These figures are disproportionately higher than the percentage share of the SC as well as ST population put together in these States (Fig. 2). Given that the proportion of multibacillary (MB) leprosy cases is high in some of these States, in addition to the tough terrain and remote locations in some areas of these States may further contribute to the ongoing transmission²².

STs make up just 14.8 per cent of the total population of Gujarat, whereas around 64.8 per cent of all new leprosy cases were identified among them in the year 2016-2017^{40,41}. Likewise, with a 21 per cent share of the total population of Madhya Pradesh, the STs account for 39.4 per cent of the new leprosy cases detected in the State. STs in Maharashtra exhibit 33.7 per cent of all new leprosy cases despite having a <10 per cent share in the total population of the State. West Bengal reported 20.3 per cent of all new leprosy cases among STs whereas these make up only



Fig. 2. State-wise proportion of SCs and STs and burden of new leprosy cases among SCs and STs in 2017 (*Source*: ORF report 2019⁴⁰). ST, scheduled tribe; SC, schedule caste

5.8 per cent of the State population. Tripura State and Dadra and Nagar Haveli UT (with 31.8 and 52% share of STs in the total population of the State/UT), report 64.7 and 98.2 per cent of the new leprosy cases among STs, respectively (NLEP)⁴⁰. The disproportionately high burden of leprosy in STs is evident from the above data for at least certain States⁴². The State-wise leprosy data from Figure 3 highlight those States where ANCDR is >10/100,000 (shown by red dots)⁴³. These five States (Bihar, Chhattisgarh, Madhya Pradesh, Odisha and Telangana) and two UTs (Dadra and Nagar Haveli, Daman and Diu) have a relatively high percentage of ST and SC population. Around 31 per cent of the total population of India lives in the above-mentioned States. Strikingly, the percentage of the ST population living in these States/UTs is around 42 per cent of the total population of the tribals in India (Census 2011)³⁹.

Meanwhile, as leprosy treatment is integrated with the General Health Services, mere identification of the leprosy cases is not easy in the settings where they remain as endemic reservoirs unless greater efforts are made to reach them. For example, the Government of India (GoI) figures from the Tapi district in Gujarat (with a tribal population of more than 80 per cent) suggest that the incidence of leprosy has risen from 9.37 per 10,000 populations in 2010 to 17.16 per 10,000 in 2014^{40,44}. However, Tapi has now achieved the elimination goal as of March 2020 (*https://nhm.gujarat.gov.in/nlep1.html*). On the contrary, the incidence has gone up in several tribal

belts between 2010 and 2017. The reason for the high prevalence of the disease in such areas could be their remote location where access to healthcare facilities and awareness is limited, leading to long diagnostic delays from the time of onset of symptoms which leads to continued transmission.

Indeed, a recent report from Raipur district (where 27% population is represented by STs) in Chhattisgarh State has shown that nearly 40 per cent of individuals did not take any action after noticing the symptoms, and nearly all the individuals (98% of the leprosy patients diagnosed between April 2017 and March 2019), attributed 'ignorance about the symptoms of leprosy as the cause of their delay in seeking proper diagnosis and treatment⁴⁵. Prevalence rates of childhood leprosy are also high, with a range from four to 34 per cent in certain pockets of the country, and are considered a surrogate marker of the recent transmission of leprosy^{46,47}. Children rely on their parents to take them to hospitals for diagnosis and treatment, but several characteristics lead to the delayed start of the treatment. Many parents believed that the disease would go by itself, which is a serious concern as such delays often lead to excessive bacterial load and deformities in patients⁴⁸. In some cases, access to a medical centre with proper diagnosis and treatment is also limited, which results in a prolonged delay⁴⁹. These data also highlight the poor access to the healthcare system by STs, which could be the main reason that the expected level of leprosy control has remained elusive despite



Fig. 3. Annual New Case Detection Rate (ANCDR) in 2019-2020, states and union territories of India (ANCDR >10 are shown in Red) (Source: NLEP, 2020⁴³). ANCDR, annual new case detection rate

much-recognized achievements in other communities of the society.

Drug resistance

Recently rising trends in drug resistance have become evident in leprosy cases⁵⁰. A survey by the World Health Organization showed that eight per cent of the samples examined in India exhibited DNA mutations associated with resistance to the anti-leprosy drug rifampicin⁵¹. Researchers have employed various molecular epidemiology tools to understand the nature of primary and secondary drug resistance in various populations worldwide52,53. Even though tribal communities have a high prevalence of leprosy, such surveillance initiatives have not been recorded. Tribal people often migrate for short durations to neighbouring districts and States to work in fields, for example, at the time of crop harvest. This compromises their treatment compliance, thereby leading to the emergence of drug resistance and can also contribute to the transmission of mycobacterial pathogens to other health members in the household or other communities. Therefore, certain innovative efforts must be made to control leprosy among tribal populations since controlling infectious diseases in these populations has broader health advantages for non-tribal societies as well. For example, with a rising proportion of MB leprosy cases in the population, there is an urgent need to evaluate the ongoing 'fixed duration treatment'

guidelines for MB leprosy²². The management of such MB cases in tribal population/those living in remote areas should involve additional measures such as field-applicable point-of-care tests for screening of biomarkers of leprosy bacilli in the lesions. A microscopic examination to determine the bacillary index and provision of patient follow up at six-month intervals can also be useful.

Surveillance: Inadequate compliance to treatment is a major issue with tribal populations as they undertake short-term migration making them prone to leave their treatment incomplete, thereby increasing the chances of emergence of drug resistance. Regular monitoring of the cases released from treatment and relapse cases is also needed to further reduce leprosy burden^{12, 21,45,54,55}.

Although, a national sample survey of leprosy was conducted by the Indian Council of Medical Research (ICMR), and other partners in 2017, only big cities in the urban clusters were covered⁵⁶. The evaluation and the comparison of the leprosy cases in the tribal population *vis-a-vis* general population could not be assessed and this was a major limitation of the study. Only one study carried out in 2017 has so for identified the regions of actual hotspots of leprosy within Maharashtra State by dividing the new cases into several categories such as child, female and MB and G2D cases found within the high prevalence areas such as Vidarbha region. By comparing the prevalence to non-tribal hotspot data, the study concluded that 'even a single new case with G2D/new child/female cases should be treated as evidence of hidden endemicity in the tribal belt'²¹. MDT has proven to be an effective tool for treating leprosy, particularly when patients are detected timely and treatment compliance is good⁵⁷. When it is not, the leprosy-affected patients can develop disability.

To visualize the distribution of leprosy situations across the country of past 10 years, a district-level report was prepared by NLEP comprising annual new cases detected, ANCDR, G2D rate and prevalence rate. The geometric mean for the 10 yr duration (2008-2009 and 2018-2019) has been considered to reflect the leprosy situation in India. Weightage was applied to each parameter according to the endemicity, such as 40 per cent weightage to the number of new leprosy cases, 20 per cent to registered prevalence, 20 per cent to the number of child cases and G2D, respectively. After the weightage, the districts were categorized into high endemic, moderately endemic, low endemic and sporadic cases. These data were compared with the population data of India, which revealed that where the tribal population is more than 10 per cent of the total population (Fig. 4). In addition, the prevalence of leprosy in 12 States (Chandigarh, Delhi, Uttar Pradesh, Chhattisgarh, Dadra and Nagar Haveli, Maharashtra, Madhya Pradesh, Jharkhand, West Bengal, Odisha, Andhra Pradesh and Telangana) is also high. Specifically, there were 324 districts in India classified as high and moderate endemic districts, of which 241 are in the above mentioned 12 States and UTs. The data clearly suggest that numerous government and non-governmental groups should emphasize towards the challenges to deal with the issues of tribal health.

Strategy for leprosy elimination in tribal areas

The integration of NLEP with other health programmes was aimed at improving case detection and treatment access; however, special efforts are required to eliminate leprosy in many tribal areas. There is often a time gap in the project preparation, execution and reporting stages. The planned timeframe for completing all these tasks is often not achieved.

Some of the underlying reasons for this situation are stated below:

Involvement of local people in the implementation of Government schemes: Tribal people are often shy. Their first preference is to go to a traditional tribal healer (Gunia). Therefore, training the tribal healers about leprosy symptoms can be an effective approach. These trained tribal healers can be given referral incentives like those given to Accredited Social Health Activist (ASHA) workers for assisting in the identification of new cases, their registration and treatment compliance⁵⁸. The Special Activity Plan and Leprosy Case Detection Campaign generated by Gujarat (https://nhm.gujarat.gov.in/nlep1.htm) can serve as a model for other States as well to achieve goals set by NLEP. The NLEP aims to eradicate leprosy in each district by 2030⁵⁹. For these programmes, such as 'Active Case Detection and Regular Surveillance' in both rural and urban regions, should be implemented to ensure regular and early detection of leprosy cases. In addition, these health assistants should be trained about the occurrence of leprosy reactions and where to refer the patients so that such presentations can be managed effectively, and the treatment compliance is not compromised.

Guaranteeing service delivery: The fact that households are often scattered and inaccessible means that service delivery is often difficult, even with improvements in the supply chain system⁶⁰. However, storage of drugs and distributing MDT can also be structured where drugs are given to patients for a longer period and are assisted by a trustworthy local individual, such as a village volunteer or representative. The health centres of the government, private sector, and NGOs should develop or extend the existing drug distribution points along with telephone service in case of any emergency. In addition, a trustworthy volunteer/local person who previously treated cases taught of symptoms of leprosy, such as signs of reaction and deterioration. For these volunteers also, there should be incentivization for successful referrals and case detection.

Spreading awareness among the communities: The main reason for hidden endemicity is a lack of voluntary reporting by the community because of continuing stigma and prejudice towards people affected by leprosy. Through communicating the need for early identification and treatment of leprosy, the SPARSH leprosy awareness campaign⁶¹ launched by the GoI made an impact that helps to eliminate this stigma and prejudice by increasing the awareness level about leprosy and detecting a greater number of new cases to provide early treatment. Various camps are organized to identify and treat people with skin diseases, including leprosy and those at a risk of developing disability. These camps have served as valuable places for raising awareness by engaging the community. In



Fig. 4. Comparison of leprosy endemicity between tribal districts vs. non-tribal districts in India from 2008-2018 (NLEP 2019). '+' denotes the tribal district. The map was constructed using gramener (https://gramener.com/indiamap/). NLEP, National Leprosy Eradication Programme

addition, the inclusion of the previously cured cases of leprosy as 'the agents of change' or as 'Leprosy Champions' (similar to the concept of 'TB champions') can address the concerns around social stigma against leprosy. Regional language(s) can be used for general communication with a community. The best way to cross language barriers is to get the full participation of local patrons.

Availability of trained staff at primary health care (PHC) centre

With over 150,000 health and wellness centres being created in India as part of the Ayushman Bharat plan, it is an opportunity to locate, detect and provide treatment to individuals who were previously not covered by the NLEP⁶². Slit-skin smear microscopy remains the only laboratory test mandated by the Ministry of Health and offered by the Public Health network⁶³. It

is a rapid and low-cost test that has high accuracy in categorizing the clinical form of the disease and hence aids in establishing the treatment plan. It seems like slit skin smear examination is a forgotten technique and probably not paid enough attention at the PHC levels. Hence, such cases which could be diagnosed even by simple microscopy can remain undetected for a long time. Most of the programmes work on the first two cardinal features of leprosy: (i) skin lesions, (ii) nerve thickening with the sensory deficit with or without motor function impairment, and the third one, i.e. (iii) the detection of AFB in slit skin smear, has not been paid due attention. The construction of an active and well-designed care network in tribal areas with well-defined local and regional reference services, with the experience of basic and simple laboratory tests for a more accurate diagnosis and effective case follow up, would help to consolidate the efforts to further control leprosy in these regions.

The current tribal area leprosy elimination strategy was built based on the experiences of NLEP and NGOs, as well as some pilot projects undertaken in a few Indian tribal regions. It would be necessary to further refine this strategy to suit the special needs of tribal populations in other parts of the country for those living in remote areas. Door-step delivery of diagnosis and treatment should be implemented in remote areas and marginalized populations. In addition, the experiences of the person involved in supply chain related to health services at the village level (such as ASHA workers, etc.) should be availed. Other data, such as sociodemographic details and information about various population groups (ST/SCs, etc.) should be documented and made available for policymakers so as to enable targeted and more effective implementation of leprosy control activities. While documentation may be a useful tool in the longer term, an ongoing, sustainable mechanism for monitoring the local leprosy situation must also be established that integrates all the documents in a single system or website, based on which local stakeholders can decide on renewed leprosy elimination activities.

Overall, the rate of decline in leprosy is much slower among tribal communities compared to non-tribal communities. Leprosy eradication attempts by 2030 would be a difficult task without paying special attention to the high-risk pockets of tribal areas. The tribal belt should be the focus of the NLEP for the effective management and efficient control of the disease through health education and communication campaign; early detection and management of cases; ensuring treatment adherence using ASHA workers and traditional healers, and possibly through direct observation of treatment; and through the provision of uninterrupted supply of treatment and MDT delivery at patient doorstep. Many of these could even potentially become the subjects for implementation research by NLEP, ICMR and partners. To reach the zero-leprosy goal, it is essential to address the leprosy situation among tribal people promptly and adequately by expanding the scope of tribal health through scientific research and development methodologies tailored to match the needs of tribal people.

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