

Commentary

Remaining Challenges to Further Reduce the Leprosy Burden in Rajasthan

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INTRODUCTION

Leprosy is known to affect mankind since the pre-historic times and continues to affect humans even in the twentieth century. A written reference to the disease is mentioned in the ancient Atharvaveda composed before the first millennium BC.¹ It is a chronic, mildly infectious disease (much lesser than tuberculosis), caused by *Mycobacterium leprae* and affects mainly the skin and the peripheral nerves. Although the other organs are also affected in the disease² the main signs and symptoms related to the disease are due to affection of these two organs of the body. As a result there is impaired to varying degree of loss of sensation in the hands, feet and eyes. There may be some disability also due to involvement and paralysis of the motor fibres as well. These parts of the body, if not properly cared for, lead to repeated injuries in these insensitive paralyzed parts. These may result in disfigurement, which immensely contributes to the fear and stigma towards the disease. The best way of prevention and cure of the disease at present is by early detection and treatment with Multi Drug Therapy (MDT). India achieved the elimination target of the disease in December 2005 at the National level. At the sub-National and State level some pockets do remain which report a prevalence of more than 1/10,000 population.³⁻⁶ While Rajasthan is a low endemic State, no such pockets of endemicity have been reported from the State. We still need to be careful and vigilant, so that the disease is properly contained and even finally eradicated. The disease has been integrated with the general health services and the data being discussed is as reported to the National Leprosy Eradication Programme (NLEP) by the State Health system.

FACTS FOR RAJASTHAN IN NATIONAL LEPROSY ERADICATION PROGRAMME

Although, Rajasthan is not endemic for the disease and had achieved the elimination target even before 2005 (when the target was achieved at the National level), the trends of the disease remain nearly the same in the last

decade. Figure 1 shows the trends of the prevalence of the disease and the number of cases released from treatment (RFT) after completion of MDT. Cure in the bar diagram means successful completion of MDT. The number of new leprosy cases being detected in the State also has a similar pattern over the years and is graphically depicted in Figure 2.

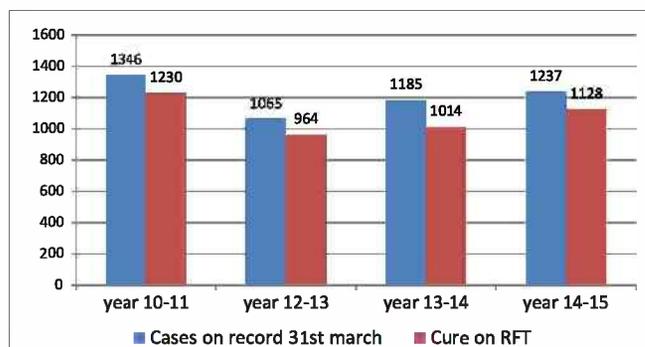


Figure 1: Trends in prevalence of the disease in Rajasthan at the beginning of each year (1st April) under report and the number RFT as reported in NLEP³⁻⁶.

Besides the new cases, the proportion of paucibacillary (PB) and multibacillary (MB) cases also remains the same. It is a matter of concern that the proportion of MB cases to the PB cases is nearly five to six times and is almost constant over the years.

In epidemiology of leprosy, the number of childhood cases detected is an indicator of the ongoing transmission of the disease. This is more so in leprosy as the organism cannot be cultured in the laboratory and thus it is difficult to work on the transmission dynamics of the disease. Except the wild armadillos found in America⁷, Mangabey monkeys found in Africa⁸ and recently the red squirrels⁹ found on the British Isles, there are no known animal reservoir of the disease which can harbor *Mycobacterium leprae* and transmit the infection to humans. By the use of molecular tools, there are now reports that *Mycobacterium leprae* can stay alive in the

environment^{10,11} and may have a role in the continuing transmission of the disease. However, active, untreated cases of leprosy are considered to be the main source of human infection, and the resulting continued transmission in endemic countries and areas. The proportion of child cases is small in the state and has been reported to be 2.05% of the total new cases detected in 2010-2011 period³; zero in 2012-2013⁴; 1.95% of the new cases detected in 2013-2014⁵ and 2.74% of new cases detected in 2014-2015⁶. This is much lower than that observed in the rest of the country as well as in states with a low prevalence rate of the disease.¹²

A lot of age old stigma due to the disease is due to the deformities and disabilities associated with leprosy. The proportion of grade 1 and grade 2 disabilities observed in the new cases detected year wise is shown in Figure 3. These have been calculated as per the total new leprosy cases detected and not based on the whole population of the state. It is observed that disabilities have been reported in a higher percentage of new cases in the earlier years (2010-2011³ and 2012-2013⁴) than more recently (2014-2015⁶)

Although leprosy is present since the prehistoric times and *Mycobacterium leprae* was the first organism to be identified as a cause of the disease, many facets of the disease are still not fully understood. Leprosy has been eliminated from most of the western world even before implementation of MDT. Poverty, unhygienic conditions, over-crowding, malnourishment all play a role in the occurrence of the disease and also influence its morbidity.

In Rajasthan, the disease is prevalent in low numbers but unfortunately this is remaining nearly constant in the recent years. Moreover, new cases also continue to occur at the same rate. In absence of a known animal reservoir, infected humans are considered to be the main cause of continued transmission of the disease.

In the State more than 80% of the prevalent cases are released from treatment, after completion of full course of MDT (Figure 1). More efforts are needed to ensure better completion of treatment by empowering the population with knowledge of the disease and its treatment, so that patients take timely full course of treatment. Less than or about 30% of the new leprosy cases are females, across all years under report. In the States (Gujarat, Goa, Maharashtra, Dadra & Nagar Haveli) with better information, education and communication (IEC) activities and disease knowledge empowerment of the population, more female cases are being detected and treated.^{3,4,5,6,12} Female cases constitute about 45 to 50% of the total cases. This has also been reported by other investigators¹³ and may be part of the

hidden cases which are missed and thus deprived of diagnosis and treatment and contribute to the transmission of the disease. Moreover, they are in more close contact with the younger generation- children and may be contributing more to transmission of the disease. Although ASHAs are utilized in the programme in the State, need more intensive training, re-orientation and prompt numeration on early diagnosis and completion of treatment, for better coverage of the population. Besides them, the other health related staff in the State programme, also need to be re-oriented to the disease dynamics, diagnosis and treatment.

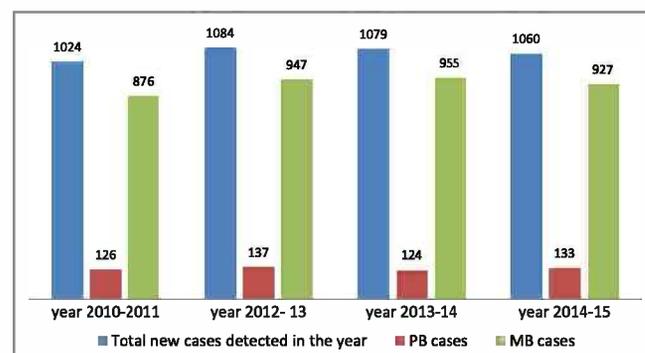


Figure 2: Number of new cases detected and the proportion of paucibacillary (PB) and multibacillary (MB) cases detected in the respective years.

New cases also continue to occur, in nearly the same rate in the State (Figure 2). As already indicated above, some of these missed cases could be female cases. Also, better case finding in the population and children in particular can be undertaken through dissemination of knowledge of the disease, its signs and symptoms, treatment by school health surveys for early diagnosis and treatment. Moreover, MB cases are about 5-6 times more than the PB cases in the State. Considering the overall small numbers, it would be practically feasible and desirable to consider re-introducing slit smear examination for acid fast bacilli (AFB), so that MB patients in particular can be better managed and monitored. Recently by the use of molecular methods and better understanding of the *Mycobacterium leprae* genome, other diagnostic markers like RLEP in slit skin smear scrapings is also available and has been put to good scientific use.^{14,15} Higher MB disease in the population indicates late diagnosis and therefore late initiation of treatment. Involvement of Anganwadi workers, Panchayat members and cured leprosy patients in the awareness campaigns and the programme will help in detecting more early cases and institution of prompt treatment. The NLEP is also now focusing its attention to Special Activities Plan (SAP)⁴, for examining of contacts of leprosy patients. All contacts of MB patients need to be examined for earlier and better detection of early cases.

Leprosy Case Detection Campaigns (LCDC) in both high and low endemic areas has also been initiated to detect more cases.⁶ Such campaign also needs to be undertaken in low endemic state like Rajasthan, so that disease can be diagnosed early and treated to disrupt the transmission chain. Adequate surveillance of RFT cases is also required for prompt diagnosis and adequate treatment of relapses and residual problems.

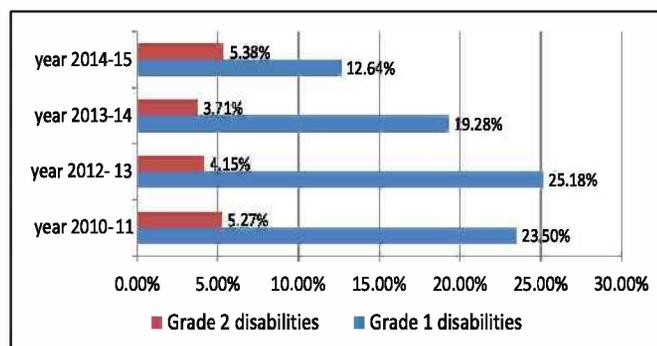


Figure 3: Grade 1 and 2 disabilities in the newly detected leprosy patient year wise.

About a fourth of the new detected cases suffer from some kind of disabilities in the State (Figure 3). These need to be promptly diagnosed and efficiently treated, so as to prevent permanent disabilities. Special efforts are needed to effectively diagnose, and efficiently treat Grade 1 disabilities. These are seen more often in MB patients and if adequately treated do not lead to permanent disabilities and problems associated with it. Emphasis needs to be given for proper suspicion and diagnosis of these. These may also occur after RFT and completion of treatment and patients need to be told about its signs and symptoms and prompt treatment. Surveillance activities are required to follow up the cases, observe and promptly treat complications or recurrences if any. Recently, more focus is being laid on enumerating the grade 2 disabilities. This is required if we aim to achieve the goal of leprosy without deformities by 2020. However, equally, if not more, importance also is required for grade 1 disabilities so that grade 2 disabilities can be prevented. In the National sample survey to assess the disease burden in leprosy undertaken in 2010-2011, four cases of leprosy were diagnosed in the urban cluster of which two (50%) had Grade 1 disability.¹²

Assessment of stigma related to the disease is not a part of the NLEP; however, some laws are still enacted in the state although there is sufficient evidence against these. In Rajasthan, a person who has once been affected with leprosy cannot fight an election even today.¹⁶ These and other medieval laws which are based on wrong beliefs need to be repealed and treated leprosy individuals should be given the right place in the society.

CONCLUSION

Rajasthan is a low endemic state for leprosy and has managed to keep the prevalence and incidence of new cases low. However, the disease continues to occur at same level for the past 10-12 years, thus we should not become complacent. There is a chance for the state to eradicate the disease, this challenge can be taken up and goal achieved.

More knowledge about dissemination of the disease, its treatment, care of insensitised hands and feet is needed for empowerment of the population for early diagnosis and effective treatment. Training and re-orientation of health staff engaged in the programme is needed for better disease diagnosis and management. Surveillance activities for RFT patients as well as those with grade 1 and 2 disabilities need to be undertaken and strengthened. This will help in taking care of relapses and reduce the burden of disabilities.

Examination of contacts of leprosy patients and LCDC exercises need to be undertaken. Skin smear testing for AFB as well as use of recently developed molecular methods like RLEP PCR can be undertaken for better monitoring of cases. Besides reconstructive surgery for patients with disabilities, emphasis needs to be given on the enablement of disabled cases so that they can lead a useful life and are socially acceptable. Old medieval laws which wrongly discriminate them should be repealed in the State as has already been done in several States and Union Territories.

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