

Hidden leprosy cases in tribal population groups and how to reach them through a collaborative effort

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Summary

Background: Tribal populations are an underserved population group and access to health services is a major challenge for them. Since leprosy treatment is integrated with the general health services, identifying leprosy cases is not be easy in these settings and they remain as endemic reservoirs, unless greater efforts are made to reach them.

Methodology: An active search operation was conducted in the tribal colonies in four pre-identified Health & Nutrition Clusters, Nellore district, Andhra Pradesh, India, in 2013. After a brief training, village health nurses and selected volunteers covered all the households, showing flash cards with photos of leprosy cases and enquiring if there was any resident with a similar condition. Suspects were listed and examined by the district leprosy supervisor and field coordinators from Damien Foundation. Follow up interviews were done after one year to assess the treatment completion rate.

Results: Village health workers covered 47,574 people living in the tribal colonies and identified 325 leprosy suspects. Among them, 70 were confirmed as new leprosy cases. The prevalence of previously undetected leprosy cases was found to be 14.7/10,000. Out of 70 cases, 19 (27%) were children, 35 (50%) were female, 32 (45.7%) were classified as MB leprosy, 6 (8.6%) had a leprosy reaction and 11 (15.7%) persons had Grade 2 disability at the time of diagnosis. The treatment completion rate was found to be 74% at the end of one year.

Conclusion: The study reveals a very high burden of leprosy among the tribal population and demonstrates how resources can be mobilized from government,

NGO and local community sources to promote early case detection among underserved population groups.

Keywords: leprosy, public private partnership, tribal population, India

Introduction

India reported a 65% decline in new case detection from 456,000 in 1993 to 161,457 in 2005, when it achieved the leprosy elimination target at the national level.¹ The declining leprosy burden led the government of India to integrate leprosy services into the general health services in different states in a phased manner during the period 2001–2004.² In the integrated set up, health staff mostly rely on passive case detection and treatment with MDT.

In 2013, India reported 126,913 new leprosy cases, contributing 59% to the global burden of leprosy. New case detection has remained almost static in the last 5 years.³ This could be due either to the occurrence of fewer leprosy cases, or to fewer cases being detected. In 2010, the Government of India conducted a National Sample Survey among 15 million people and detected 2,177 cases with a weighted new case rate estimated at 2.5/10,000. This suggests that nearly half of the new leprosy cases are not being detected by the program.⁴

Wherever special case detection activities were initiated, considerable numbers of new leprosy cases were detected. This shows that there are undetected leprosy cases, especially in areas which are not reached by the general health service for various reasons.^{5–9} The prevalence of undetected leprosy cases is likely to be higher in marginalized population groups who lack access to health services both physically and socially. In the Indian context, Scheduled Tribes (ST) are considered as socially disadvantaged groups with a higher chance of living in adverse conditions. Analysis of health indicators by caste from national surveys shows poor access to maternal and child health services, with the highest infant and child mortality among ST population groups.¹⁰ According to the 2011 census, the proportion of ST population in India is 8.6% but during 2012, the proportion of new leprosy cases among ST population was found to be 18.5%, revealing a disproportionate burden of leprosy among the tribal population.^{11,12}

The judicious combination of voluntary reporting with active case detection in endemic areas and high risk populations will be the key to reducing the number of undetected cases in the community. This study aims to demonstrate how resources can be mobilized in these settings to detect and treat hidden leprosy cases.

Methodology

STUDY SETTING

The study was conducted in Nellore district, Andhra Pradesh, India. The district, with a population of 3,008,229 is divided into 17 Health and Nutrition Clusters (HNC). Each HNC caters to the health care needs of the rural population through 4–6 Primary Health Centres. The District Nucleus Team (DNT) has the mandate to organise leprosy care services in the district. In Nellore district, the team is comprised of District Leprosy Officer, Medical Officer, Health Educator, Non-Medical Supervisor and a physio-technician. The district also

has 23 Non-Medical Supervisors with long experience in leprosy control, who were posted to the PHCs.

The Damien Foundation Leprosy & Tuberculosis Centre at Nellore was established in 1993 and provides support to government leprosy control efforts through its hospital and field staff. The hospital serves as a referral centre for managing leprosy related complications, such as the management of leprosy reactions, providing ulcer care and reconstructive surgery. The field teams assist the government staff in updating the list of persons affected by leprosy with disabilities, training those with disabilities in practicing self-care, and referring persons with leprosy related complications and those in need of reconstructive surgery to the referral hospital.

According to the 2011 census, Nellore district had a tribal population of about 286,000 which is 10% of the total district population; the majority of them belong to the *Yanadhi* tribes. Traditionally, Yanadhis were semi-nomadic but now most of them are settled in houses built by the government in colonies. These colonies are usually located outside the main villages. In 2012–2013 the tribal population contributed 36.4% of new leprosy cases detected in the district. The district reported a prevalence of 0.84 per 10,000 population in 2012–2013. The District Leprosy programme officer indentified the high burden of leprosy among the tribal population in Nellore district as a priority issue and organised a coordination meeting between the District Nucleus Team (DNT) staff and Damien Foundation (DF) field staff. During this meeting the decision was taken to conduct a survey in the tribal colonies in four Health and Nutrition Clusters (HNC), namely Vakadu, Allur, Kota and Indukurpet, where 18% of the district tribal population lives. The primary health care needs in these four clusters were delivered by 27 Primary Health Centres. The list of tribal colonies in these four clusters was collected from the Integrated Tribal Development Agency (ITDA), Nellore. As per the 2011 census, 51,316 people were living in 49 tribal colonies in these clusters.

INTERVENTION

Damien Foundation assisted the DNT staff in preparing the microplans for the survey and provided mobility support. The search team adopted the Rapid Enquiry Survey methodology which has been shown to be effective in detecting large numbers of leprosy cases in a short period among tribal populations in India.¹³ After a brief training on leprosy, 118 village health nurses and 312 volunteers made house visits in the tribal colonies and enquired of available family members by showing a flash card with pictures of people affected by leprosy. DNT members and DF field coordinators examined the suspects identified by village health nurses and volunteers and confirmed the diagnosis of leprosy. The entire survey was completed in 2 weeks during the months of August and September 2013. Damien Foundation had spent approximately 828 USD (1USD = 62 INR) towards travel expenses and refreshments during the survey. Village health nurses and volunteers were involved in the delivery of MDT blister-packs and follow up after treatment.

DATA COLLECTION

Village health nurses and volunteers collected information on the total number of family members living together, during house to house visits. They prepared a list of persons suspected of having leprosy and brought them for examination. Verbal consent was obtained by health workers during the survey and prior to the examination of those suspected of

leprosy. DF field coordinators checked and compiled the information from survey sheets used by village health volunteers at the cluster level. DNT members and DF field coordinators examined the suspects and collected information such as age, years of schooling, sex, classification, disability, leprosy reaction, and health seeking behaviour. 'Previously undetected leprosy cases' were defined as those cases who had not taken MDT in the past; 'Previously detected leprosy cases' were defined as those cases who were taking MDT but had not been declared cured or released from treatment at the beginning of the survey. All the cases detected during the survey were interviewed after one year by DNT staff and the Damien Foundation field coordinator to assess treatment completion.

Results

SURVEY FINDINGS

Village health workers and volunteers interviewed 47,574 people, 93% of the total ST population living in the four surveyed clusters. The survey team identified 325 leprosy suspects, and among them 70 were confirmed as new leprosy cases. The prevalence rate of undetected leprosy cases in the surveyed population was 14.7/10,000. Among the 70 confirmed cases, 19 (27%) were children, 43 (61%) had never gone to school, 44 (63%) were unskilled physical labourers, 35 (50%) were female, 32 (45.7%) were classified as MB leprosy and 6 (8.6%) had a leprosy reaction. There were 11 (15.7%) people with grade 2 disability at the time of diagnosis.

Out of 70 cases, only 24 (34.3%) had noticed their patches or other symptoms before this survey. Among those who noticed symptoms, 15 consulted health workers at a government health centre and most of them received ointments and vitamins.

Table 1 depicts the population covered by cluster, suspects examined and the number of leprosy cases detected, along with prevalence of leprosy.

Table 2 shows the prevalence of leprosy by cluster before and after the survey. The overall prevalence of leprosy among the ST population in these four clusters increased from 9.8/10,000 at the beginning of the survey to 24.6/10,000 after the survey.

TREATMENT OUTCOMES

Out of 70 cases detected during the survey, only 52 (74%) were found to have successfully completed the treatment at the end of one year. Two patients died before completing treatment, while among those who defaulted from treatment, seven migrated for work and

Table 1. Results of the rapid enquiry survey among the tribal population, Nellore district, Andhra Pradesh

	Allur	Vakadu	Kota	Indukurpet	Overall
Enumerated population	12,926	10,030	8,957	15,661	47,574
Suspects identified	42	72	77	134	325
Previously undetected leprosy cases	14	20	15	21	70
Prevalence of previously undetected leprosy cases (/10,000)	10.8	19.9	16.7	13.4	14.7

Table 2. Prevalence of leprosy before and after the survey among the study population

Name of the cluster	Population enumerated	Previously undetected leprosy cases	Previously detected leprosy cases	Total	Prevalence/10,000 population		Overall
					Previously undetected leprosy cases	Previously detected leprosy cases	
Allur	12,926	14	21	35	10.83	16.25	27.08
Vakadu	10,030	20	20	40	19.94	19.94	39.88
Kota	8,957	15	1	16	16.75	01.12	17.86
Indukurpet	15,661	21	5	26	13.41	03.19	16.60
Overall	47,574	70	47	117	14.71	09.88	24.59

they could not be traced further, five patients refused to continue treatment due to improvement in their skin lesions and four patients did not take treatment due to problems in MDT supply.

Discussion

The study reveals a large number of hidden leprosy cases among the underserved tribal population and demonstrates that with effective partnership between the district leprosy program and NGOs working in leprosy, it is possible to detect them in a short period of time. The burden of leprosy among this tribal community was found to be 29 times higher than the reported burden of leprosy in Nellore district. The prevalence at the beginning of the survey was found to be high in Allur & Vakadu clusters because the government health staffs were aware of the hidden leprosy cases among tribal communities and conducted active searches. But they could not carry out further intensive search drives due to lack of mobility support and personnel to screen the suspects for confirmation of leprosy diagnosis.

The high proportions of cases with MB leprosy (45.7%) and Grade 2 disability (15.7%) during an active case search indicates significant delay in detection of these cases. Around one third of leprosy cases detected during this survey were children, which highlights the ongoing transmission of leprosy infection. A review of childhood leprosy in India over the past two decades concluded that the community survey is the most effective method to detect leprosy among children.¹⁴ The treatment completion rate after 1 year (74%) was found to be better than leprosy cases detected at a tertiary level hospital where a 50–60% default rate was reported.¹⁵ Good counselling at the time of treatment initiation and close follow up by local volunteers will reduce the default rates among semi-nomadic tribal populations.

Recent community level studies strongly recommended active case detection for leprosy to overcome the inherent problems associated with self-reporting, such as the low level of community awareness, lack of physical discomfort in the patches, and failure to associate the patches with neurological symptoms.^{7,16} It may be difficult to carry out active case detection covering whole population in India particularly in the context of declining leprosy expertise. The WHO Expert Committee on Leprosy observed the uneven distribution of leprosy within countries and advised countries to focus on areas of higher endemicity and underserved populations.¹⁷ Based on the Expert Committee recommendations, the Government of India is

planning to launch a Block Leprosy Control Campaign (BLCC) in 2015. Intensive awareness drives along with house to house active searches for early detection of leprosy cases is planned in 1,453 blocks of 214 districts in 16 states/union territories. The guideline for block level campaigns stresses the need to give special emphasis to underserved, tribal and urban slum population groups.¹⁸ Active case detection campaigns should be repeated every year during an anti-leprosy fortnight.

In the past, the government has partnered with Non Governmental Organizations (NGOs) to improve case finding and access to MDT in high endemic states of India. Partnership with NGOs led to dramatic improvements in MDT coverage, treatment regularity, monitoring and discharge of patients and capacity building of local staff.¹⁹ But the intensity of this partnership decreased after integration of leprosy into the general health services. In 2013, recognizing the need to partner with the NGOs effectively, the government of India developed various schemes for NGOs to support leprosy control services. The scheme for “Comprehensive Care for Underserved Areas” focuses on early case detection in underserved populations.²⁰ The government and NGOs working for leprosy should come together and pool their resources to promote detection of hidden leprosy cases and effective follow up of detected cases among underserved populations.

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