Lepr Rev (2017) **88,** 452–462

Enhanced active case-finding, identifying leprosy cases missed by recent detection campaigns in Munger District, Bihar, India

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Accepted for publication 20 August 2017

Summary In India, some indicators of leprosy transmission are on the rise and suggest that many cases of leprosy currently go undetected. The lack of active case-finding outreach activities, aiming to find hidden cases in communities, are possible reasons for this. Lepra, an international non-governmental organisation, ran an active case-finding project in Munger District, Bihar, from 15th June to 15th December 2016, screening 85,560 people. A combined approach using Contact Surveys, Focal Surveys and Special Searches was implemented. A total of 321 new leprosy cases were found (28% Multibacillary, 47% women, 37% child cases, 59% belonging to scheduled castes, 10% to scheduled tribes, and 3% with disability and complications). The research supports evidence generated by other non-governmental organisations of a high transmission of the disease in India. Finding 303% more cases than traditional government-led detection campaigns, it shows that many cases in affected communities remain undetected in Bihar. This method was also found to be more efficient at finding vulnerable groups, child and female cases, as well as cases within scheduled castes and tribes.

Introduction

Since declaring leprosy eliminated as a public health problem in 2005,[i] India has displayed static epidemiological trends in leprosy. The country Prevalence Rate (PR) was 0·69 per 10,000 in 2014/15 and 0·66 per 10,000 in 2015/16,[1,2] with 86,028 leprosy cases on record in April 2016. Reported Annual New Case Detection Rates (ANCDR) - 9·73 per 100,000 population in 2014/15 (125,785 people) and 9·71 in 2015/16 (127,334 people), are stable and indicate a slow decline in endemicity.[1,3] However, prevalence rates in leprosy are very

[i] Defined as a point prevalence under 1/10,000.

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 0305-7518/17/064053+11 $1.00

sensitive to factors such as treatment duration and case-finding methods.[4] As a result, alternative disease transmission indicators are used to monitor leprosy,[5,6] and these suggest that current PR and ANCDR trends do not reflect the real status of leprosy in India.[7–9] Increasing numbers of child cases and higher levels of Grade 2 Disability among new cases show continued transmission of leprosy and a late detection of cases.[10] There is now accumulating evidence that disease transmission is high and many cases go undetected.[4,11–16] WHO recently called for intensified efforts to prevent the transmission of leprosy.[17]

The reduction of investment in active case-finding in the years following the declaration of Elimination as a public health problem appears to have had a significant impact on the ANCDR.[5,18] Several studies show a correlation between increased active case-finding campaigns and increased ANCDR.[19–21] This implies that the slow decrease is due to a lack of case identification and reporting, rather than due to a genuine decline in disease transmission. In fact, some estimate that only one-third of people affected by leprosy voluntarily report to health centres.[22] Active case detection is therefore crucial.

Furthermore, the following evidence suggests that active case detection is necessary to ensure equal access to leprosy services. Between the years 2002 and 2004, considered as the 'Elimination' period in Odisha State, a fall in the female proportion in ANCDR was found to be rapid,[23] and current trends show an uneven gender split in ANCDR, with women constituting only 38% of all new cases.[1] There is no medical evidence that women should be less affected than men, so this disparity probably lies in an unequal access to health care between men and women in India.[24] Further, when leprosy programmes do not primarily rely on self-reporting and when active case-finding is enhanced, the female proportion in ANCDR increases to 50%.[20,25] A similar pattern of underreporting is observed for child cases.[12,23] In their pursuit of new cases, active search operations have found between 14% and 27% of child cases against a national average of 9%, recorded in the National Eradication Leprosy Programme (NLEP) 2015/16 Annual Report.[1,10] Active case-finding also demonstrates that disadvantaged groups who live in adverse conditions do not come forward for treatment despite being dramatically affected by leprosy. A study conducted by the Damien Foundation in the tribal colonies of Andhra Pradesh, where a majority of people belong to Scheduled Tribes, found a prevalence of previously undetected leprosy cases of 14·7/10,000.[20]

Acknowledging the importance of active case-finding, the NLEP launched Leprosy Case Detection Campaigns (LCDC) in highly endemic districts in India.[26] Among others, LCDC includes block-level health practitioner training sessions, Information Education and Communication (IEC) activities and house-to-house case detection. The latter is conducted by a female Accredited Social Health Activist (ASHA) and one field worker, who are tasked to cover the whole population of an endemic district. The LCDC guidelines stipulate that *"No house should be left unvisited"*.[26] In theory, the LCDC approach should capture all cases of leprosy in a given community. Yet alternative sources of data indicate that it fails to do so. All active case-finding campaigns have systematically found hidden cases of leprosy in affected communities.[19–21]

In order to strengthen leprosy surveillance control, Lepra initiated an active case-finding project in the Munger District in Bihar in 2016. This project aimed to find hidden and new cases of leprosy and, as LCDC was launched in Munger District, Bihar in 2015, to establish whether current governmental campaigns succeed in finding all leprosy cases.

Material & Methods

THE STUDY AREA

All activities were implemented over a 6-month period, from 15th June to 15th December 2016, in Munger District exclusively. This District consists of nine Blocks and has a total population of 1,359,054 people; 72% of the population is rural and the female literacy rate is 66%. The government health facilities include one district and one sub-divisional hospital, nine Primary Health Centres and 225 Health Sub-Centres. In 2015/16, the PR in Munger was 0·73 per 10,000 and ANCDR, 13·94 per 100,000. Child cases represented 16·03% of all new leprosy cases, women accounted for 43·83%. A total of 50·74% of all new cases were Multibacillary (MB), 3·13% of the new cases presented with a Grade 2 disability and 0·12% with Grade I. In Munger District, before the project began, there had been no household contact examinations conducted by general health services staff.

LEPRA

Lepra is a UK registered international charity that works with individuals and communities affected by leprosy and lymphatic filariasis in India, Bangladesh and Mozambique. In India, Lepra works together with LEPRA Society, a non-governmental organisation that promotes quality health care, and supports National Health Programmes in the prevention and control of diseases such as leprosy, lymphatic filariasis and other neglected diseases initiates. LEPRA Society works in Andhra Pradesh, Bihar, Delhi, Jharkhand, Madhya Pradesh, Odisha and Telangana States. In Munger District, LEPRA Society has been implementing leprosy-related activities since 2005, through a Referral Centre based in Munger. On average 250–275 new leprosy cases are registered annually in the District, mostly diagnosed at this Referral Centre.

SURVEY DESIGN

The survey combined three types of active case-finding tools: a Contact Survey, a Focal Survey and a Special Search. A 'contact' of a leprosy patient is defined as any person who has a history of prolonged interaction with a known leprosy patient and usually lives in the same household. In a Contact Survey, once a person in a family is diagnosed with leprosy, consecutive physical examinations of household members should be done every 6 months for 5 years for multibacillary (MB) leprosy patients and for 2 years for paucibacillary (PB) leprosy patients. A Focal Survey goes beyond the family by examining 20–25 households in the neighbourhood of child and MB cases. A Special Search targets a particular group for detailed examination. In this study, Schedules Tribes (ST), groups officially designated in the Indian Constitution as historically disadvantaged indigenous people, were targeted by the Special Search. Attention was also given to people from Scheduled Castes (SC) as they belong to more disadvantaged groups (Figure 1).

A leprosy patient was defined as a person presenting with skin lesions consistent with leprosy, with definite sensory loss and with or without thickened nerves. A skin smear test was used at the Primary Health Centre (PHC) as a tool for differential diagnosis. Paucibacillary (PB) and Multibacillary (MB) leprosy types were defined according to the WHO classification as one to five skin lesions for PB type and more than five for MB type.

Three paramedic workers were recruited for this intervention and trained in leprosy case detection through Contact and Focal Surveys and Special Searches. This team was supported

Figure 1. Survey design.

by the LEPRA Society physio-technician and supervisor in Bihar. From the District Leprosy Office master register, the team collected details of 1,414 cases released from treatment (RFT) in the last 5 years, spread across 323 villages and a number of municipal wards in the district. All 1,414 (718 multibacillary (MB) and 696 paucibacillary (PB)) index cases were included in the planned Contact Survey. For the Focal Survey, all MB cases (adult 636 and child 82) and 131 child PB cases were included. Over the course of 6 months, the team visited the families of 1,198 people who had been diagnosed and treated for leprosy. In total, 5,091 people were examined through Contact Surveys and 54,129 people were examined through Focal Surveys. To avoid over-sampling, the number of people examined in Focal Surveys excluded people examined through Contact Surveys. In each village and municipal ward, as the team proceeded in conducting Contact and Focal Surveys, they also conducted Special Searches in the areas of the village where people from Scheduled Tribes live; usually in the southern part of the village. A total of 26,340 people were examined through the Special Search.

Potential cases were diagnosed at the Primary Health Centre (PHC) by the government Medical Officer and LEPRA Society Team. A Slit Skin Smear (SSS) facility was available at Munger Referral Centre to help with the diagnosis of difficult to diagnose cases. The team checked that all cases had not been previously treated. Four forms were designed to capture Contact, Focal, and Special Survey/Search information. In order to ensure quality, 10% of the surveyed households were randomly selected for cross checking by a Zonal Coordinator, who looked at the percentage of family members screened by the surveyors, the method used for

screening, and the referrals of possible cases to PHCs for formal diagnosis and treatment. Within 6 months of the completion of the study, 90% of the diagnosed new cases had started Multi-Drug Treatment.

Results

Three hundred and twenty-one new cases of leprosy were found by Lepra through combined Contact and Focal Surveys and through Special Searches, and these have been reported here. The socio-demographic information of these 321 cases is shown in Table 1.

A total of 126 new cases of leprosy were detected by Special Searches (39%), 98 by Contact Surveys (31%), and 97 were detected by Focal Surveys (30%). Of the 321 new cases, 169 (53%) were male cases and 152 (47%) female cases. While male cases were mostly detected by Special Searches (57%), Contact Surveys detected a higher proportion of female cases (55%) compared to Focal Surveys (45%) and Special Searches (43%).

A total of 119 child cases (defined as those below 15 years of age) were detected, representing 37% of the total number of new cases. Special Searches detected a larger proportion of children (41%), compared to Contact (33%) and Focal (36%) Surveys. Out of the 321 cases, 190 (59%) belong to Scheduled Castes and 31 (10%) to Scheduled Tribes. Over 67% of the total cases detected by Special Searches were from Scheduled Castes, compared to 52% detected by Focal Surveys. Conversely, Focal Surveys detected a higher proportion of people from Scheduled Tribes compared to both Contact (6%) and Focal (8%) Surveys.

Table 2 shows that very few cases reported complications (2%) or disability (3%).

Furthermore, among a total of 321 new cases, 89 (28%) had the Multibacillary (MB) form of leprosy. Both Focal Surveys and Special Searches detected larger proportions of Paucibacillary cases (76% and 73% respectively) compared to Contact Survey (67%) which detected higher percentage of MB cases (33%) compared to the other two detection methods.

Gender differences were observed. As presented in Table 3, of the total MB cases ($n = 89$), 57 (64%) were male cases and 32 (36%) were female cases. Whilst Special Searches were able to detect a higher percentage of male cases (37%) compared to Focal (30%) and Contact (32%) Surveys, Contact Surveys detected a larger proportion of female cases (33%) compared to the other detection methods.

An analysis of new cases in relation to their closest Primary Health Centre (PHC) shows that MB cases were not equally geographically distributed (Table 4).

Table 1. Distribution of socio-demographic factors among new cases

Detection Method	Gender		Age		Caste				Total
	Males	*Females*	*≤14*	*≥15*	*SC*	*ST*	*OBC*	*General*	
Contact	44 (45%)	54 (55%)	32 (33%)	66 (67%)	55 (56%)	6 (6%)	36 (37%)	1 (1%)	98 (100%)
Focal	53 (55%)	44 (45%)	35 (36%)	62 (64%)	50 (52%)	15 (15%)	31 (32%)	1 (1%)	97 (100%)
Special	72 (57%)	54 (43%)	52 (41%)	74 (59%)	85 (67%)	10 (8%)	29 (23%)	2 (2%)	126 (100%)
Total	*169 (53%)*	*152 (47%)*	*119 (37%)*	*202 (63%)*	*190 (59%)*	*31 (10%)*	*96 (30%)*	*4 (1%)*	*321 (100%)*

SC: Scheduled Castes; ST: Scheduled Tribes; OBC: Other Backward castes.

Table 2. Distribution of clinical factors among new cases

Detection Method	Type		Complications		Disability Grade			Total
	MB	*PB*	*N/R*	*None*	*Gr-0*	*Gr-I*	*Gr-2*	
Contact	32 (33%)	66 (67%)	3 (3%)	95 (97%)	95 (97%)	–	3 (3%)	98 (100%)
Focal	23 (24%)	74 (76%)	1 (1%)	96 (99%)	93 (96%)	3 (3%)	1 (1%)	97 (100%)
Special	34 (27%)	92 (73%)	2 (2%)	124 (98%)	123 (98%)	–	3 (2%)	126 (100%)
Total	*89 (28%)*	*232 (72%)*	*6 (2%)*	*315 (98%)*	*311 (97%)*	*3 (1%)*	*7 (2%)*	*321 (100%)*

MB: Multibacillary; PB: Paucibacillary; N/R: Neuritis or Reactions.

At 21%, the Dharhara PHC had the highest proportion of MB cases. Bariyarpur presented 19% of total MB, followed by Kharagpur with 12%. Additionally, while most MB cases belonging to Scheduled Castes were detected close to Dharhara (34%), Scheduled Tribes were mainly concentrated in Bariyarpur (50%), Dharhara (17%) and Kharagpur (33%). Only 19% of the cases from Scheduled Tribes were MB cases.

Some differences were observed in gender and age distributions. About 43% of affected people aged 15 or more were detected in Bariyarpur and Dharhara (25% and 18% respectively). However, while 29% of cases aged below 15 were detected close to Dharhara, only two cases (7%) were detected close to the PHC of Bariyarpur. In terms of gender, over 43% of male cases were detected in Dharhara and Bariyarpur (25% and 18% respectively), compared to 38% for female cases. Overall, the proportion of female cases was more homogeneously distributed among PHCs compared to the distribution of males. PHCs of Jamalpur, Sadar and Sangaranpur together accounted for 26% of the total MB cases detected.

The PR for the population screened through the approach was 37·5 per 10,000, and 2·4 per 10,000 when calculated for the total population in Munger.

Discussion

A total of 321 new leprosy cases were found through the combined approach bringing the PR above the 1 per 10,000 Elimination level (37·5 per 10,000 for the population screened and 2·4 per 10,000 for the total population of Munger District). The gender ratio was 47% women, 53% men; however, only 36% of MB cases were female cases compared to 64% male cases. About 59% of total cases belonged to Scheduled Castes and 10% to Scheduled Tribes. Child

Table 3. Distribution of new cases by bacillary load and by gender

Detection Method	Males			Females			Total
	MB	*PB*	*Subtotal*	*MB*	*PB*	*Subtotal*	
Contact	14 (32%)	30 (68%)	44 (100%)	18 (33%)	36 (67%)	54 (100%)	98
Focal	16 (30%)	37 (70%)	53 (100%)	7 (16%)	37 (84%)	44 (100%)	97
Special	27 (37%)	45 (63%)	72 (100%)	7 (13%)	47 (87%)	54 (100%)	126
Total	*57 (34%)*	*112 (66%)*	*169 (100%)*	*32 (21%)*	*120 (79%)*	*152 (100%)*	*321*

MB: Multibacillary; PB: Paucibacillary.

Table 4. Distribution of Multibacillary leprosy among new cases by socio-demographic factor and per Primary Health Centre

	Gender		Age		Castes				
PHC	*Males*	*Females*	*≤14*	*≥15*	*SC*	*ST*	*OBC*	*Gral*	Total MB
Asarganj	5 (9%)	–	1 (4%)	4 (7%)	3 (6%)	–	2 (7%)	–	5 (6%)
Bariyarpur	10 (18%)	7 (22%)	2 (7%)	15 (25%)	6 (11%)	3 (50%)	8 (28%)	–	17 (19%)
Dharhara	14 (25%)	5 (16%)	8 (29%)	11 (18%)	18 (34%)	1 (17%)	–	–	19 (21%)
Jamalpur	6 (11%)	2 (6%)	3 (11%)	5 (8%)	7 (13%)	–	1 (3%)	–	8 (9%)
Kharagpur	7 (12%)	4 (13%)	4 (14%)	7 (11%)	5 (9%)	2 (33%)	4 (13%)	–	11 (12%)
Sadar	2 (4%)	5 (16%)	–	7 (11%)	1 (2%)	–	6 (20%)	–	7 (8%)
Sangarampur	3 (5%)	5 (16%)	4 (14%)	4 (7%)	7 (13%)	–	1 (3%)	–	8 (9%)
Tarapur	3 (5%)	–	1 (4%)	2 (3%)	1 (2%)	–	2 (7%)	–	3 (3%)
Tetiabamber	2 (4%)	3 (9%)	4 (14%)	1 (2%)	1 (2%)	–	4 (13%)	–	5 (6%)
U. Munger	5 (9%)	1 (3%)	1 (4%)	5 (8%)	4 (8%)	–	2 (7%)	–	6 (7%)
Total	*57 (100%)*	*32 (100%)*	*28 (100%)*	*61 (100%)*	*53 (100%)*	*6 (100%)*	*30 (100%)*	–	*89 (100%)*

PHC: Primary Health Centre; SC: Scheduled Castes; ST: Scheduled Tribes; OBC: Other Backward castes; Gral: General; MB: Multibacillary.

Table 5. Prevalence

Detection Method	PR per total population screened (85,560)	PR per total population in Munger (1,359,054)
Contact Survey	11·45	0·72
Focal Survey	11·34	0·71
Special Search	14·73	0·93
Total	37·52 per 10,000	2·36 per 10,000

cases were high (37%), but low levels of disability and complications were found amongst the new cases (3% and 2% respectively).

The total of MB cases was low (28%). Most MB cases came from Dharhara (21%), Bariyarpur (19%) and Kharagpur (12%). These three Primary Health Centres included all MB cases detected among people belonging to Scheduled Tribes.

The majority of cases were identified by Special Searches (39%), but Contact Surveys detected higher proportion of female MB cases (33%) compared to other detection methods. Special Searches, however, discovered a greater percentage of male MB cases (37%). Whilst Special Searches detected a larger proportion of child cases (41%), Focal Surveys identified a higher proportion of people belonging to Scheduled Tribes (15%).

Results suggest that many leprosy cases in affected communities remain undetected and that the current burden of leprosy is high. The project suggests a PR of 37·52 per 10,000 (based on the actual population screened), which is alarmingly high and well above the 'Elimination' target. Additionally, the approach, which brings together Contact Surveys, Focal Surveys and Special Searches, appears to be particularly efficient at identifying vulnerable groups.

In fact, Lepra's combined method may lead to more women being detected. National data constantly reports more men being affected by leprosy than women. For instance, in the NLEP 2014/2015 report only 37% of the new cases in Bihar were female,[2] 40% in the NLEP progress report of 2015/16,[1] 43% in the Munger District report in 2016/17;[27] this trend is observed all over India. Compared to NLEP figures, with 47% of new cases recorded as female, the Lepra survey found 30% more female cases. In a country where 80% of women need to ask permission from their husband to visit their PHC,[24] relying on the self-reporting of people affected by leprosy is not sufficient. Home-based detection campaigns can offer a viable model in finding new female cases.

An alarming 37% of the new cases found were child cases compared with a national percentage of 9% and of 14·2% for Bihar [1] and 16·03% in Munger,[27] and most of them were detected through Special Searches. In Odisha, a similar pattern to the women health-seeking pattern was observed for children,[28] which the present study confirms. This is also in line with a study conducted by Damien Foundation[20] where 27% of child cases were found in tribal communities. Some parallels in the health-seeking behaviour of children and of their mothers could be drawn here, however more qualitative research is needed to explore this further.

High numbers of child cases are indicative of high leprosy transmission in communities. With most child cases being found through Special Searches, the disease transmission seems to be particularly high amongst disadvantaged indigenous communities. Out of the 321 new cases found by Lepra, 69% came from Scheduled Castes and Scheduled Tribes. This means

that these communities need to be given particular attention as they appear to be affected by leprosy more than other communities.

The low levels of MB cases, disability and complications found in the project mean that Lepra's approach may provide an efficient active detection method able to identify leprosy cases early and therefore to reduce the risks for people to contract disability later in life. Focal Surveys seem to have been more effective at finding cases early as MB type, disability, complication and reaction levels were particularly low amongst new cases found through them. With the long incubation period of leprosy, going back 5 years in the contact screening and extended contact identification is key.

The risk of acquiring leprosy for individuals living in households with multibacillary patients is 5–10 times higher, and with paucibacillary patients 2–3 times higher, than in people not living in such households.[29] Unrecognised cases and subclinical infections in contacts, nonetheless, contribute a significant proportion of all new leprosy cases.[28] The present research confirms previous findings that transmission goes beyond the household with 30% of cases being found through Focal Surveys conducted outside the household.[29]

During the recent 2015/16 Leprosy Case Detection Campaigns (LCDC) organised by NLEP in the Munger District, 102 new leprosy cases were detected through house-to-house surveys in eight Blocks (84% of the population, 833,692 people, were covered and 780 suspected of having leprosy were examined).[27] This means that Lepra's initiative found three times as many new cases of leprosy (303%) in the same area. With LCDC guidelines clearly stipulating that *"No house should be left unvisited"*,[26] these campaigns should capture all cases of leprosy in the community. However, cases are missed and there seems to be a difference in method efficiency. Where LCDC in Munger in 2015/16 found one new leprosy case per 10,000 of the population it screened in Munger, Lepra found 40 per 10,000. LCDC confirmed 102 new leprosy cases out of the 780 it suspected, for a rate of 13·1%, whereas in Lepra's project, 100% of the cases referred for diagnosis were confirmed with leprosy.

This can be explained by the fact that the level of diagnostic skills of staff conducting campaigns (one ASHA and one field worker in the case of LCDC) is key and has been found to be poor especially at local level.[10,21] Inconsistencies in the geographical coverage of house-to-house surveys and the timing of surveys are also questioned.[30] Importantly, most new MB leprosy cases come from three areas, covered by three PHC – Bariyarpur (19%), Dharhara (21%) and Kharagpur (12%); which suggests that issues are concentrated in these areas. This finding shows the need to geo-map cases to allocate resources where they are most needed. It has been suggested that a simple computerized information system should be developed by NLEP[22] the present study highlights that geographical data analysis is in fact essential.

Some trend analyses do not support a thesis of rapid progress in leprosy control,[3] although they are based on data (ANCDR and PR) provided by NLEP. The present study confirms that enhanced active case-finding is associated with higher case detection rates and that government efforts such as LCDC miss leprosy cases. Additionally, of all the new cases found in Lepra's study, 10% have not yet been provided with MDT and, since starting MDT is the trigger for a case to be registered in government data, this 10% will not be counted by NLEP for the moment. This has major implications for future policies. It means that government data present an under-estimate of the real leprosy burden in communities and that efficient active case detection campaigns are essential in sustaining and/or achieving complete 'Elimination'. The reasons behind this pitfall remain to be investigated. The present

study does not provide a thorough account of the differences between LCDC and Lepra's combined model designs, and this should be explored further.

Understanding why affected people do not come forward for treatment is also a crucial step towards effective leprosy 'Elimination'. Stigma is often pointed out as the main reason for people not reporting but the lack of knowledge about the disease in communities has also been mentioned.[31] The present results suggest that socio-demographic factors also strongly come into play. Reasons why women, children and people who belong to SC/ST require active methods to receive adequate treatment should be explored through qualitative research.

Replicating this combined model in other locations is also critical in confirming the present findings. Lepra aims to replicate the study in other areas and is initiating discussions with NLEP to take the learnings from this initiative forward.

Conclusion

The study found that many leprosy cases in affected communities remain undetected and that investing in active case detection campaigns is key to finding these hidden cases. This is particularly important for vulnerable groups such as women, children and scheduled castes and tribes. The high percentage of child cases found by the study indicates a high transmission of the disease and this is a special concern. On the other hand, the low levels of disability amongst the new cases show that the approach applied by Lepra was able to detect cases at an early stage. Understanding why government campaigns are currently challenged in finding all new cases is also a priority.

Acknowledgements

We would like to thank LEPRA Society teams in Bihar and Hyderabad for their constant drive for innovation and for developing and conducting the early stages of the project. We would also like to thank Professor Diana Lockwood for her valuable proofreading.

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