One year follow up of a cohort of suspected leprosy cases: findings from a Leprosy ‘Selective Special Drive’ in Gadchiroli District, Maharashtra, India

VANAJA P. SHETTY & SHUBHADA S. PANDYA
The Foundation for Medical Research, 84-A, R.G. Thadani Marg, Worli, Mumbai – 400 018, India

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Summary

Objectives: The study involves a follow-up visit in 2010, to hyper-endemic Gadchiroli district of Maharashtra, India, to evaluate the current status of those suspected in 2009 of having skin/nerve lesions suggestive of leprosy, and to study the interactions between such people and the State leprosy programme.

Design: The study cohort comprised of those confirmed with leprosy \((n = 151)\) and 157/233 absentee ‘suspects’ who were not examined by the study team in 2009 in 14 of 45 Primary Health Centres (PHCs). At follow-up, the treatment status of the confirmed cases was checked from PHC registers and cross-checked by direct questioning of patients and their views were sought on PHC leprosy services. The 157 absentee ‘suspects’ were queried about the reasons for their absence.

Results: Thirty nine ‘absentee suspects’ were found to have leprosy. A notable feature of the follow-up visit was that 114 people in the communities, other than those listed as ‘suspects’ by Community Health Workers (CHWs), voluntarily sought out the team for their opinion on hypopigmented/anaesthetic lesions, which resulted in a further 39 new cases being brought to light. (Total new cases \(= 78\)). The follow-up revealed discrepancies (100% vs. 75%) between PHC records and testimonies of the registered patients about regularity of treatment; irregularity of MDT supply was cited by some for dropping out of treatment. Other reasons proffered for irregularity were lepra reaction, fear of stigma, ignorance about leprosy and preference for faith healers. Medical Officers of PHCs were not trained in the management of lepra reactions; that task, along with disability care being entrusted to a paramedical worker of an NGO during periodic visits.

Conclusions: There are remediable lacunae in the recording and dispensing of MDT by the State apparatus, as well as a need for refresher training in leprosy diagnosis for PHC staff, and in lepra reaction management for medical officers. The large number (78) of new cases detected in the follow-up, in part of Gadchiroli district strongly suggests more to-be-discovered cases in the communities.
Introduction

In 2005 India officially declared ‘leprosy elimination’ – defined as a national Prevalence Rate (PR) < 1/10 000. However, it was known that there remained districts in some states where PRs were higher than that figure. In 2006 a ‘sustained activity plan’ was formulated to focus on the states with leprosy-endemic districts. On a request from the State Joint Director of Health Services (Leprosy and TB), Government of Maharashtra, a ‘Selective Special Drive’ (SSD) for leprosy was conducted by a team led by the Foundation for Medical Research (FMR) between March and May 2009 in selected villages covered by six Primary Health Centres (PHCs) in Karjat taluka of Raigad district, and 45 PHCs in Gadchiroli district. The findings have been reported. District Gadchiroli has a total population of 1.5 million and is highly prone to internal insurgency from time to time. A year later in March 2010 the team undertook a follow-up visit in some parts (14/45 PHCs) in Gadchiroli district to review the outcome of the 2009 SSD. The present study describes the follow-up visit to learn the realities on the ground and identify factors contributing to high PR and new case detection rate (NCDR). The aims of the 2010 follow-up were to ascertain the clinical status and whether people with symptoms and signs suggestive of leprosy “suspects” detected during SSD in 2009 had heeded advice to attend the PHCs; and the status of patients diagnosed during the 2009 ‘SSD’ and their treatment experience.

Material and Methods

A total of 1053 CHWs (126 in Karjat taluka of Raigad district and 927 in Gadchiroli district) were trained for one day about the signs and symptoms of leprosy. The CHWs then carried out a one-day house-to-house leprosy awareness drive in their areas, listed persons with suspicious lesions, and urged them to present themselves at the respective PHC on a designated day for confirmation of diagnosis. The strategy was devised to bring to light previously undetected cases. Unfortunately, in both regions of the State, >40% of the ‘suspects’ did not heed instructions and could not be examined by the team. In the 2010 follow-up visit it was decided to focus on selected 14 of the 45 PHCs in Gadchiroli district surveyed in 2009 (Table 1).

The present study cohort (Figure 1) comprises those who were listed as ‘suspects’ by the respective CHWs during the 2009 ‘SSD’ including those confirmed as leprosy, those kept under observation, as well as the absentees).

The PHCs were selected on the basis of high New Case Detection Rates (NCDR) in the 2009 SSD; a large proportion of those not attending for examination, and villages that were reasonably accessible.

At the follow-up the registers at the PHCs and sub-centres were scrutinized to verify the registration status and other details (start and completion of Multi Drug Therapy (MDT), Release from Treatment (RFT), occurrence of reactions, new deformity, drug toxicity, etc.) of those whom the team had confirmed the previous year. The team, guided by the local CHW, then went to the villages to visit the study cohort at their homes. The current status of lesion/s was ascertained, and enquiry made about treatment and any untoward events. Subjects were asked their views about the State Leprosy Services, and their account of treatment regularity was compared with the information gained from the PHC register. The ‘absentees’ of the
previous year were examined and reasons for their non-attendance at the PHC clinic were enquired into, as was any recourse to any private treatment.

Results

Figures 1 and 2 show that the team was able to examine 415/491 (85%) of the study cohort and leprosy was confirmed in 190/415 (46%).

CURRENT TREATMENT STATUS OF 151 CONFIRMED LEPROSY PATIENTS

Of the 151 new cases detected during the 2009 SSD, 138 were registered at the respective PHCs and placed on treatment; the remaining 13 (9%) were not registered. The reasons for non-registration were: five were considered as ‘not leprosy’ by another expert, five (mainly from the three PHCs of Sironcha Block) had left the village, and one was advised by PHC staff to shift to another PHC. In two the reason/s could not be ascertained. The Clinic registers showed good treatment compliance (defined as >90% regularity) in 130/138 (94%); but when the same patients were directly quizzed about treatment regularity, only 103 (75%) confirmed ‘good compliance’. There was an improvement in MDT availability in 2010 as compared to the situation in 2009. Sironcha PHC was an exception, with staff reporting irregular delivery of child MB and PB packets.

CHWs reported that by and large patients were reluctant to seek medical attention at the PHCs, even if they lived close to the centre. They said that in others it was seen that if for some reason the MDT packet was not delivered in time by the Health Worker, the treatment was not taken. The reasons advanced by the patients for dropping out or for taking the treatment irregularly were:

Table 1. Lists the study areas, the villages visited and the population examined in 2009

<table>
<thead>
<tr>
<th>Public health centre</th>
<th>No. villages visited/Total no. villages (%)</th>
<th>Population examined/Total population (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Amgao</td>
<td>14/49 (28%)</td>
<td>6293/30662 (20%)</td>
</tr>
<tr>
<td>2) Amirza</td>
<td>16/29 (55%)</td>
<td>15237/28976 (53%)</td>
</tr>
<tr>
<td>3) Ankisa</td>
<td>8/27 (30%)</td>
<td>11142/21290 (52%)</td>
</tr>
<tr>
<td>4) Bhakrondi</td>
<td>12/30 (40%)</td>
<td>5967/11259 (53%)</td>
</tr>
<tr>
<td>5) Delanwadi</td>
<td>9/14 (64%)</td>
<td>5748/9820 (58%)</td>
</tr>
<tr>
<td>6) Koregaon</td>
<td>10/17 (59%)</td>
<td>9036/22919 (39%)</td>
</tr>
<tr>
<td>7) Kunghada</td>
<td>11/42 (26%)</td>
<td>5973/26150 (23%)</td>
</tr>
<tr>
<td>8) Markhanda</td>
<td>11/16 (69%)</td>
<td>6984/19557 (36%)</td>
</tr>
<tr>
<td>9) Porla</td>
<td>29/46 (63%)</td>
<td>9742/45857 (21%)</td>
</tr>
<tr>
<td>10) Regedi</td>
<td>7/19 (37%)</td>
<td>7508/10738 (70%)</td>
</tr>
<tr>
<td>11) Sironcha</td>
<td>8/26 (31%)</td>
<td>7557/26541 (28%)</td>
</tr>
<tr>
<td>12) Tekadtala</td>
<td>12/20 (60%)</td>
<td>5664/10009 (56%)</td>
</tr>
<tr>
<td>13) Vairagad</td>
<td>8/24 (33%)</td>
<td>26379/41771 (63%)</td>
</tr>
<tr>
<td>14) Waddha</td>
<td>10/35 (28%)</td>
<td>9844/30694 (32%)</td>
</tr>
<tr>
<td>Total</td>
<td>165/394 (42%)</td>
<td>133074/336243 (39%)</td>
</tr>
</tbody>
</table>
(a) non-delivery of the MDT packet by the health worker \((n = 15)\)
(b) the hypopigmented lesion subsided or disappeared \((n = 8)\)
(c) development of lepra reaction after starting MDT \((n = 6)\)
(d) severe ‘drug reaction’ \((n = 5)\) [suspected by the private dermatologist to be due to dapsone].

The opportunity for home visits was utilised to locate and examine 29 such people. Seven had Grade 2 deformity; in two others lesions appeared erythematous. The patients were advised to re-attend the clinic for consideration of their restarting MDT. PHC staff, including

![Diagram](image-url)

**Figure 1.** Results of Selective Special Drive in 2009 in the 14/45 Primary Health Centers at Gadchiroli district.

![Diagram](image-url)

**Figure 2.** Results of Follow-up Visit in 2010 in 14 selected PHCs in Gadchiroli district.

<table>
<thead>
<tr>
<th>Community health workers’ ‘suspected cases’ unexamined by team in 2009 and re-instructed in 2010 to attend clinic 233</th>
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<tr>
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<tr>
<td>Leprosy confirmed 39/157* (PB = 29 MB = 10)</td>
</tr>
<tr>
<td>Note: 15 of 39 had in the interim 2009–2010 period heeded advice to attend PHC and were on treatment.</td>
</tr>
<tr>
<td>The remaining 24 of 39 (MB = 7, PB = 17) were detected by the team at the home visit; they had not heeded advice to attend the PHC.</td>
</tr>
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<td>Diagnosed non-leprosy 118 (75%)</td>
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medical officers, as a rule did not prescribe steroids. In the remaining 27 people, the skin lesions appeared inactive.

The treatment course in the majority (>80%) was uneventful, and they were satisfied with the outcome. As expected, in most patients with PB and all with MB leprosy, skin lesions remained visible a year later; in three PB patients with partial sensory loss, sensations had recovered. Six people with MB leprosy who developed lepra reaction after starting MDT were dissatisfied. Some sought private treatment.

The Medical Officers (MO) and Health Officers (HO) with whom the team interacted appeared to be unaware of WHO guidelines for the treatment of lepra reactions, and steroids were not dispensed by PHC staff. For example, an HO said that in instances of lepra reaction, MDT was stopped and the patient referred to the Leprosy Referral Centre (LRC). Three patients developed reaction/neuritis and Grade 2 deformity during the course of MDT. Four stopped taking MDT and consulted private practitioners and dermatologists.

**DIAGNOSTIC CHALLENGES**

Those presenting with dry, anesthetic skin lesions without hypopigmentation were liable to be labeled ‘not leprosy’ by PHC staff (15/39 = 38%). The team was able to demonstrate lesion-associated enlarged cutaneous nerves (n = 9) to the PHC staff. Eleven people with hypopigmented patches with partial loss of sensation were also ‘missed’ by PHC staff (11/39 = 28%), as were those with diffuse, ill defined lesions.

Of the nine cases who were classified during the 2009 SSD as ‘not suffering from leprosy’ (but kept under observation), two were found at the 2010 follow-up to have leprosy. The common causes of diagnostic difficulty were *Taenia versicolor* and birthmarks in children.

**CURRENT STATUS OF UNEXAMINED ‘SUSPECTS’**

Of the 233 ‘absentees’ suspects of the previous year, 157 (67%) were examined during the home visit in 2010. Thirty nine cases (27%) turned out to be cases of leprosy (Figure 2). On checking their registration and treatment status, fifteen among them were registered and were on treatment at the respective PHCs while the remaining 24 patients (62%) were not registered and had not received any anti leprosy treatment. Six cases (6/39 = 15%) were seen with Grade 1 or 2 deformity. The reasons commonly proffered for not seeking treatment were absence of pain or discomfort in the skin lesions (~40%), ignorance about the disease (~35%), and apprehension of social stigma (~25%). A few had patronised faith-healers.

**OTHER OBSERVATIONS**

During village visits as many as 114 people (other than those listed by CHWs) with hypopigmented skin lesions or anesthetic areas sought the team’s advice, resulting in 39 additional new leprosy cases (39/114 = 34%) being recognised. For example, in the villages served by Amgaon PHC, 14 (MB = 6, PB = 8) cases were detected, one being a 15 year-old boy with florid nodular lepromatous leprosy who lived barely one kilometer from a sub-centre.

In one family, the husband was registered at the PHC and taking treatment for MB leprosy. Meanwhile the wife developed lesions suggestive of PB leprosy which was not reported
to the PHC. The husband shared his tablets with her and three packets of his MDT were consumed by her. On enquiry by the team, she replied that this was done on the advice of the Auxiliary Nurse Midwife (ANM). The team encountered two other patients who were taking MDT but were not registered with the PHC. The patients’ explanation was that ‘Babusaheb’ viz., a Multipurpose Worker (MPW) would give them the MDT packets at their home.

A local dermatologist interviewed claimed that leprosy cases were ‘increasing in number all over Gadchiroli’, with each of the six or seven dermatologists who practice in Gadchiroli town seeing about ‘70–100 new cases’ every year. Corroborating the team’s observations, he added that inadequate and timely supply of MDT was a reason for patients to seek treatment privately (although private treatment was not free). Another was lack of expertise at PHCs for management of lepra reaction. He denied that stigma was a major issue any more. When the team enquired how early in the disease patients sought private treatment, he answered that most came only when they developed some complications such as reaction, nerve pain, fever or joint pains. Depigmented lesions (vitiligo), on the exposed part of the body also frequently led people to seek private treatment.

**Discussion**

The most significant finding of the follow up study reported here was the validation of the methodology. A day of training and information imparted to Community Health Workers (CHWs) enhanced their diagnostic skills and alertness about leprosy, and stimulated them to urge people with possible leprosy residing in their community to seek examination and treatment at the PHC. The method was extremely cost effective (3-day programme held in each PHC, all inclusive Rs \( \sim 30000/\text{PHC} \)). Unfortunately not all ‘suspicous’ cases listed by them heeded advice to attend the PHC Clinic for confirmation of the diagnosis.

The team’s 2010 follow-up visits to clinics and villages by increasing coverage of the population, identified 39 additional cases. Using these statistics the new case detection rate was 15 to 20 per 10 000 in the study population. It is not unreasonable to suspect that significant numbers of yet unknown people with leprosy exist in the communities.

Almost 25% of those detected in the SSD of 2009 and ‘Released from Treatment’ during the study period after the full course of MDT, were found to have Grade 2 deformity. Delayed diagnosis and poor management of reaction/neuritis were contributing factors. There is a need to counsel patients and children’s guardians on the possibility of reactions manifesting during the course of treatment.

WHO recommended standard treatment for reaction i.e. corticosteroids were not available at any of the PHCs visited; neither were the MOs trained in their appropriate use. Steroids were administered only by the paramedical worker of the Non-Government Organisation run LRC who visited once a week and also attended to POD activities (plantar ulcers and provided footwear). This deficiency requires the attention of the State’s leprosy officials. The diagnostic skills of PHC staff including medical officers requires to be upgraded in order that undoubted cases of leprosy are not kept ‘under observation’ or dismissed as ‘not leprosy.’ A significant number of those in whom leprosy was confirmed in 2009 said they dropped out due to reaction. In some PHCs irregular drug supply also contributed to delay and drop-outs.
CHWs reported that patients were reluctant to seek medical attention at the PHCs, even if they lived close to the centre, possibly not appreciating the significance of the lesion/s. On direct questioning the reasons commonly proffered by the patients were absence of pain or discomfort in the skin lesions (40%), ignorance about the disease (35%), and apprehension of social stigma (25%). A few had patronised faith-healers. In others the team noted that if for some reason the MDT packet was not delivered to the patient in time by the health worker, the treatment was not taken. This study did not address the question of social stigma.

Acknowledgements

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