Perceptions, health seeking behaviour and access to diagnosis and treatment initiation among previously undetected leprosy cases in rural Maharashtra, India

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Summary
Objectives: To study sociodemographic profiles, perceptions about leprosy and health seeking patterns among adult leprosy patients and parents of children with leprosy detected through a prevalence survey conducted earlier, in rural areas of Panvel tehsil in Maharashtra.
Methods: The study was cross-sectional and used mixed (qualitative and quantitative) methods. Of the 97 confirmed rural leprosy cases who had been detected through the initial prevalence survey, 58 newly detected adult leprosy cases and parents of 22 children detected with leprosy were interviewed with a semi-structured interview schedule between May 2008 and March 2009.
Findings: The study revealed that most of the leprosy patients belonged to the poor socioeconomic strata. Nearly 58% of the adult patients reported that they had been detected through the survey within 3 months of noticing their symptom(s) for the first time. Despite having been diagnosed and receiving treatment, only 48% of adult cases knew their condition as leprosy, reflecting their poor knowledge of the disease and lack of communication between providers and patients. The symptom ‘patch on the skin’ seems to have percolated in the community. Despite approaching the private or public sector for help in the first instance, many patients and children remained undiagnosed and untreated for leprosy.
Conclusion: Active surveys for leprosy case detection should substitute the self-reporting approach until IEC measures are sufficiently effective to achieve a
significant impact on transmission. Nevertheless both approaches will need the presence of staff with active diagnostic skills and optimal drug availability at PHCs.

Introduction

The National Leprosy Control Programme (1955) in India was re-launched in 1983 as the National Leprosy Eradication Programme (NLEP) and its integration into the general health services in India was initiated in 2001.\textsuperscript{1} According to the WHO report in 2006, India accounted for 56\% of leprosy cases occurring globally; nevertheless with the massive efforts by the Government of India, the annual case detection dropped substantially between 2001 and 2005, which reduced the prevalence of leprosy by 80\%.\textsuperscript{2} Of concern, however, was the sharp and precipitous drop in the prevalence rate alongside the cessation of active surveillance for detection of leprosy cases. With an incubation period of 2–10 years and 5\% of the general population being nasal carriers of \textit{Mycobacterium leprae} in leprosy endemic countries, it is difficult to halt the transmission of leprosy.\textsuperscript{3,4}

Taking cognizance of this fact, the Foundation for Medical Research in Mumbai carried out an investigation into the magnitude of the leprosy problem in an urban and a rural setting of Maharashtra State between June and November 2007 by undertaking a total population survey aimed at detecting the undetected active cases and determining the actual prevalence of leprosy in the community.\textsuperscript{5} A major finding from this survey was that the prevalence rate was much higher (6·72 per 10 000) than the reported rate 0·83 per 10 000 for India as on August 2007.\textsuperscript{6} It further revealed that a significant number of adults and children with leprosy, especially in rural areas, remained undetected in the community. Moreover, 48\% provisionally diagnosed cases of leprosy in rural areas were multi-bacillary (MB) and 18\% patients had deformity of either Grade 1 or Grade 2. The high proportion of multi-bacillary and Grade 2 deformity cases are pointers to extended delays in diagnosis, whereas a large number of children with leprosy indicate the high degree of its active transmission in the population surveyed.

These findings underscored the need to inquire why so many patients remained undetected in the community and what could be the possible reasons for delay in the diagnosis of leprosy among these patients.

With this background, the present situational analysis was undertaken in the rural site of this prevalence survey with the following objectives:

1. To study the socio-demographic profile of patients who were detected through the survey and its relation with help seeking
2. To study these patients’ perceptions about leprosy
3. To explore patterns of health seeking among these patients

Material and Methods

The study was approved by the Institutional Ethics Committee (IEC) of the Foundation for Medical Research (FMR), Mumbai.
SETTING

The survey of leprosy cases was conducted in the rural areas of Panvel, a sub-district of Raigad district in Western Maharashtra, which has a population of 1,96,694. This area is catered to by five primary health centres (PHCs). The situational analysis was conducted between May 2008 and March 2009. Patients detected through the prevalence survey constituted the sample for this study.

SAMPLE SELECTION

Of the 97 confirmed rural leprosy cases detected through the survey, 58 newly detected adult leprosy cases and one of the parents of 22 children detected with leprosy, whom we were able to contact and interview, formed the sample for this study. A written consent in the local language was obtained from each adult patient and the parents of the children who participated in the study.

RESEARCH TOOL

Qualitative research methods were used since the focus of the study was to get insights from leprosy patients (detected through the survey), the reasons for their remaining undetected, patterns of health seeking etc. Patients were interviewed using a semi-structured interview schedule, which inquired into areas such as socio-demographic profile, clinical history, illness experience, (patterns of distress - physical problems, social and psychological problems including stigma associated with leprosy), perceived causes, help seeking behaviour (patterns of help seeking) and barriers, if any in accessing health services.

ANALYSIS

Quantitative data were analysed using SPSS version 16.0 and were presented in the form of frequency tables. Qualitative data were analysed using data management software MAXQDA (VERBI GmbH), which facilitated a thematic analysis of the narratives of respondents. Using SAS, Cronbach’s alpha was calculated to check the internal consistency of the stigma items for including them into the stigma index. Generally, a value of Cronbach’s alpha > 0.7 is considered as reasonable consistency of items.

Results

SAMPLE CHARACTERISTICS

Characteristics of the sampled adult leprosy cases are presented in Table 1.

A little less than one-third (31%) of the cases belonged to the group likely to have lesser social support (unmarried, divorced and widowed). Significantly more women than men belonged to this group (47% vs 21%; \( P = 0.04 \)).

Nearly 75% were non-tribal and the rest were tribal patients. Half of the patients were illiterate and had annual household income less than INR 30,000 indicating they were absolutely at the Bottom of Pyramid (BoP).
Among children included in the investigation, there were 17 male and five female children. They were in the age range of 5–14 years (mean age 10·1 years). There were eight tribal and 14 non-tribal children. There were 13 paucibacillary cases (PB) and nine multibacillary (MB) cases. Parents of tribal children were mainly involved in hunting-gathering activities \( (n = 2) \), fishing \( (n = 2) \) and manual labour \( (n = 4) \), whereas those of non-tribal children were involved in some trade \( (n = 4) \) (grocery shop, milk selling etc.) or services such as security guard \( (n = 2) \), farm manager \( (n = 2) \), while others were involved in construction or other type of manual labour \( (n = 6) \). Half of these families \( (n = 11 \text{ of } 22) \) were residing in small houses (area < 150 sq. ft), with an average annual income just below the poverty line. Many of the parents \( (n = 14) \) were illiterate, and others had some primary school education, indicating that these children belonged to the lower socio-economic strata.

**IDENTIFICATION OF ILLNESS**

When asked what they were suffering from, only 48% patients correctly knew their disease as ‘Kustharog’ (leprosy in Marathi, the local language), despite having been diagnosed and given treatment. Significantly more men than women knew about their condition (60% vs 28%; \( P = 0.02 \)). About 34% patients did not know what their condition was and the rest referred to it as ‘Shinda/shilda’, a kind of patch, which was a common condition experienced by the community.

The parents of only four children \( (18\%) \) could mention the condition as ‘Kustharog’. Others referred to it as ‘shinda/shilda’ similar to adult patients, and they had no further information about it.

Table 1. Characteristics of sampled adult cases

<table>
<thead>
<tr>
<th>Parameters</th>
<th>Categories</th>
<th>( n = 58 )</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>( n )</td>
</tr>
<tr>
<td>Age group</td>
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<td>14</td>
</tr>
<tr>
<td></td>
<td>25–34 years</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>35–44 years</td>
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</tr>
<tr>
<td></td>
<td>45–54 years</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>55 + years</td>
<td>9</td>
</tr>
<tr>
<td>Sex</td>
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</tr>
<tr>
<td></td>
<td>Female</td>
<td>21</td>
</tr>
<tr>
<td>Marital status</td>
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</tr>
<tr>
<td></td>
<td>Married</td>
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</tr>
<tr>
<td></td>
<td>Separated</td>
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<tr>
<td></td>
<td>Widow/er</td>
<td>5</td>
</tr>
<tr>
<td>Education</td>
<td>Illiterate</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td>Primary (1–4th standard)</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Secondary (5–7th standard)</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>High school (1–4th standard)</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>Higher secondary (11th and 12th standard)</td>
<td>4</td>
</tr>
<tr>
<td>Occupation</td>
<td>Unemployed</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Student</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Housewife</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Unskilled labor</td>
<td>21</td>
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<tr>
<td></td>
<td>Farmer</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Trade</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Other professionals</td>
<td>4</td>
</tr>
</tbody>
</table>
PERCEIVED CAUSES OF ILLNESS

Three-quarters of the patients (75%) did not know the cause of their illness. Others attributed it to contact with a leprosy patient (7%), insect bite (3%), bacteria or viruses (12%) and alcoholism (3%).

“I think it happened because of “fursa” (an insect which lives in the grass) bite while cutting the grass in the farm.”
(20 year old girl)

“I think it could be because of alcohol consumption. I was drinking too much.”
(60 year old male)

In the case of children, 18 parents could not mention the cause of the disease. Others linked it with heredity, vitamin deficiency, sharing of utensils and seasonal variation.

“We feel that his (the child’s) grandmother had similar illness, which might have been transmitted to him.”
(Father of a 10 year old boy)

“He had had a similar problem (leprosy) and he (the child) used to eat food in the grandfather’s plate. Perhaps that’s why he also suffered from this problem.”
(Mother of a 9 year old boy)

NOTICE OF SYMPTOMS

When questioned about their awareness regarding symptoms, nine adult patients (15%) mentioned that they did not notice the patch, being in an area which was not easily visible (e.g. on the back).

“My mouth and ears turned red in the initial stage. Also patches developed on my face. These were the initial symptoms. After that patches started growing in size and became dark.”
(45 year old male)

“I could not see the patch because it was on my back.”
(40 year old male)

“There was a patch on my left hand in May 2007. I did not pay attention because there was no problem because of that patch. Then it became large and I started getting a tingling sensation.”
(25 year old female)

DURATION BETWEEN NOTICING SYMPTOM(S) AND DETECTION THROUGH SURVEY

More than half (58%) of the adult patients reported that they had been detected through the survey within 3 months of noticing their symptom(s) for the first time. Strikingly, a delay of more than one year was observed in case of 14 out of 58 (24%) of the patients (Table 2).
Among child cases, the duration between the parent noticing the symptom(s) for the first time and detection through the survey was less than 6 months for five cases whereas for half of the children (n = 11), it was between 6 months and 1 year; and more than 1 year in six cases. Parents attributed such a long duration to three major reasons viz. innocuous patch(es) with no other symptoms, a belief in self-healing and use of palliative treatment. While many parents (n = 15) had ignored the condition, some mentioned that they used palliatives. There was no difference noted for delay in diagnosis for boys and girls.

“When we noticed patches on his hand, we used ‘mina khoki powder’ (a kind of talcum powder), because of that the patches were looking dark and prominent. Then we stopped using that. After that, we started using ‘fair and lovely’ cream’ (a commercially available cosmetic product).”

(Mother of 5 year old boy, tribal)

HELP SEEKING

When asked about help seeking in adult patients, nine patients (15%) mentioned that they did not seek help because the patch remained unnoticed. The remaining 15 (26%) who had noticed their symptom(s) but did not seek help quoted reasons like: (a) no experience of physical discomfort (n = 13) and (b) attribution of symptom(s) to deviant beliefs such as a wrong way of sleeping (n = 2).

“I did not go to any other hospital because I did not know that I had a patch on my back. The health worker came for the survey and at that time she noticed my patch the first time.”

(28 year old female)

“There was a patch on my right hand three years ago, I did not pay attention to it. Then after a few days it started aching. But I thought it could be because of wrong way of sleeping.”

(27 year old male; Figure 1)

Fifty nine percent of patients had sought help from different sources such as traditional healers (n = 6), PHCs (n = 4), private clinics/hospitals (n = 18) and clinics run by NGOs (n = 6) prior to the diagnosis of leprosy through the survey for reasons such as prior positive experience with the doctor, closer availability and advice by friends/relatives.

<table>
<thead>
<tr>
<th>Symptom(s)</th>
<th>0–3 mths (n = 34)</th>
<th>4–7 mths (n = 9)</th>
<th>8–11 mths (n = 1)</th>
<th>&gt;1 year (n = 14)</th>
<th>Total (n = 58)</th>
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<tr>
<td>Patch on the skin</td>
<td>24</td>
<td>8</td>
<td>0</td>
<td>8</td>
<td>40</td>
</tr>
<tr>
<td>Tingling</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Numbness</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Deformity in hands/feet</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Redness of skin/lepra reaction</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>6</td>
</tr>
</tbody>
</table>

Table 2. Duration between noticing symptom/s and detection through survey
A visible patch on the extremities was reported as the key symptom, which motivated help seeking in more than half the patients (Table 3).

“When I saw patches on my right hand, I immediately went to a private doctor and showed him the patches. He examined my patches and gave me a cream to apply. I applied it. We visited there four times. But there was no effect from his treatment. Then he advised me to take treatment from NGO1. So I went there. There I took medicines for one-month. But it was far away.”

(19 year old female)

“A small patch developed on my back in March 2007. My friend noticed it for the first time. After a few days I experienced itching at that place. So I showed it to Dr. X. He gave me a cream to use on that patch and prescribed medicines, for which I spent Rs.350/-. He charged Rs. 50/- as fees. I visited the doctor twice. There was no effect due to this treatment. Then I went to the municipality hospital at Panvel. The doctor there observed my patch and advised me to go to the FMR\textsuperscript{1} Clinic. During the same period one health worker came to our home. I showed him that patch.”

(38 year old male)

About half of those patients (18/34) who made contact first in the private sector did not continue the treatment there for reasons such as no visible effect of treatment (n = 5), high cost (n = 10) and distant location of the private clinics (n = 3).

For the four patients who had approached PHCs before being picked up by the survey, the reported reasons for remaining untreated were: a) non-availability of drugs (n = 2) and b) the condition not being diagnosed as leprosy (n = 2).

“We first went to the PHC. There the doctor examined my patch and said that the treatment is not available here.”

(20 year old girl)

“I showed my patch at the PHC. The doctor examined my patch and told me ‘This is not a leprosy patch. You should do a detailed check-up at the FMR Clinic’.”

(45 year old male)

\textsuperscript{1}FMR runs a clinic for diagnosis and treatment for leprosy in Panvel city
Six patients, all of them males, had approached traditional healers as the first source of help seeking. Two of them narrated their experiences, which indicated that traditional beliefs still prevail in the community, and the decision to approach a traditional healer was influenced by neighbours/friends. The process of shopping around at different healers had eventually delayed the diagnosis and initiation of treatment for leprosy among these patients.

“In December 2006, my body started itching. I told my neighbor (about the problem). My neighbor advised me to use the leaf of “Bershingi” plant. He asked me to boil leaves of ‘bershingi’ plant in water and inhale the vapor of that boiled water. I did that twice but there was no effect, hence I went to a faith healer at X village. He gives magic water. He sprinkled water on my body twice within two weeks. But I did not believe him because there was no effect from his practice. Then I went to another healer at Y place. He did the same procedure of sprinkling magic water twice within two weeks. Then my nephew sent me to Dr. X (private doctor). I went there once and took treatment for one month. It was very expensive. He charged Rs 100/- for consultation and Rs 350/- for medicines. We thought that it is very expensive so we stopped his treatment. Once the health worker came to our home (for the purpose of leprosy survey) and asked about patches. That time I showed him my patch.”

(60 year old male)

“Initially I showed the patch to the Bhagat (faith healer) at X village. He observed my patch and asked me how it happened. He chanted “mantras” and said it could be because of killing of a snake. He charged Rs.200/- I did not believe him so I showed it to the health worker during the survey.”

(23 year old male)

The narratives of some patients who approached NGO clinics revealed that they approached these clinics due to reasons such as their prior experience for general conditions, availability close to their homes, or someone else’s experience of receiving treatment for leprosy. However, they could not get diagnosis/treatment for leprosy due to reasons such as non availability of medicines, absence of the doctor.

“When I saw a patch on my right hand, initially I ignored it for about a month. But it was still there. Hence I went to NGO1 and that was sometime in May 2007. We go to NGO1

<table>
<thead>
<tr>
<th>Symptom(s)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patch on the skin</td>
<td>20</td>
<td>58.8</td>
</tr>
<tr>
<td>Numbness</td>
<td>5</td>
<td>14.7</td>
</tr>
<tr>
<td>Redness of skin (Lepra reaction)</td>
<td>4</td>
<td>11.8</td>
</tr>
<tr>
<td>Tingling</td>
<td>3</td>
<td>8.8</td>
</tr>
<tr>
<td>Injury/ulcer</td>
<td>2</td>
<td>5.9</td>
</tr>
</tbody>
</table>

Table 3. Symptom(s) that motivated help seeking
for general treatment. It is very near to my house. I can walk to their clinic. However, treatment was not available there; hence the doctor told me to go the FMR clinic.”
(25 year old female)

“I went to NGO2 for treatment. My aunt (father’s sister) was admitted there for treatment, so I knew about it. Since the doctor was not available, the health worker gave me the address of the municipal hospital and advised me to take treatment from there. My face was swollen so I showed it to the private practitioner in our village. He gave me injection and some medicines. He charged me Rs 100/-. There was no effect of treatment so I went to the municipal hospital.”
(33 year old male)

In the case of children it was noted that parents of girls were more likely to seek care from multiple facilities (5 of 5) as compared to parents of boys (6 of 17). Often in case of a female child, the parents expressed their concerns about arranging her marriage and this probably prompted them to seek early help for her illness. It was also observed that parents involved in unskilled labour work were less likely to seek help early.

The following narratives suggest a lack of faith and information on the availability of treatment for leprosy in the PHCs, and long waiting periods were some of the reasons for them not opting for treatment at PHCs.

“We don’t know whether they (PHCs) give treatment for leprosy and government clinics are generally crowded.”
(Father of a 13 year old girl)

“We don’t get proper treatment for leprosy in the public clinics.”
(Father of 9 year old girl)

“At the PHC, the doctor comes from outside. So they do not give treatment regularly.”
(Mother of a 10 year old boy)

STIGMA

Stigma has traditionally been associated with leprosy and has been reported as a barrier in accessing health services.9,10 We made an attempt to assess this. For this purpose, eight interview questions, indicating stigma for leprosy were formulated to inquire about the social response towards the leprosy patient and his/her family (Table 4).

More than two-thirds (67%) of patients mentioned that they had not disclosed their condition to the community, suggesting an anticipation of stigma. However, the majority of patients (86%) mentioned that they had disclosed their condition to their family, and many (64%) acknowledged support from their spouse. Forty percent of patients mentioned that they had less self respect due to the condition. Only one patient reported his painful experience. Due to the variation in responses and a lower value of Cronbach’s alpha (0.37), we could not construct a stigma index.
The majority of the parents of children with leprosy (n = 18) denied the existence of stigma; others mentioned about feeling ashamed of the disease. Some expressed concerns about problems that would arise in arranging marriage, especially for a girl.

“She thinks - ‘Why did this problem occur to me?’ We have a fear that a problem may arise in her marriage.”

(Father of 12 year old girl)

“We did not tell anyone about the illness because we are scared. If people know about it they will not behave well and remove us from the village.”

(Mother of 5 year old boy)

While most of the respondents denied the experience of stigma in the community, one respondent narrated an experience of her male child.

“People don’t send their children to play with him. They don’t let their children eat what he gives. People talk about his illness. People feel that their children may get it (the disease).”

(Mother of a 10 year old boy)

However, many parents also acknowledged the support from school teachers.

### Table 4. Stigma indicators for adult cases

<table>
<thead>
<tr>
<th>Stigma indicators</th>
<th>Yes</th>
<th>No</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>Hiding the disease from the community</td>
<td>39</td>
<td>67.2</td>
<td>19</td>
</tr>
<tr>
<td>Hiding the disease from the family</td>
<td>7</td>
<td>12.1</td>
<td>50</td>
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<tr>
<td>Less self-respect</td>
<td>23</td>
<td>39.6</td>
<td>35</td>
</tr>
<tr>
<td>Fear of spreading the disease to others</td>
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<td>13.8</td>
<td>50</td>
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<tr>
<td>Problems in fixing marriage</td>
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<td>1.7</td>
<td>7</td>
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<tr>
<td>Lack of spousal support</td>
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<td>5.2</td>
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<tr>
<td>Family fears getting the disease from the patient</td>
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<td>3.4</td>
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<td>Distressing reactions from others</td>
<td>1</td>
<td>1.7</td>
<td>57</td>
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</table>

The role of the PHC has thus become crucial in leprosy case detection and treatment subsequent to the dismantling of the vertical programme and its integration into the general health services. Despite this approach, the prevalence survey indicated much higher prevalence figures as compared to those reported by the government along with a worrisome number of pediatric cases that remained undetected in this study area. While exploring reasons for patients remaining undetected for leprosy, the present study findings reiterate some basic issues.
First, lack of physical discomfort despite their illness condition apparently (as a basic human nature) resulted in delay in self-reporting and diagnosis for a significant number of patients. The second most common reason for remaining undetected was patches on parts of the body not easily visible to patients, and failure to associate leprosy with early neurological symptoms such as tingling and numbness. Additionally some patients were influenced by beliefs such as heredity having a role in transmission of disease. These factors are consistent with findings from studies conducted in Bangladesh and West Bengal.\textsuperscript{12}

One of the paradoxes, however, was despite being interviewed after starting treatment for leprosy, many patients as well as parents of children with leprosy could neither mention the cause of their illness nor their condition as \textit{kushtharog} (leprosy), indicating continued poor knowledge about leprosy in the community. It also suggests poor communication between the health care providers in public and private (including NGO) sectors and patients, which has been unable to reach patients and their families belonging to the poor socioeconomic strata.

Although the Government of India’s strategy is to conduct high profile IEC activities using media such as TV, radio, posters, IEC pamphlets, film shows and folk dances,\textsuperscript{11} it does not seem to have had much impact in the study area, an observation similar to that reported in a study in Uttar Pradesh.\textsuperscript{13} Nevertheless, the symptom of a ‘patch on the skin’ seems to have percolated in the community, since a majority of the patients and parents of children with leprosy reported it as a symptom that motivated them to seek help from formal health care providers. It is, therefore, necessary that IEC activities should now place emphasis on other symptoms as well, along with a focus on hidden patches. Since there is a perception of disease transmissibility in the community, IEC should also convey instructions on importance of early diagnosis and appropriate treatment to reduce disease transmission. This study reports that more than half of the patients were diagnosed within 3 months of the survey; this finding indicates the importance and need for continuing active surveillance to detect and treat leprosy cases without delay until effective IEC campaigns are implemented and the messages percolate in the community.

Since only a few patients reported that they approached a PHC/government health facility as the first point of help seeking, this study strongly suggests the need for a detailed inquiry into two areas - first, the awareness in the community regarding availability of free treatment for leprosy in the government health facility and second, whether patients have any faith in the public sector. Despite approaching PHCs, four patients did not get diagnosis and treatment. In this context, it is important to understand the constraints and barriers in the general health services to provide leprosy care. ‘Observations from a selective drive’ conducted recently by FMR in Karjat tehsil and Gadchiroli district indicate reasons such as non availability of or inadequate skills to diagnose and treat leprosy among the PHC health staff; non availability or irregular supply of drugs and lack of faith in the public sector are some of the deterrents.\textsuperscript{14} A similar finding such as inadequate skills to diagnose and treat leprosy among dermatologists was reported in a study in China.\textsuperscript{15}

One third of the study patients had approached the private sector as the first source of help seeking for the reasons such as prior positive experience with the doctor, closer availability and advice by friends/relatives. This care seeking behaviour by patients may hint towards problems in the public sector to tackle the disease as well as increasing dependence of the community on the for-profit unregulated private sector. However, as solely reported by patients, they were unable to get a diagnosis and/or complete the full course of treatment for reasons such as ineffective treatment and/or the high cost of treatment, there might be a ‘reporting bias’ introduced to some extent in this study.
The help seeking behaviour of patients in this study has some similarity with that of tuberculosis (TB) and its management by the private sector, which led to the initiation of the public–private mix (PPM) in TB control.\textsuperscript{16} Involvement of private practitioners in leprosy control may be required, by emulating the lessons from or joining forces with PPM-TB.

Since the majority of patients acknowledged family and spousal support, the communication of leprosy diagnosis to the patient and the parent of a child with leprosy should be made possible through the involvement of family members and school teachers respectively. This would also be useful in ensuring treatment adherence and help in reducing ‘anticipated stigma’ for leprosy among patients.

The study suggests that active surveys for leprosy case detection should substitute the self-reporting approach until IEC measures are sufficiently effective to achieve a significant impact on transmission. Nevertheless both approaches will need the presence of staff with proper diagnostic skills and optimal drug availability at PHCs.

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References

3 Klatser PR, vanBeers S, Madjid B et al. Detection of \textit{Mycobacterium leprae} nasal carriers in populations for which leprosy is endemic. \textit{J Clinic Micro}, 1993; 31: 17–51.
5 Shetty VP, Thakar UH, D’Souza E et al. Detection of previously undetected leprosy cases in a defined rural and urban area of Maharashtra, Western India. \textit{Lepr Rev}, 2009; 80: 22–33.

