



Field Survey Using Schedule Method

Forty-five leprosy patients and 36 panchayat representatives were interviewed with the assistance of separate semi-structured, open-ended questionnaires for both groups. The patient questionnaire was divided into three sections. The first section deals with general information on the patient; their family status, understanding of leprosy and their relationship with their family/community. The second section gauges the LAP's understanding of the disease and treatments. The last section includes questions to both understand the patient's psychology and suggest how the treatment system can be improved.

The questionnaire for the panchayat representatives has been framed to ascertain their views on leprosy, LAPs, and knowledge of government efforts to treat and eradicate the disease.

4.1 Patient's Survey

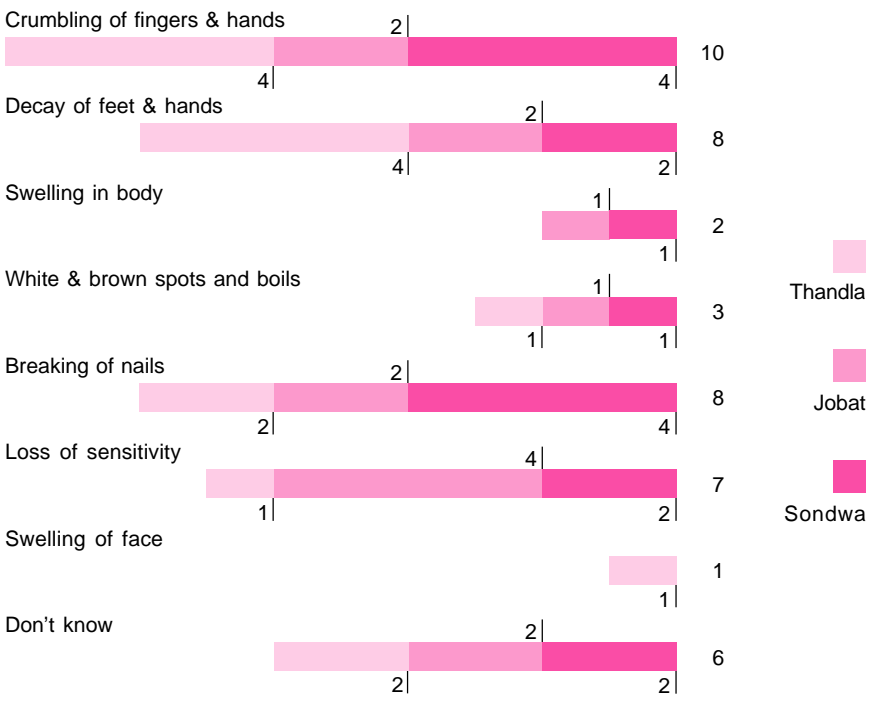
In Jhabua, the study area, there is a prevalence of skin diseases, mainly from the

unclean water and the unhygienic habits of the people. The tribal inhabitants of Jhabua have developed their own set of local indicators to pin-point the severity of a disease.

Symptoms of leprosy

Only one fifth of the 45 respondents interviewed were able to correctly identify numbness or a patch on the skin as early symptoms of leprosy. The majority was able to identify leprosy only when severe nerve damage had led to deformities and disabilities.

Figure 4.1.1- Awareness Regarding Leprosy Symptoms



Only 45 respondents were interviewed.

Why and how does leprosy start?

No one was able to give a correct answer. Their explanations were either half-truths or myths.



Figure 4.1.2–LAPs' Perception of Cause of Disease



Only 36 patients were asked this question.

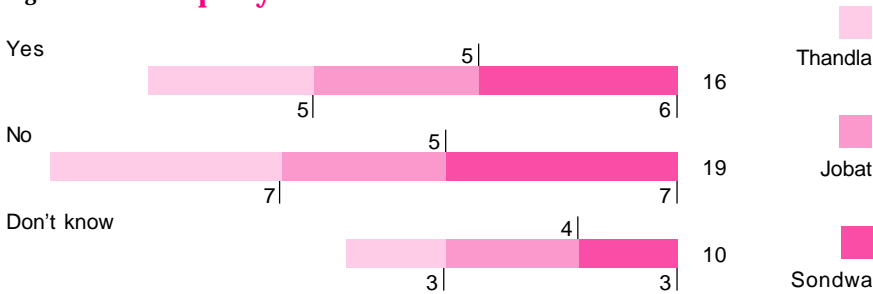
The LAPs were asked what other people thought were the cause of their disease. Forty percent were unable to answer; 29 percent said people feared the LAP could spread the disease by breathing or touching them, 26 percent thought it was a hereditary disease while 4 percent believed the LAP was being punished for past sins.

Leprosy: Is it curable?

This question seeks to understand the health seeking behaviour of the LAPs. The majority of respondents (42 percent) said there was no cure, 36 percent believed it could be treated, while the remaining 22 percent had no opinion.



Figure 4.1.3–Is Leprosy Curable?

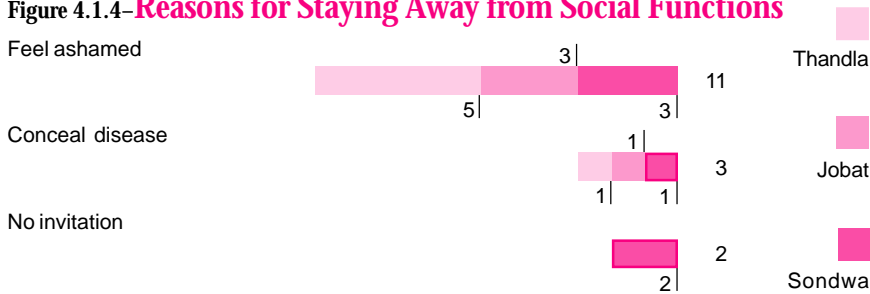


Only 45 patients were asked this question.

Social behaviour of disabled LAPs

Physically disabled patients, who have had to have fingers or toes and limbs amputated because of gangrene or the result of accidents because the person cannot feel pain, were questioned about their social life. Only two of the 16 admitted to being ostracised by the village.. Eleven of the 16 respondents said they never ventured out for fear of harassment, they were ashamed of their condition. Three said they had concealed their condition.

Figure 4.1.4–Reasons for Staying Away from Social Functions

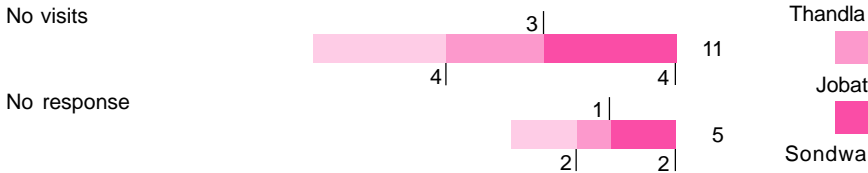


*Only the 16 disabled patients were asked this question

Visits of relatives

Of the 16 respondents with disabilities, the majority admitted to a definite drop in visits by relatives as soon as they got to know. Five respondents chose to remain silent on the issue.

Figure 4.1.5–Social Interaction (Relatives)

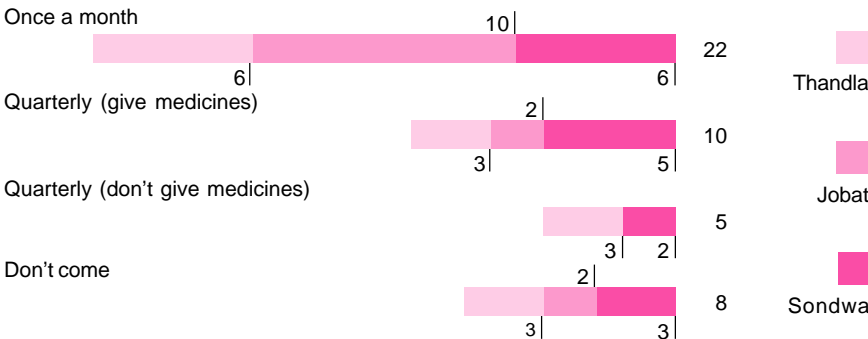


Only 16 respondents with disabilities were asked this question.

Village visits by Health Department staff for leprosy

Fifty percent of the respondents said health workers visited once a month. Twenty three percent said the government employees visit once in three months, while 11 percent reported quarterly visits. Some 8 respondents said no one from the government’s Health Department had ever been to their village.

Figure 4.1.6–Periodicity of Visit of Leprosy Staff

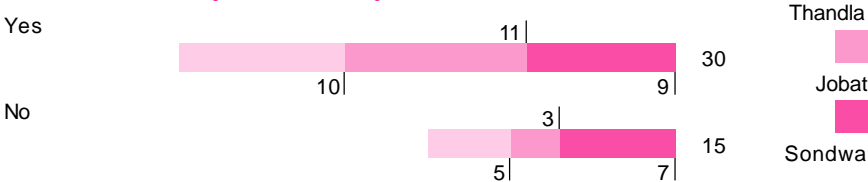


Only 45 respondents were asked this question.

Timely availability of medicines

A third of the respondents, most of them from Sondwa, said they were not getting medicines regularly. Thirty of the 45 respondents were satisfied.

Figure 4.1.7–Timely Availability of Medicines

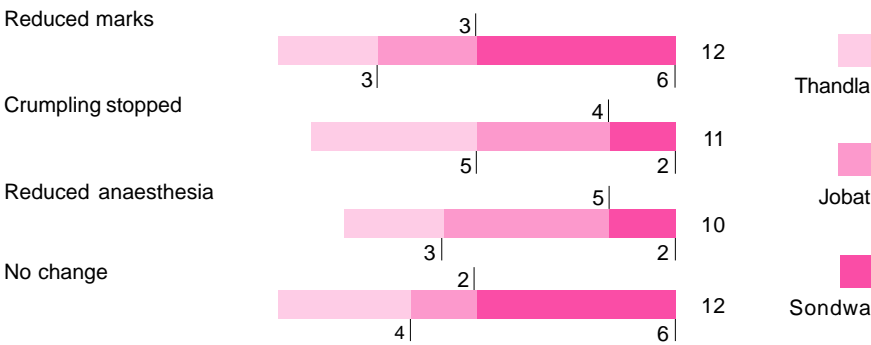


Only 45 respondents were asked this question.

Effect of medicines

Thirty-three respondents (73 percent) reported improvement. Eleven (24 percent) said the decaying of fingers and toes had stopped, while ten respondents said the numbness was improving and the red marks (lesions) and patches (lighter pigmentation) had started disappearing. Still 26 percent of the respondents (among them defaulters) said the medicines were not effective.

Figure 4.1.8–Effect of MDT

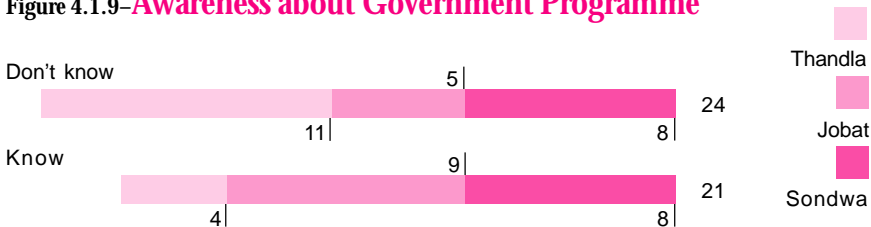


Only 45 patients were enquired.

Awareness of leprosy programme

Twenty-four of the 45 respondents (11 from Thandla) had never heard of the government’s efforts.

Figure 4.1.9–Awareness about Government Programme



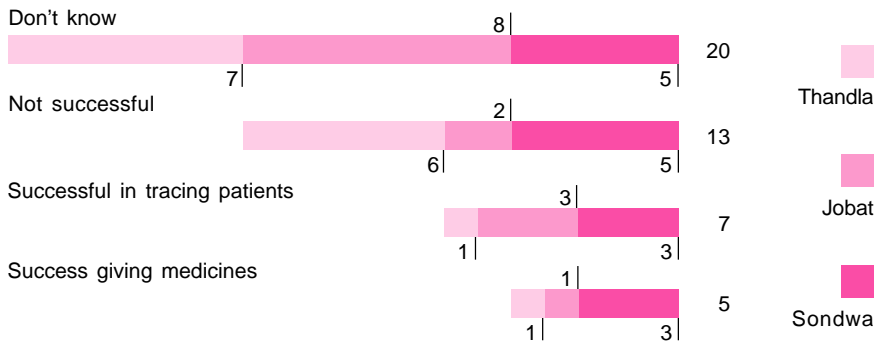
Only 45 respondents were asked this question.

Success of leprosy programme

Most respondents had no idea of the programme’s success rate. Seven of the respondents said the health workers and doctors were successful in finding patients



Figure 4.1.10–Success of Leprosy Programme

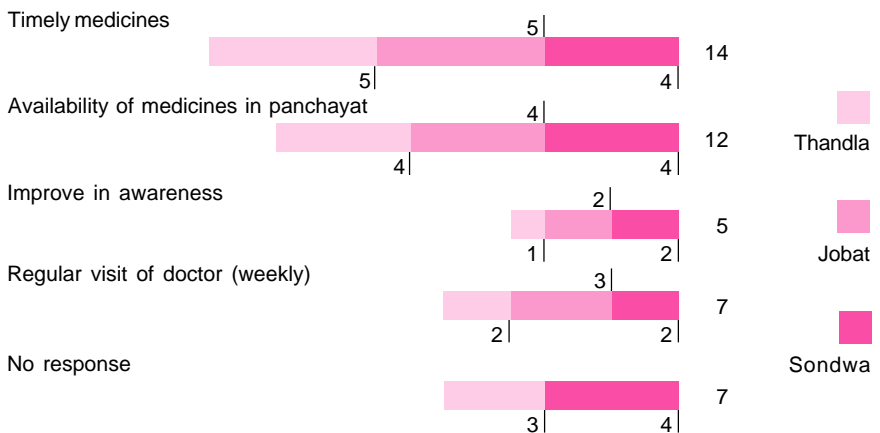


Only 45 respondents were asked this question.

Suggestions for improvement

A third of the respondents said medicines should reach on time (14 respondents); medicines to be in the panchayat (12); awareness and sensitisation programmes (5); and weekly doctors visit (7).

Figure 4.1.11–Suggestions to Improve Government Programme



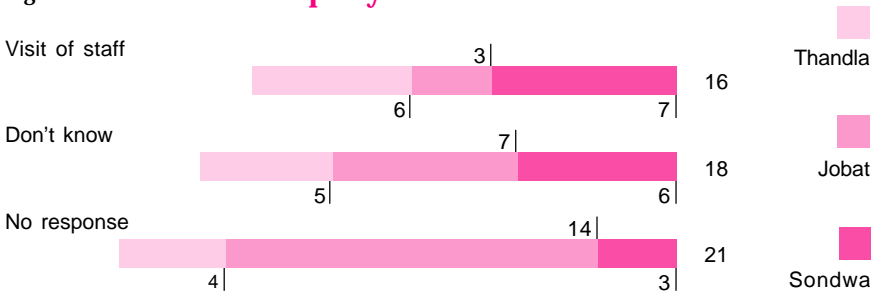
Only 45 respondents were asked this question.



Knowledge of government-run leprosy eradication schemes

Eighteen respondents (40 percent) were unaware of the schemes (majority in Jobat), 16 (35 percent) had heard from doctors and nurses who visited the village. Surprisingly the majority (21 respondents or 46 percent) had nothing to say.

Figure 4.1.12–Access to Leprosy Schemes

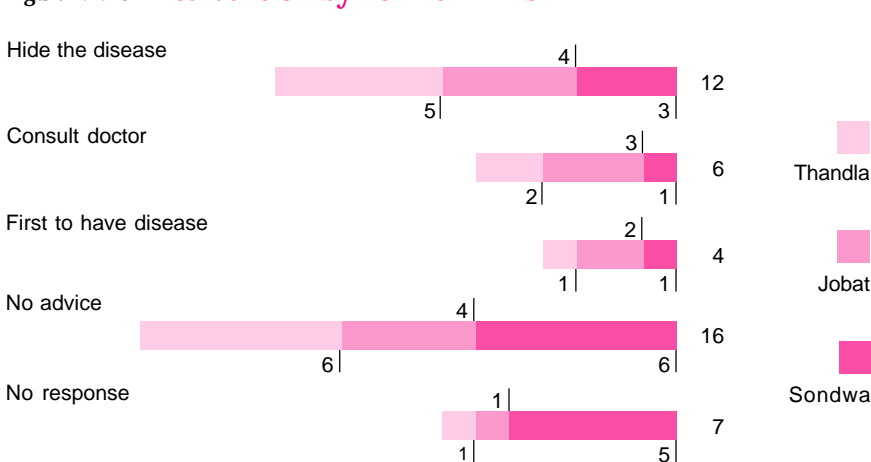


Only 45 respondents were asked this question.

Patients as educators

Sixteen respondents had not been advised about the treatment process by former patients, many of whom were still reluctant to disclose they are cured LAPs. Six respondents said they were told by former LAPs to see a doctor. Seven respondents did not reply and four said they were the first people in the village to be infected.

Figure 4.1.13–Intervention by Former LAPs

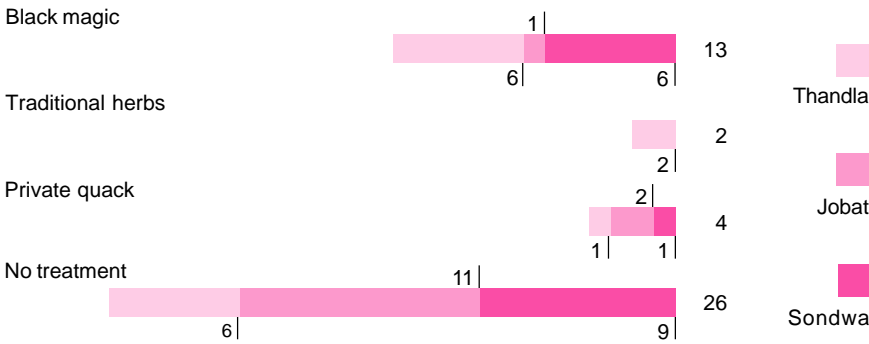


Only 45 respondents were asked this question.

Before MDT

Twenty-six respondents (58 percent) admitted they had tried local medicines before MDT. Thirteen (29 percent) had tried *Badvai* (black magic); four had been to private doctors; and two had tried *jadi butti*. Only one patient said local treatment had given him relief.

Figure 4.1.14—Treatment before MDT

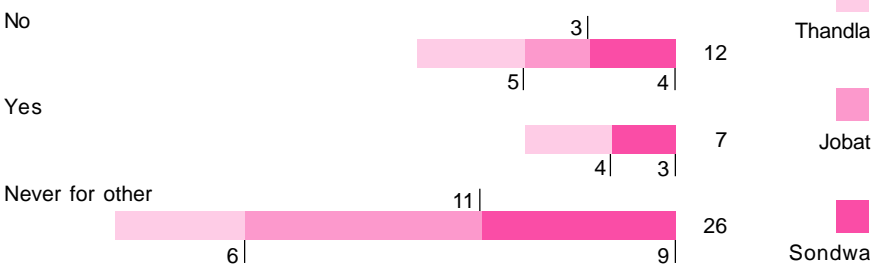


Only 45 respondents were asked this question.

MDT and local treatment

Only seven said they were taking both treatments; because MDT was a long duration course and had side effects like itching and body heat. Twenty-six (58 percent) of the 45 people questioned said they were exclusively on MDT. Twelve respondents (27 percent) said they could not afford the local treatment, nor does it improve the hands and legs.

Figure 4.1.15—Government and Other Treatment

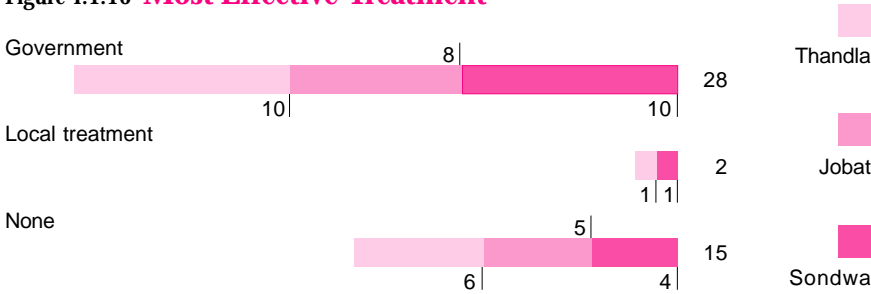


Only 45 respondents were asked this question.

Comparative effects of local and modern leprosy treatment

Twenty-eight respondents (62 percent) voted for the government treatment and two for the alternative treatment of local doctors or herbalists. Fifteen respondents were of the firm view that neither was effective in curing leprosy.

Figure 4.1.16–Most Effective Treatment

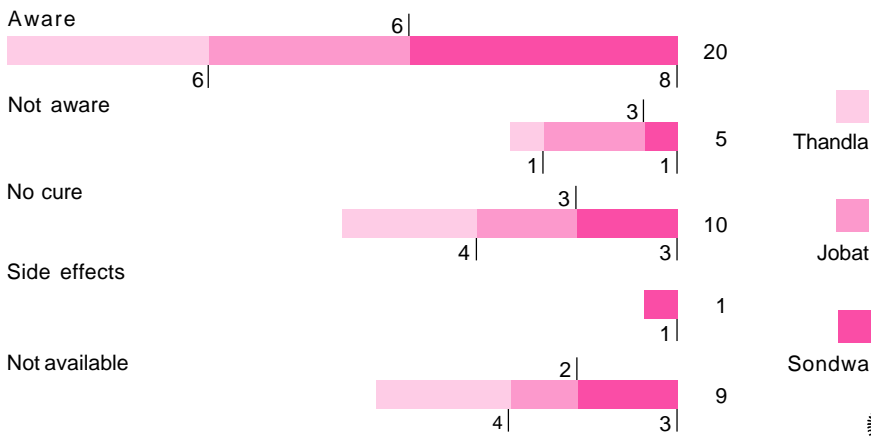


Only 45 respondents were asked this question.

Awareness about MDT

Questions on the reach of MDT revealed that 20 LAP respondents (44 percent) knew about the medicines, but were not taking the treatment because leprosy was an incurable disease (22 percent); side effects make the face darker (2 percent); and medicines were not available (20 percent). Five respondents (11 percent) said they had never heard of MDT.

Figure 4.1.17–Awareness about MDT



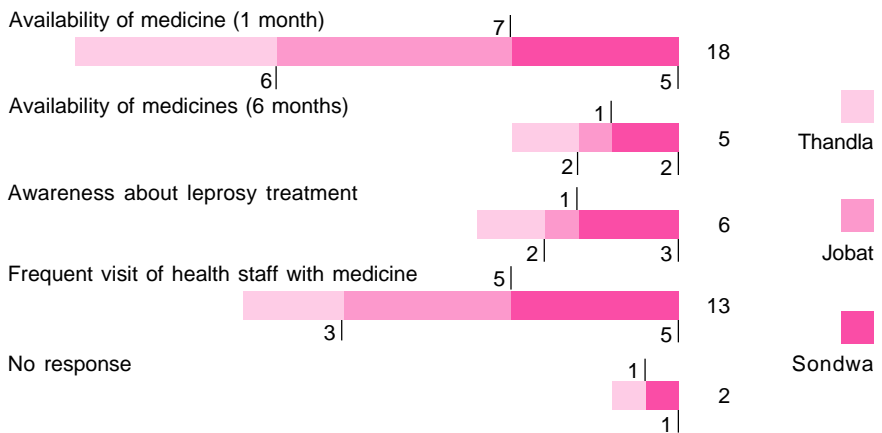
Only 45 respondents were asked this question.



How to improve MDT delivery system

Thirteen respondents said doctors (leprosy workers) must make frequent visits; and carry medicines with them. Eighteen (the majority) said they wanted monthly stocks of medicines for the village; five said at least six months medicine supplies must be made available in the village. Six respondents said the leprosy team must visit and counsel LAPs. Six respondents said the leprosy team must visit and counsel LAPs.

Figure 4.1.18–Suggestions to Improve MDT Delivery System

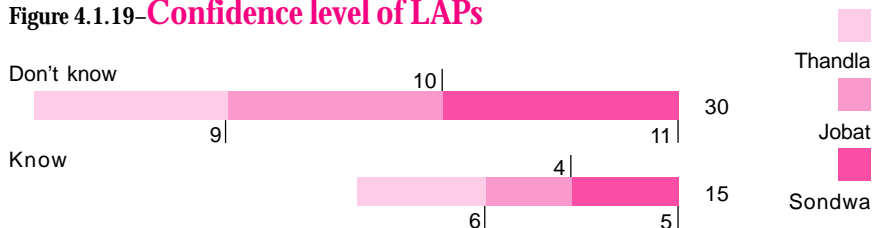


Only 45 respondents were asked this question.

Level of self-confidence to tackle leprosy in others

Two-thirds of the LAP respondents could not even identify their disease as leprosy. Only one-third were able to recognise the early symptoms of leprosy.

Figure 4.1.19–Confidence level of LAPs



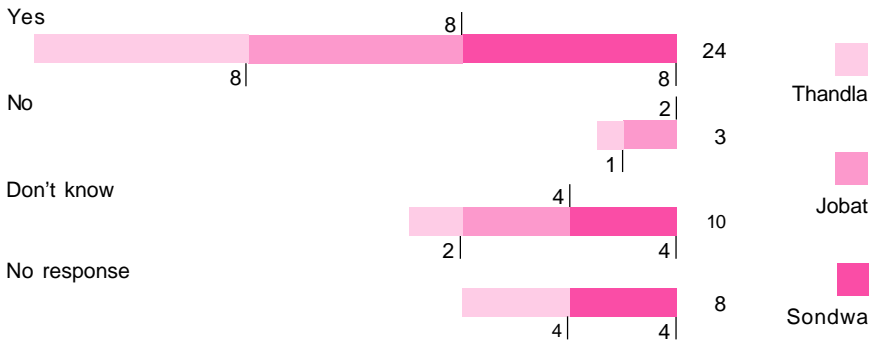
Only 45 respondents were asked this question.



Inspiration for other patients

Around 53 percent (24) said they had encouraged others to take MDT. Only 3 openly admitted to doing nothing, while another eight were reluctant to speak. Ten respondents said they had not got an opportunity of first contact with a patient.

Figure 4.1.20–Have You Inspired Other Patients to Join Treatment?



45 respondents were asked this question.

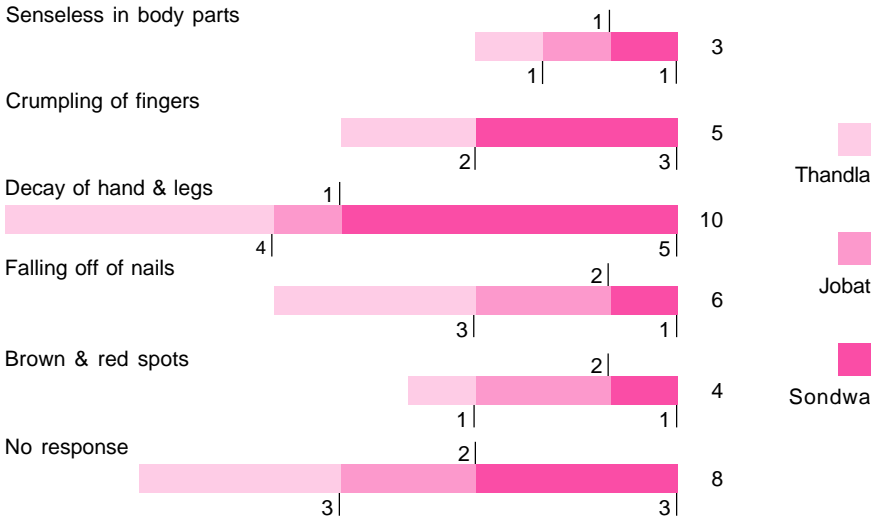
4.2 Panchayat Representatives Survey

An evaluation of the knowledge of leprosy and efforts to eliminate the disease among panchayat members was undertaken. Not all the representatives were available for interviews.

Awareness regarding basic symptoms

The majority (18 respondents or 57 percent) failed to recognise the early symptoms correctly. Only 9 percent (3 respondents) said loss of sensation (numbness) in hands and legs and 12 percent (4) identified loss of sensation in a patch of skin as main symptoms. The majority (incorrectly) pointed out bending of limbs, falling off of fingers and breaking of nails. The remaining 23 percent (8) were unable to pinpoint any one reason.

Figure 4.2.1—Awareness Regarding Leprosy Symptoms

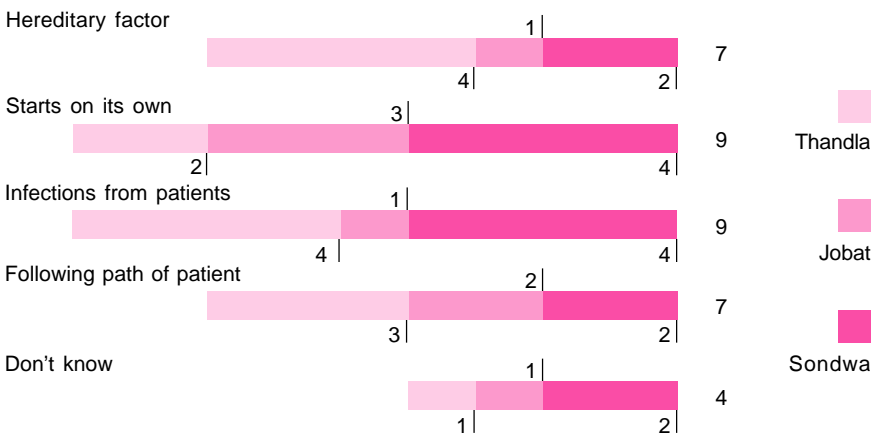


Only 36 patients were asked this question.

What is the cause of leprosy?

Not one person was able to give a correct answer. The replies were varied: an infectious disease that spreads by mere sitting, eating or sleeping with a LAP (9 respondents or 26 percent); hereditary (7 respondents or 20 percent); it just happens (9 respondents or 25 percent); even walking on the same path as a LAP can cause the disease (7 respondents or 20 percent).

Figure 4.2.2—Cause of Leprosy

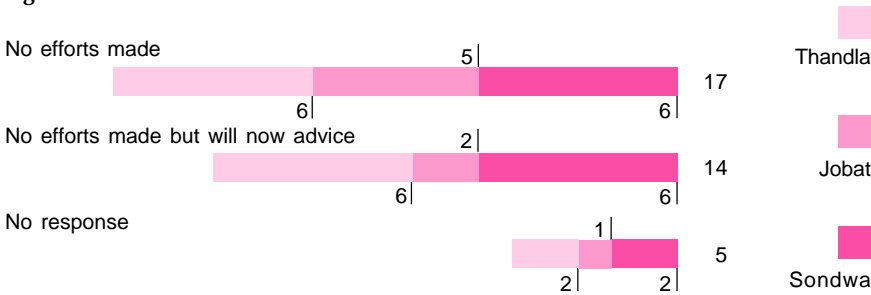


36 patients were asked this question.

Efforts to raise awareness among leprosy patients

Seventeen respondents (47 percent) said they had made no effort. Fourteen said they would now encourage the patients to take government treatment.

Figure 4.2.3–Efforts to Push LAPs Towards Treatment

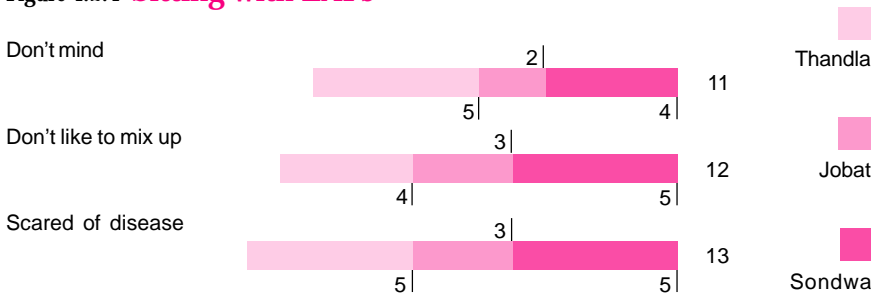


36 respondents were asked this question.

Interaction with LAPs

Of the 36 panchayat representatives, 11 said they don't mind sitting with the patients, 12 said they keep away, while 13 admitted that fear of contracting the disease kept them away.

Figure 4.2.4–Sitting with LAPs



36 panchayat representatives were asked this question.

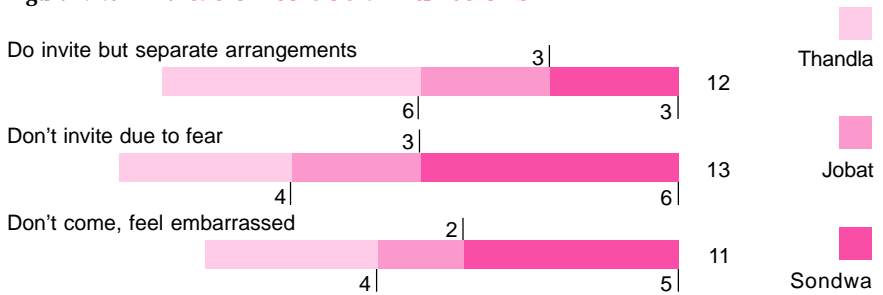
Social interaction with leprosy patients

Twelve respondents said LAPs are invited to social gatherings but they make separate arrangements for them. Thirteen representatives disapproved of their being invited because of the fear of infection. The



remaining 11 said LAPs themselves kept away from village functions.

Figure 4.2.5–Invitation to Social Functions

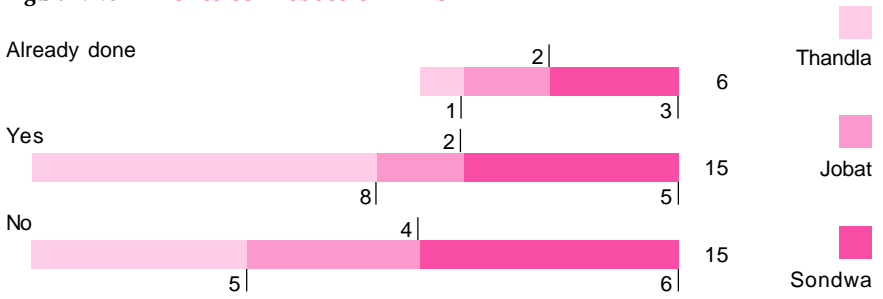


Only 36 respondents were asked this question.

Resettlement of leprosy patients:

Fifteen respondents said they had made no effort to resettle patients, while an equal number said they would like to create a separate place for them. Six respondents said they had done so in their respective areas.

Figure 4.2.6–Efforts to Resettle LAPs



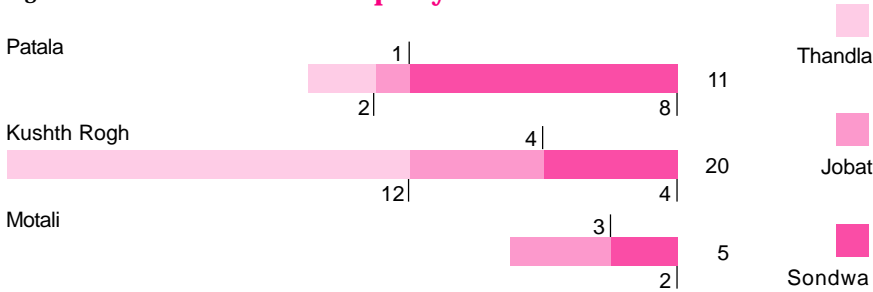
Only 36 respondents were asked this question.

Local names for leprosy

Twenty respondents recognised it as *Kushth Rogh*. Eleven called it *Patala* and five said *Motli*, *Motala Mat* and *Bada Dukh*.



Figure 4.2.7–Local name for Leprosy



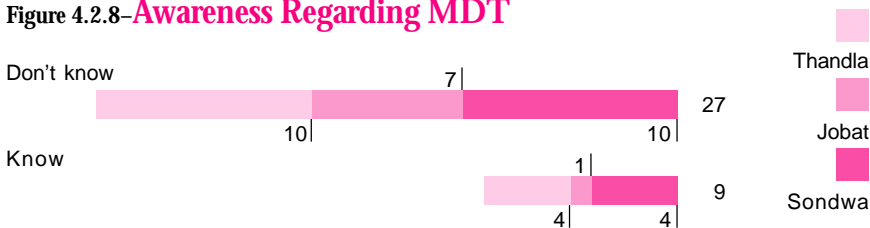
Only 36 respondents were asked this question.

Forty four percent said that periodically they inform LAPs about government treatment programmes and the availability of free medicines. The rest said they were not aware of the anti-leprosy programme. It was observed that some panchayat representatives were confusing government leprosy treatment programmes with its general health campaigns.

Awareness of MDT

Twenty-six (78 percent) of the 36 respondents had never heard of the treatment. Only nine (22 percent) recognised MDT as a course of medicines for leprosy. And only one of these, in Jobat, had ever shared her/his knowledge with leprosy patients.

Figure 4.2.8–Awareness Regarding MDT



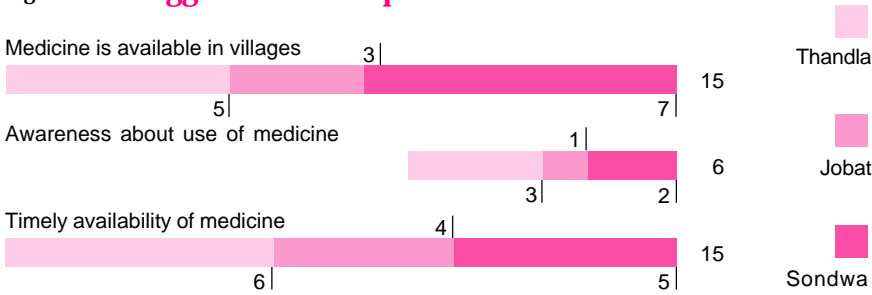
Only 36 respondents were asked this question.

Twenty-seven respondents had no idea if the LAPs in their villages were taking MDT regularly; 30 percent answered the same question in the affirmative; while 14 percent had no answers. Nine (21 percent) respondents expressed satisfaction with the programme; 79 percent were dissatisfied, mainly because government facilities were not reaching the villages in the interior.

Suggestions to improve health services for LAPs

Fifteen respondents stated that the medicine (MDT) should be available in the village. An equal number of respondents said the patients should get the medicine on time, while the remaining 6 wanted improvement in the awareness programme for the use of medicine.

Figure 4.2.9–**Suggestions for Improvement**



Only 36 respondents were asked this question.

4.3 Perception of Leprosy Workers

The NLEP staff was found beating their own drum; fighting a dreaded disease like leprosy is obviously not an easy task, that too all alone. There was a noticeable lack of coordination between the NLEP and other government departments. No network other than the health department's has been enlisted to communicate messages on the availability of a cure for leprosy. Even the strong local systems of communication in tribal villages have not been tapped. For example, the *kotwal* or *chaukidar* who goes from village to village, beating a drum, making public announcements, could be used in the leprosy campaign. Neither have *Anganwadi* nor pulse polio workers been mobilised in the awareness raising programmes. (In some areas the *Anganwadi* worker has been given orientation training.)

Tribal villagers were found to be influenced by the *Kabir Panth*, *Ram Nandbi* (*Ram Bhakt*), *Gayatri Sangha* and other groups who organise regular meetings in villages, that are out of bounds for LAPs. It was proposed that the heads of the *sanghas* could be motivated to join hands with government workers to promote MDT and the leprosy eradication programmes.

Problems of the leprosy worker

The majority of health workers complained of an impossible workload, which prevented them from being effective in the field. They said a worker could only be effective if they had no more than 10 villages to oversee. At present, each health worker is responsible for at least 50 villages. Apart from everything else, it is physically impossible to cover all villages in a month. They reason that even if a worker was to visit one village every day, they would cover no more than 30 or 31 in as many days. Yet the Health Department expects each leprosy health worker to submit a monthly report for all 50 villages.

In one of the blocks, the posts of health workers were lying vacant. The authorities have saddled leprosy workers from nearby villages with additional responsibility of these villages instead of trying to urgently fill the empty posts.

Many villages are not on the bus route. Health workers are given neither transport nor an allowance, and expected to make their own way to these villages. Moreover, according to health workers, the Jhabua Health Department takes months to sanction the TA/DA, and even then the amount is never more than half the amount that was claimed. As a result villagers in the interior suffer. Who is going to spend money out of their own pockets to eradicate leprosy in the less accessible villages, health workers repeatedly ask?



Many villages are not on the bus route. Health workers are given neither transport nor an allowance, and expected to make their own way to these villages.

4.4 Main Findings of Field Survey

Patients' perception

- ◉ Leprosy is commonly known as *Korb*, *Vaabi* (*Kala Vaab*), *Motala* / *Motali Mata*, *Patbala* and *Bada Dukh*. *Motali Mata* / *Bada Dukh* are commonly used in Jobat,






Most sufferers refuse to believe they have leprosy. Instead they claim it is a skin problem like eczema, or just blisters, acne, numbness, white spots, etc.

Pathala is common in Sondwa, whereas Korh and Kala Vaah are the local names for leprosy in Thandla.

- Most sufferers refuse to believe they have leprosy. Instead they claim it is a skin problem like eczema, or just blisters, acne, numbness, white spots, etc.
- The early signs and symptoms of the disease are not recognised.. When LAPs realise the disease is leprosy they may already be showing symptoms of advanced stages of the disease like disfigurement and disabilities.
- No one seems aware of the cause of leprosy. The varied answers indicate a total lack of understanding of the disease.
- There is a universal belief that leprosy has no cure.
- A fear that it is highly contagious, spreading also when a body is cremated.
- LAPs stay away from social gatherings. They are generally not invited, but if they are they are fed separately.
- LAPs are made to live apart from the family to ensure the disease does not spread.
- There is a general lack of awareness about the various stages of the disease, including among LAPs under MDT treatment.
- Delay in field visits by health workers often contributes to a situation where the LAP stops the treatment, due to either unavailability of medicines or lack of awareness of side effects of the medicines, which are temporary.
- Unable to rely on government treatment, LAPs try the informal systems of alternative medicine like black magic and herbal medicines or unqualified private doctors promising cure.



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- ◉ Only regular patients are aware of MDT, and only some among these know that the medication dispensed under the programme is distributed free.

Perception of panchayat representatives

- ◉ Leprosy is a dangerous disease; highly infectious and also hereditary.
- ◉ There is a lot of confusion about the symptoms. Loss of limbs and numbness are identified as symptoms, although in terms of progress of the disease, numbness is a symptom in the initial stages of the disease while loss of limbs happens in the terminal stage.
- ◉ Nothing has been done to promote the anti-leprosy campaign. Some representatives promised to begin anti-leprosy work.
- ◉ More than half was unaware of the existence of programmes for the treatment and elimination of the disease. Only a few knew of the free distribution of drugs under MDT.
- ◉ Most village representatives, who were aware of the government run leprosy eradication programme, did not know if MDT was an effective treatment.
- ◉ Most panchayat representatives admitted that they have never listened to the complaints of LAPs. While some representatives said they are trying to relocate LAPs outside the mainstream.
- ◉ The panchayat representative respondents admitted that they were reluctant to have anything to do with LAPs with disabilities. Only a few said they had no problem in sitting with them, for instance. Similarly, the majority was against inviting them to social gatherings. They said they were scared that they might catch the disease.