



## Field Investigation Through Case Studies

### 3.1 Group Discussion on Leprosy in Selected Villages

Group discussions using the timeline method were conducted with old and experienced villagers who had some knowledge of leprosy. The exercise enabled investigators to build up the history of leprosy in a village and observe the changing attitudes and beliefs over time.

#### **Village Navgaun Somla (*Thandla*)**

The disease is just 3-4 years old in our village. There are three or four patients. Leprosy is infectious. Naigai Koto was the first person in our village to be infected. His toes and fingers have decayed. His family members do not touch him, he stays in one corner of the house, and he is given food separately. His family members behave very badly with him and when they are angry with him they throw him out of the house. Even during the winter and rainy season they throw him out and do not care if he is wet in the rain or shivering in the cold outside. They punish him till their anger cools down.

The *Badva* does only black magic. He does not give any medicine. He asks for (*Mabua*) wine and cock, and he prays. Even doctors cannot cure this disease then what can a priest do? We don't know why this disease occurs. A LAP is

buried, and all the village goes to bury the person. We do invite them to marriages and other function in the village, but they are told to sit separately and even their food is served separately. The government gives free medicines, grain and money to the sufferers. If the sufferer takes treatment right in the beginning of the disease then the disease can be cured. Government should ensure that the disease is completely cured, and LAPs should be given food and shelter so that if their family members harass them they have some place to stay.

### **Village Roopgad (*Thandla*)**

Leprosy has no cause; there are no warning signs. It generally happens to those whose relatives have suffered from the disease. There is very little chance of cure; death is the only relief. Some symptoms we are aware of:

- ◉ Loss of sensitivity
- ◉ Finger bones start bending
- ◉ Fingers shrink.
- ◉ Fingers start melting.
- ◉ Big patches on the body
- ◉ The face swells, and big red spots appear
- ◉ The condition of the body only deteriorates, the fingers decay

One person in our village, 70-year-old Ravji, died of this disease. Ravji was kept isolated; he was given food separately. There is an old one saying in our village, “if a leprosy patient is standing in your way, don’t take the same route, don’t even look that way”. We would rather climb a mountain than go the same way.

There is some treatment for the disease for the last 15 years. Ten years ago Dattu in our village died from the disease. But 6-7 years back, Fattia was treated and got

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well. He was the first person to take government treatment and he got well; now we go to his house for social functions and also invite him to ours. We know that treatment is possible in government hospitals.

### **Village Badi Dhamni (*Thandla*)**

In Badi Dhamni we are not aware of leprosy. Nobody has the disease. Even if there had been cases, it would have been kept hidden from the village. The family members would certainly have kept the LAP away from the house, and fed them separately. Even today if this disease happens to any one, we will isolate the person and give them food separately, even if the person is a member of our village and our own family.

### **Village Morghire (*Thandla*)**


We call the disease *Motali Mata* when the toes and fingers start crumpling. We have known of the disease for the last 10 years. Rasli was the first to contract the disease. She took a lot of treatment but it did her no good. No one in this village goes to her house. Everyone says she has leprosy, and she will never recover.

We also don't go to her house; we are scared that we may get infected. Even the doctor's can't tell why the disease happens? According to us even the doctor cannot cure this disease. Previously, the villagers used to drag the sufferers out of their house. Family members would not talk to them; everyone avoided them. The sufferers would generally avoid going out of their house, and they would hide themselves. They would not attend family functions.

### **Village Daulatpura (*Thandla*)**

In our village we are scared of leprosy. We have known of





it for the last 10-12 years. In the nearby village Rupgarh one person named Rajima died of the disease. Now his younger brother has the disease for the last 4-5 years. In our village, Kanu Samsu was first to contract the disease, her whole face has been ruined by leprosy. No one in our village speaks to her family members and we don't go to their house, because people are scared that they may also get the disease. Leprosy is a very dangerous disease, it happens to any one who stays with a patient. It is a sin to talk to LAPs. The victim generally become handicapped and lose her/his hands and legs. Previously the doctor treating LAPs were not allowed by us to enter the house, but now people's attitude has changed. In the panchayat faliya, Badhur son of Samsu has the disease. His fingers have become stubs.

Initially the villagers used to consult the Badva, but now they don't go to the priest. The villagers believe that if a person with leprosy crosses your path then you can never succeed in your work. The villagers consider even their house impure, and think that just the shadow of a leprosy patient falling on you can give you the disease. LAPs have only one option, and that is death. No one wants to talk to them, no one marries them. It is better for such people to die. In Roopgad there is one person called Nanji, he has lost his fingers due to this disease. He cannot do anything with his hands; such persons should not come out of their house.

The medicines distributed by the government are not effective. If the government were to give proper medicines to such patients they would not suffer to this extent. The government should make a separate place for such patients, this would stop the disease from spreading. We have never seen anyone recover from the disease.

### **Village Chhoti Khattali (*Jobat*)**

In our village we had a disease named Bada Dukh (leprosy), this is a 30 to 35-year-old story. Those who had the disease have died, and the few people who still suffer do not disclose their condition, and hide themselves. In our village there is another dangerous disease called TB. In the last two decades, 7 people have died from TB.

## WHY IS THE DISEASE CALLED BADA DUKH?

It brings a lot of sadness to the family and the affected person. The LAP is buried alive. It would be a greater suffering if s/he were to stay alive. When the village goes to get the LAP, they make their way very silently, they never take the name of god. The LAP is taken to the graveyard by a route that is not used by the village. There is a reason for this: if the person's soul tries to return to the village, the soul cannot find the way, and so the village will be safe.

There are two main reasons for burying LAPs alive: it puts them out of their misery, and in the process of dying they resolve not to let their soul re-enter the family and return to the village.

The sufferer is not cremated because the flames carry with it germs from the body. Those who have come to burn the person may catch the disease.

There is a village called Banda Bada close to our village. Twenty years back there was a family whose head was Guman Singh. His entire family had *Bada Dukh*. Only his youngest son did not. The family left him with relatives and went to a place where patients like them get free food and shelter. The son is now grown up and is still in the village. The disease has ruined the family. Once Guman Singh came to meet his son, but his son refused to accept him, so he went back.

There is no treatment for this disease. One who gets it has only one option for survival, begging. If the LAP does not leave her/his house, the family members make their life so miserable that they are forced to leave.

In village Badi Khattali, the wife of Abhay Singh, Kanibai Patlan, died of the disease. Another person had become a beggar and later died of the disease.

In nearby Chamar Bagda, (4-5 years back) one person named Dursingh had this disease; his family members killed him and threw his body into a dry well. His hands and legs were no longer working because of the disease. After 20 days the police took out his dead body from the well, by which time the body had decayed. The family members had covered the body with *neem* leaves, so no one knew where Dursingh was.

One who gets this disease loses the use of their hands and legs. They can neither work nor stay at home; they can only be beggars. In Badi Khatalli village two potters, Sundaria and Gangaram, both have this disease. No one from our village buys their pots, because we may get infected drinking water from their pots. This is how our village is safe from the disease. Another person from Badi Khatalli called Pannalal is taking treatment from Ranapur.



An infected person goes to Dhar or some other place, because here there is no proper treatment. We don't know how this disease happens, it happens by itself. The patient does not get fever or cold, only the skin of the hands and the legs start decaying.

In village Umda, which is near Khattali, one person named Bhau Dala, died 4-5 years back. He also had the same disease, although he belonged to a very good family. It is our belief that if a LAP is cremated following the common death rituals, the disease will not leave the village, it will enter someone in the village. We maintain relations with the affected family, but we do not drink or eat in that house. In case a mad dog bites, we don't even go to see the person.

There is no doctor in our village nor does the doctor visit our village. When we are in need we go to Khattali. There is no bus to our village, so we have to walk. How can we walk every time? A person who is sick cannot walk. But the doctor who has a vehicle could come to our village. When we go to hospital the doctor tells us to see him in his room, where he asks for money, saying that if we should be willing to spend money for treatment, or be prepared to die. If the government were to keep medicines in the village, we would not have to go to the doctor.



*The LAP is taken to an unknown place and buried alive.*

### **Village Sevariya (Jobat)**

There has been leprosy in the village since 1950. The disease killed nine people. We don't know why it happens? It is an infectious disease. A LAP is made to stay away from the other family members. They cannot participate in village functions. It is difficult for the person to marry. When they die, they are buried in an isolated place; their clothes and vessels are buried with them. This is to prevent the disease from spreading. If someone touches the toilet or urine of such person then they may get the disease. The village priest does not treat such patients. This disease cannot be cured by medicines. What can a priest do? Neither can it be cured in the big hospitals, then how is it possible in a small village? However, if the treatment is taken in the initial stage of the disease, it can be cured.


We have to go to Jobat (10 kms away) to see a doctor. We should have a hospital in our village so that we don't have to go to other villages. Many villagers die because there is no hospital. Previously there was no treatment for Bada Dukh. Even the priest would avoid such patients for fear of contracting the disease. That is how nine people in our village died. They went out of the village for treatment, but they did not get proper treatment. Their hands and legs decayed and they died. Now, there are one or two LAPs. Nobody goes to those houses, nor do the family members let them come out. They live separately in the house. They are not allowed to fill water from the hand pump. The doctor from Jobat brings them free medicine.

### **Village Chhoti Khattali (Jobat)**

#### ***Why is leprosy called Bada Dukh?***

It makes people useless, like they were dead. Their hands and legs become insensitive (numb), they get boils on





the body, white and dark spots, fingers start getting shorter and hands and legs start falling off. That is why the disease is called *Bada Dukh*. It is an infectious disease, and can be contracted from the LAP by staying or sitting with her/him, talking, sleeping, sharing the toilet or walking on the same path.

Thavalia's wife had leprosy, her mother also had the disease and her mother's father also had leprosy. Thus the disease passes from generation to generation. A LAP is taken to an unknown place and buried alive. There is a reason: it makes the LAP hate the family members so much that s/he never comes back to the same family. Thavalia and Obasingh Patel's wives were buried alive. The police had made inquiries about the incidents, and the villagers told them about their beliefs. Thavalia's mother had leprosy and she was burnt in the normal manner, so his wife got the disease. After this a village committee meeting was called, and it was decided that a LAP would be buried alive, not burnt. People who accompany the patient to the graveyard do not talk with each other nor do they look back, they even change the route to the graveyard and back. We believe the LAP's soul loses its way and will never be able to come back to the village.

For example, in Chhoti Khattali, Rayasia's wife had this disease. This was 10-15 years back. Rayasia admitted his wife to a hospital in Indore and ran away to the village, leaving her behind. He told the villagers that he had abandoned his wife in the hospital to save his other family members from the disease.

### **Village Hardaspur (*Jobat*)**

No one in the village has leprosy. It is in Sevariya. The village priest cannot treat LAPs. Their bodies start decaying, and they never recover. They generally die. If a healthy person eats with a LAP, s/he can get infected. LAPs are fed separately if they visit someone. No one marries them for fear of being infected. No one knows what causes the disease. Nor have we heard of the government programme to eradicate leprosy. We never use the same toilet as a person with leprosy. They are allowed to live in the village only if they have land. The ladles are forced to leave. They go to the nearby villages and towns.

The disease is very dangerous, and it is passed from one generation to the next. There is no cure in small towns; it can be treated only in big cities.

### **Village Kesaria (*Sondwa*)**

In the old days there were no hospitals or medicines, only herbal medicines were available and we used to manage with that. In those days there were not many diseases and if there were, nobody knew about them. Even 70 years back people with this disease were seen around like they are now. They cooked their own food in separate vessels. They would not step out of their houses, and if they had to go somewhere they carried their vessels. One of the Badvas, Gurja, who is 70 years old, says he treats all types of patients and they recover, but he has no cure for leprosy. Their suffering ends only with death.

They are not invited to any public function like marriages nor can they go to meet anyone. They can only function like normal people if the village does not know they have leprosy.

As soon as a person starts getting spots on his/her face or hands, and their legs start decaying, those are sure signs of leprosy. After this no one visits them. They do not come out of their houses.

Singha had this disease. Initially he consulted a doctor but he got no relief. Then he showed himself to the *guru* (teacher) and to the priest but nothing worked. Everyone knew he had leprosy. He was socially ostracised. In a similar way Duniya's father was made to live separately from the rest of his family. He was made to stay in a small hut. His family would cook for him and serve him in a separate vessel. He did not take any treatment and died. If LAPs are treated at the right time, they recover.

### **Village Badi Bankhed (*Sondwa*)**

We do not know much about leprosy, the only thing we know is that it is an infectious disease. Since it spreads from one person to another, we must not go to the houses of infected people. Even by eating at their place we may catch the disease. Those who contract the disease must be forced to leave the village. The villagers do not invite them to social functions. In nearby Bhopalia an old woman who had the disease was forced to leave her house, and now no one has the disease in that house. So we should not let the patient stay in the house.

When we come to know that a relative has this disease we break off relations with her/him. Once a person gets infected, whether they live or die, the disease can recur in one of the family member's even 10-15 years later. Only a doctor has a cure, not the village priest. If we get to hear of two or three LAPs living in a certain hamlet, we must bury them alive. This is the way to control the disease. In the past, villagers had once planned to bury an old LAP alive, but they decided not to.

*The doctor generally goes to the patient's house to dispense medicines, but the patients don't like it.*

In nearby Bharvada, around 20-25 years back, the villagers had buried a LAP alive. They feared that since the husband had leprosy his wife would get it. However, now that two or three LAPs have recovered through treatment, the villagers have got some confidence. The doctor generally goes to the patient's house to dispense medicines, but the patients don't like it. They feel insulted (embarrassed), so they go to the hospital themselves to collect the medicines. They tell the doctor not to tell anyone they have leprosy, for fear of losing their position in the village.

### **Village Atava (*Sondwa*)**

Leprosy patients lose their legs and hands. The disease runs in a family. It does not happen to other people. Timely treatment can cure the patient. The village priest has no cure. Fatara's father had the disease, then his son got the disease and he committed suicide. We stop all interactions with the family. We do not invite them to any social function. We do not eat in their house, only the LAP's family may eat in their house. No one will marry them; only someone with the same disease can marry them. We should not even talk to LAPs, not even greet them. When they die, they are buried separately, and at night so no one gets to know. It is our belief that they cannot get better, so we do not take them to the doctor.



*We don't exactly know what is leprosy. Nor have we heard of the government schemes for treatment.*

This disease make LAPs sweat profusely, then their bodies start to decay. After 10-12 years they know they have the disease.

We don't exactly know what is leprosy. Nor have we heard of the government schemes for treatment. Doctors do call on patients who have leprosy, but the patients themselves do not go to the doctors. We don't know whether this disease is curable or not.

Forty-five years back, a son of Fatua named Bucchia had leprosy. He tried a lot of different treatments but did not get well. The villagers used to behave very badly with him, so he committed suicide. A girl named Harla who was married into our village from the nearby village, had this disease and because of her leprosy has spread to our village also. Kalsingh's mother had this disease, we don't know where she went, may be she is staying in the ashram.

Previously, patients were not treated, they thought this was an incurable disease, a disease for life. The village priest has no cures, he asks for (Mahua) wine and a cock.

The disease spreads from one generation to the next. We neither invite someone with leprosy to our marriages, nor do they get married. Everyone avoids going near LAPs. The LAP's family members generally make a small hut for her/him, attached to the main house. Their food is served to them from a distance. We don't greet LAPs. The family members kill and bury the LAP overnight, without anyone getting to know.

We don't have much knowledge about government schemes. We know that the medicines for leprosy are given free.



## **Village Puvasa (*Sondhwa*)**


The disease has been in our village even before we were born. But some 25 years ago, patients were abandoned in a place called “Patal Pani”. There were many patients staying in Road faliya. Some left the village on their own; some died of the disease. Those who didn’t leave on their own were driven out by the villagers who shouted abuses, saying they had a dirty disease. Yet the disease has not vanished from our village. There are a few LAPs staying in Patel faliya. We have never seen a patient recover, we have seen them die. They should die as quickly as possible because eventually their fingers become stubs, nails start cracking and they can’t do anything. They (LAPs) should die themselves.

According to us, people should not be treated for this disease because they don’t recover, so why waste money. Even the priest says there is no treatment. Why this disease occurs we don’t know, only god knows? LAPs are not invited to marriages. Our village has lost prestige because of the disease. It is a curse on our village. Surbhan, Habji and Narsing from our village have all died (of leprosy). Surbhan had lost his eyesight and Habji both his hands.

We don’t participate in the burial of LAPs. All the villagers pool money together and call the village sweeper to bury the dead body; if we don’t find a sweeper we pay the low caste people staying in our village. When we (the higher caste Patel and Tadvi) visit the nearby villages and those villagers ask us about the disease, we feel very ashamed. If the government makes a provision for keeping all such patients in a place away from our village, we will contribute money for their transportation.

The doctor from Umralli visits our village frequently and says that the disease is curable now, but we have not seen any improvement. If at all there is a treatment, why are there LAPs in our village. A LAP can never get well, neither can god save them nor can a doctor, they have to die. The government should invent a medicine that will detect leprosy before it even happens.

People with the disease are treated very badly in our village; their wives/spouses leave them, even the villagers don’t speak to them or go to their fields. The



family members shift them into a separate hut, and serve them food separately. They have to go far away from the village to defecate.

## 3.2 Main Finding of the Timeline/FGD

### **What is *Bada Dukh*?**

It is incurable, and hereditary. It is the result of sins committed, sometimes in a past life. Some times it is a consequence of eating non-vegetarian food and alcohol. It can be contracted by eating or touching and speaking with an infected person.

### **Attitude of the village community to LAPs**

- ◉ They must not be allowed to live in the village. The government should make provisions to house and feed them
- ◉ LAPs must be buried alive, for their own salvation, and to save their fellow villagers from the curse of the disease.
- ◉ Never take the same path as a LAP. Villagers say they would rather climb a mountain than walk on the route taken by a LAP.
- ◉ They are excluded from village social gatherings. LAPs must not marry.
- ◉ Family members of the LAP must not take care of them. They must be made to live separately.
- ◉ Those who are poor are thrown out of the village, and forced to turn to begging.

### **Access to government leprosy programmes**

- ◉ Villagers in the interior, not connected to a road, are rarely visited by health officials. The nearest hospital is often very far away, and sometimes a LAP has died without ever having consulted a doctor. Leprosy health workers and doctors must regularly visit the interior villages.
- ◉ There is a general lack of faith in the curative ability of modern medicine. No one has seen a patient getting well. The general belief is that medicines distributed by government doctors and health workers are not effective.

