



Background and Investigation Methodology

1.1 Background

The World Health Assembly in 1991 recognised leprosy as a serious public health problem and resolved to eliminate the disease by the year 2000. There were two major challenges: to identify “latent cases” of leprosy and to reach out to leprosy affected patients (LAPs) living in backward, inaccessible areas. The Danida Assisted National Leprosy Eradication Programme (DANLEP) is working in Madhya Pradesh together with the state’s Health Department. The two are actively involved in leprosy elimination, using Multi Drug Therapy (MDT).

The Special Action Project for Elimination of Leprosy (SAPEL) is an innovative initiative aimed at providing MDT services to patients in difficult areas or to those belonging to neglected population groups. SAPEL is intended to promote self-reliance and self-help by actively involving community members and utilising community resources. It has enlisted the help of local NGOs who are in a position to identify local issues.

The findings of the various agencies involved in efforts to eliminate the disease were shared at a workshop in Western Madhya Pradesh in May 2000.

DANLEP's concern over the findings led to a rethinking. The need was felt to assess the perception of the local tribal population to leprosy and its drug treatment. It was proposed that the study would focus on one tribe, the Bhils of Jhabua.



1.2 Study Objectives

The study aims to determine the knowledge, attitude and practices regarding leprosy of both village communities and leprosy affected patients (LAPs), their perception of the availability, accessibility, utilisation and effectiveness of government facilities for treatment and the reach of government campaigns on leprosy awareness. The study also seeks to propose strategies for increasing coverage and acceptance of MDT services, including ways of improving coordination between government and non-government agencies.

1.3 Scope of the Study

(1) Indigenous knowledge systems and practices - information on:

- Traditional knowledge, beliefs, taboos and practices regarding leprosy.
- Myths related to the disease and the logic of the myths.
- Names for leprosy in the local dialect and their meaning.
- Social system in the fight against the disease and to rehabilitate patients.
- Attitude of family members towards LAPs.
- Attitude of the village community towards LAP/family.

(2) Impact of government efforts in leprosy treatment

- Availability and utilisation of diagnostic and treatment facilities.





- Weaknesses in the medical service provided.
- Accessibility of medical facilities.
- Impact and reach of awareness raising campaigns.

(3) Strategies for widening coverage, acceptance and co-ordination:

- How to remove distrust and popularise government efforts.
- What changes are required to improve services?

(4) Behaviour of LAPs

- Treatment seeking behaviour.
- Time gap between symptom and diagnosis.
- First approach for diagnosis and treatment.
- Immediate reaction of family and community.
- First experience with the Health Department personnel

1.4 Study Area

Jhabua district can be broadly divided into three distinct areas: the Bhil villages in the central-western part bordering the states of Gujarat and Rajasthan; the Bhilalas in the south, along the Narmada river and Nimar region; and Patlias in the east and north on the Malwa plateau.

It was thought necessary to give equal representation to all three areas in the study. Jhabua district's 1.1 million people are divided in 12 blocks. Consequently, three blocks and tribes were identified: Sondwa (Bhilala), Jobat (Bhils) and Thandla (Patlia).

The study area was further narrowed down to six villages in each block. To ensure uniformity, the selected villages were divided in three categories. Two of the villages are large-sized, two moderate-sized villages located near the road, and two villages in the interior. The main criteria for selection was the presence of leprosy affected




BLOCKWISE PROFILE OF JHABUA DISTRICT

Jhabua	Total Population	ST (%)	SC (%)	Sex Ratio	Literacy	Leprosy Prev. Rate
Bhamra	72134	92.20	1.32	970	8.31	4.3
Jhabua	103465	82.38	0.99	993	8.95	3.6
Rama	83713	94.34	1.38	984	9.61	4.0
Ranapur	88042	89.02	1.15	986	8.74	3.5
Jobat	60580	86.70	2.84	994	9.55	4.6
Udaygarh	58757	94.46	2.13	981	8.81	4.2
Alirajpur	84247	77.66	4.25	1005	8.94	4.0
Kathiwada	72317	82.02	12.06	994	7.74	2.9
Sondwa	106450	92.73	4.34	984	7.93	7.9
Meghnagar	98116	87.20	1.62	966	15.69	3.6
Thandla	107702	86.76	1.07	973	10.39	5.0
Petlavad	143242	74.71	1.09	970	16.22	4.4

Source: 1991 Census

SELECTED VILLAGES FOR STUDY IN JHABUA DISTRICT

Villages	Location		Size	
	Road side	Interior	Large	Small
Thandla Block				
Roopgad		*	*	*
Daulatpura		*		*
Morghire	*		*	
Badi Damni	*		*	
Parvada	*			*
Navgaun Somla	*			
Jobat Block				
Kasba Jobat	*		*	
Choti Khattali		*		*
Dabdi	*		*	
Semariya or Sevariya	*			*
Hardaspur		*		*
Dehtala		*		*
Sondwa Block				
Puvasa	*		*	
Badi Bankhed	*			*
Kesaria		*		*
Padtala		*	*	
Sakdi		*	*	
Atava		*		*



patients (LAPs) in the village. The selection was done in consultation with the local health department workers (BMO / NMS).

1.5 Study Methodology

The field investigation started in November 2000 and continued till the end of December 2000. Local youth, both educated girls and boys, were recruited to carry out the investigation under the supervision of CARD's Research Personnel. The team was given a two-day orientation, which included the use of micro planning tools and case study methods. The local non-medical supervisor (NMS) also conducted a one-day orientation course on leprosy: on its early symptoms; the various stages of the disease and symptoms; the consequences of neglecting treatment; the side effects of various medicines, etc. The investigators were made familiar with the various government and non-government programmes for leprosy eradication.

1.6 Investigation Tools

During the fieldwork it was seen that LAPs were more relaxed when interviewed alone. Consequently the investigators made it a point not to

DISEASE TIMELINE

This is a group exercise conducted in each *faliya* (hamlet) with a select group of old and experienced persons who are asked to reconstruct their village history with respect to leprosy. Initially when the exercise was conducted, the participants would quickly withdraw and leave. A new strategy was adopted. Photographs of LAPs who were cured by MDT were passed around the group. The investigators also shared medicine samples, and talked to the group about its effectiveness. Slowly the villagers were drawn into the group exercise. A number of questions are covered.

- ⊙ Since when have LAPs been present in the village?
- ⊙ Who was the first LAP?
- ⊙ What was the attitude then of the village to the LAP?
- ⊙ Did doctors visit the village in those days?
- ⊙ What were the then traditional methods to get rid of leprosy?
- ⊙ What was the social position of the LAP in the old days? What methods of treatment did they try?
- ⊙ What are/were the major problems faced by the LAPs, specifically in getting married, and at social functions?
- ⊙ What is the attitude of family members to the LAP?
- ⊙ What government schemes are there for the cure/eradication of leprosy?

single out LAPs in group discussions or in front of other villagers. This method was found to be very effective for information gathering.

Data collection methods

Participatory Social Mapping: The mapping exercise was conducted in only the first few villages surveyed by the investigators. It was discontinued because it was proving to be very embarrassing for the LAPs and their families.

Participants were made to map their village, pin-point the houses of LAPs, sources of drinking water, public toilet spaces, bathing places, the market etc. The exercise was an attempt to ascertain the attitude of the family and villagers to LAPs; to see if LAPs have separate bathing places, water sources etc.

The general observation was that the village would have liked to bar LAPs, for instance, from the village pumps and wells had there been more sources of drinking water in the village.

Data collection relied on the following methods.

- ◉ Disease Timeline
- ◉ Disease Ranking
- ◉ Focus Group Discussion
- ◉ Individual case studies
- ◉ Semi-structured interviews with patients and panchayat members

Focus group discussion

The team made sure that it always involved the village elders and the educated in the focus group discussion, a major tool for information gathering during the study.



LAPs were more relaxed when interviewed alone.



Case studies

Interviews for two case studies were conducted in each village. The exercise sought to create as complete a case history of the LAP as possible. It covers details like name and background, and also attitude of family members and neighbours to the LAP. Has s/he been to a government hospital/clinic? How has the family/village behaved with the LAP? What is the attitude of the LAP towards herself/himself? Has s/he faced any difficulty in getting MDT medicines?

Interviews using semi-structured schedule

Three patients and two panchayat representatives were interviewed in each village. It was observed that a doctor or health worker had never visited some *faliyas*. The LAP was asked to identify their disease. Most LAPs did not admit to having leprosy, saying it was either eczema or some other skin disease.

The survey began in Sondwa block. At first the investigators stuck to the questionnaire. But seeing that the LAPs were unwilling to talk about leprosy, they changed the format of the interview. Information was gathered through indirect questions. All questions of a personal nature — regarding the disease and its implications — were introduced only after gaining the confidence of the LAP.



