

# **LEPROSY**

**Perceptions and Practices of Gonds  
in Betul, Chhindwara and Hoshangabad**

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2002

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# Abbreviations

ANM	Auxiliary Nurse Midwife
CHC	Community Health Centre
Danida	Danish International Development Assistance
DANLEP	Danish Assistance to the National Leprosy Eradication Programme
FGD	Focus Group Discussion
GSA	Gram Sampark Abhiyan (Village Contact Drive)
IEC	Information, Education and Communication
KAP	Knowledge, Attitude and Practices
LAP	Leprosy Affected Person
MB	Multi Bacillary
MDT	Multi Drug Therapy
MLEC	Modified Leprosy Elimination Campaign
MPW	Multi-Purpose Worker
NLEP	National Leprosy Eradication Programme
NMA	Non-Medical Assistant
NMS	Non-Medical Supervisor
PB	Pauci Bacillary
PHC	Primary Health Centre
PRA	Participatory Rural Appraisal
RFT	Released From Treatment
SSL	Single Skin Lesion
ST	Scheduled Tribe



## Glossary

<i>Bahera</i>	Fruits of Terminalia Chebula.
<i>Bengali Doctor</i>	A generic/colloquial term used for a local, by and large non-Registered Medical Practitioner. He usually holds a diploma in <i>ayurveda</i> or homeopathy but practises allopathy.
<i>Bhagat-Bhumka</i>	Local expert in soothsaying. One in almost all villages.
<i>Chatte wala rog</i>	Leucoderma.
<i>Guniya</i>	A local healer with an expertise in tantra.
<i>Haat Bazar</i>	Local Market place.
<i>Jankar</i>	The second rung authority in the hierarchy of local healers after Parihar. Generally one between every five to eight villages.
<i>Jhaad Phoonk</i>	Rituals to remove spells cast by evil spirits.
<i>Korh</i>	Used for leprosy when it is perceived by the community as incurable.
<i>Kushth</i>	Used for leprosy when perceived by the community as curable.
<i>Lamjan</i>	An arrangement wherein the son-in-law comes and stays with his in-laws at their residence.
<i>Madai</i>	Annual fair of villagers.
<i>Maharog</i>	Generally used for leprosy at colloquial level (especially in the area adjoining Maharashtra).
<i>Muglai</i>	Hoshangabad plains.
<i>Parihar</i>	The apex authority in the hierarchy of the local faith healers. Knows everything from soothsaying to pulse monitoring to tantra.
<i>Sept</i>	A group believing itself derived from a common ancestor.
<i>Vaidya</i>	A local healer with expertise in herbs.

## Study Districts of Madhya Pradesh





## Executive Summary

The health seeking behaviour of any individual or community is dependent on their current status of understanding or knowledge dimension, the socio-cultural factors that lead to the formation of an attitudinal set, and the enabling social, technical and economic environment that helps convert the attitude into practice. An understanding of the Knowledge, Attitude and Practice (KAP) of specific social and cultural groups is therefore, essential for effective intervention. It is against this background that DANLEP-Madhya Pradesh has commissioned a study of the perception and practices regarding leprosy among the Gonds of Chhindwara, Betul, and Hoshangabad.

The study attempted to identify the existing KAP, the knowledge pathways by which information and beliefs with respect to the leprosy spread, and to determine the views of these communities regarding the availability, accessibility, utilisation and effectiveness of government facilities for the treatment of leprosy.

The incidence of leprosy is not as high among the Gonds as compared to the total population. This was corroborated during the study where it was observed that the higher the tribal population in a block the lower the prevalence rate. It was also noticed that the villages near markets and stations, where non-tribal populations exist, had greater numbers of patients. In the PRA exercises, the occurrence of the disease is seen to have increased after the 1950s, the time period when railways expanded and migration to *muglai* (fertile plains of Narmada in the Hoshangabad district) increased.

The study strongly depended on participatory rural appraisal (PRA) tools, focus group discussions (FGD) and case studies of leprosy affected persons (LAPs), to arrive at the current perception and practices and their reasons. Based on this a framework for a communication strategy was developed. In addition, *haats*, folk art and folk art groups were also studied to identify their potential role in the communication strategy. Field work was conducted over 12 villages in four blocks of the three districts of Chhindwara, Hoshangabad and Betul in July–August 2001.

With regard to the existing knowledge levels it was observed that most villagers were unaware of the prevalence of such a disease. Close relatives and at times even patients who had taken Multi Drug Therapy (MDT) were not aware of leprosy. Also, most of them believed that leprosy or *kushth* was a more recent introduction into their society. Depending upon the physical manifestation of the disease, leprosy was understood (misunderstood) and confused with different ailments. This was perhaps because the physical manifestation (especially at sight) of the disease varies from person to person and from case-to-case, even within the same family. The association of the symptoms of leprosy with common ailments like most skin diseases were found to be very strong. The Gonds identified leprosy only with its terminal stage manifestations, namely disfigurement of limbs. Another universal confusion noticed was between the terms *korh* and *kushth*. While technically and linguistically, these words signified the same thing, they are understood differently at the village level among the Gonds. By *korh*, the Gonds referred to leucoderma, which they considered incurable whereas by *kushth*, they referred to leprosy, which they considered curable. Thus Gonds ranked leucoderma (*korh*) as a far more serious affliction than leprosy (*kushth*).

With respect to the knowledge base on the cause of leprosy, the respondents, both the LAPs and villagers at large, scored poorly. Those who ventured a guess attributed it to contaminated water, wrong food habits like consumption of non-vegetarian food and alcohol. Regarding the process of spread of leprosy, a very clear pattern emerged from the FGD. In all those villages where occurrence of leprosy was isolated or

diffused, the disease was considered non-contagious. However, in the case of villages where leprosy occurred in large numbers and/or was concentrated in one or two families, the disease was considered contagious.

It was seen that the existing knowledge set on identification, cause, spread and cure of leprosy either originated or is transmitted/reinforced to a large extent by the alternative health service providers such as *Parihars* (faith healers), *Jankars* (herbal medicine doctors), *Bengali* doctors (private, usually non-Registered Medical Practitioners). As most of them are not conversant with leprosy and its symptoms, the patients end up taking the wrong treatment for leprosy and case detection is delayed. Despite the functioning of the National Leprosy Eradication Programme (NLEP) for longer than one decade, more than 90 percent of the alternative service providers were not aware of its existence.

With regard to the attitude to disease, it was noticed that the Gonds understood and regarded health in economic terms. To them better health meant less expenditure on health-related concerns. Also, a Gond considered him/herself healthy as long as her/his economic productivity i.e. ability to earn was not impaired. This proves to be a major constraint in dealing with leprosy as the initial manifestation of the disease is generally benign and does not affect economic productivity.. Thus, the patient does not construe it as a health problem at all. In cases where the NLEP has identified patients through surveys, the patient does not feel the need to take the medicines regularly as s/he is not convinced of her/his affliction. To them a disease exists only when accompanied by symptoms such as fever, vomiting or diarrhoea. Thus, they find it difficult to believe that discoloration of skin in patches can ever be the forerunner of a disease as grave as leprosy.

Also, the fact that the MDT only consists of oral drugs is a deterrent. An average Gond believes that injectables are the best form of treatment. S/He does not have faith in tablets as s/he thinks that tablets, being cheaper than injectables are less effective. Also, a Gond does not expect an average treatment to exceed three days. Thus, s/he is not able to accept the concept

of MDT treatment for leprosy extending to months and years. To add to this, the Gonds believe in immediate symptomatic relief when it comes to taking medicines. Thus when a Gond LAP finds that there has been no appreciable change in the symptoms of the disease after the intake of medicine, s/he immediately loses faith in the medicine and discontinues the treatment. The fact that MDT may not help revert to the original physical state is a barrier. Thus if MDT cures them of the infection, but does not cure them of symptoms such as loss of sensation and discoloration of skin, they do not accept it as a cure.

With regard to the LAPs' feeling about self and their place in society, the LAPs exhibited a spectrum of attitudes and emotions towards life. These attitudes were by and large a function of exposure to urban living, literacy and knowledge base of the individual about the disease. It was seen that the initial reaction of the LAP to the receipt of the news that s/he is afflicted with leprosy is that of shock and disbelief. In terms of attitude of the family towards the disease, the attitude is a result of the knowledge base acquired by the family from the elders in society and alternative health providers/local healers. Thus often the physical isolation of the LAP within the family is a result of the recommendation of the local healer. Socially and emotionally, a Gond family does not isolate the LAP except in rare cases. Within a family, occurrence of leprosy in one spouse does not result in her/his estrangement or isolation.

The attitude of the community or the village towards the LAP was found to vary directly with the degree of incidence within a family/village. Where leprosy cases are unusually high and concentrated within a family, the village construed the disease as contagious and at times even took strict preventive steps, such as physical isolation of the patient.

With regard to the current practices of Gonds seeking treatment for leprosy, their behaviour can be classified under two broad categories, referral and treatment. The behaviour of the LAP in the referral process depended upon the manifestation of symptoms. The first stage, in which the patches, initial numbness or swelling begins, is characterised by absence of active

health seeking behaviour. This apathy was present even in families with previous treated cases of leprosy. However, in case the symptom was in the form of blisters and boils, the patient seeks the help of local healers or in rare cases non-registered allopathic practitioners. The spreading of patches, numbness and at times an outbreak of blisters all over the body characterised the second stage. At this stage, the patients or their guardians discuss among themselves or with close acquaintances. In case of blisters, they are likely to consult a local healer or a non-registered allopathic practitioner. In case these symptoms are manifested along with a number of misfortunes in the family, they may consult a faith healer. The third stage is usually one when fingers/toes start disintegrating or get clawed or the patient loses total control over a limb, the family takes desperate action and the patient is taken to private doctors or in rare cases government doctors. The fourth stage is characterised by advanced disfigurement of limbs and total loss of sensation. In this stage, the patient seeks treatment at district hospitals or the missionary hospitals at either Padhar (Betul District) or Kothara (Maharashtra), depending upon their economic status.

This chain in the referral/treatment process is broken only when the NLEP functionary intervenes after having identified the LAPs through a survey or they are referred to the functionary by a doctor. The primary reason for the delay in seeking treatment in the initial stages of the disease is most often because they are not inconvenienced by the disease and also because their most preferred service provider, the *Bengali* doctors, are unaware about the disease.

An average Gond's faith in the government health system is rather low. There is a general distrust of government service providers, which has only been augmented by their casual attitude towards the Gonds. The preference is for private health service providers who may or may not be qualified, but who according to them remember their personal details, are available at all times of the day and night and if needed also provide credit for treatment and medicines.

To find a strategy to overcome the problem discussed, the study took a critical look at the existing communication mechanism so suitable strategies for its improvement could be suggested. The existing communication mechanism was analysed within the basic elements of communication, viz., the Sender, the Message, the Medium and the Receiver. As in other rural areas, here too the primary level sender who communicates various messages of leprosy to the target community is the Non Medical Assistant (NMA). While field work showed that the NMA is well qualified and trained to act as the Sender of the messages, the number of Senders is small, consequently the duration of the Message Reiteration Cycle is too long for an effective absorption rate among the target audience. Hence there is an urgent need to reduce the duration of the Message Reiteration Cycle.

This can be done by generating more Senders. The current Senders are the NMAs. However, with the integration of leprosy services and also because of the high cost involved in increasing staff, the school teacher, *anganwadi* worker and ANM can be trained to give preliminary counselling on leprosy and to identify initial symptoms of leprosy. Once trained, the school teacher can easily undertake preliminary leprosy diagnosis for all the students studying under her/him and make a referral list. The ANM and health worker have the advantage that village women would feel less hesitant in subjecting themselves to visual examination for symptoms of leprosy.

With regard to the message it was noticed that currently the contents of the message are primarily focused upon annulling the myths that leprosy is hereditary, contagious, the result of evil deeds and incurable. While these myths need to be removed from the perception of the target audience, the messages also need to emphasise other dimensions of the disease and its treatment process such as the symptoms of leprosy, how to identify it, what is the cause of leprosy, why does it take long to cure, what is the physical meaning of being cured of leprosy, why are leprosy medicines available free of cost, why are there only tablets and no injectables in leprosy treatment, and why should the treatment be started early and not be discontinued?

Also there is a need to reconsider the medium of communication. The current medium and channels of communication are characterised by on-to-one interaction between the NMA and the patients, or village meetings addressed by the NMA. The NMA also distributes information material such as posters and booklets in Hindi. However, the reach of these mediums and channels of communication is very limited, because of low levels of literacy among target audiences, the easily perishable nature of the visual communication aids such as posters and the lack of enthusiasm on the part of the target audience to attend such meetings.

There is also a need to piggy-back on the state awareness and training programmes. The theme of the *Gram Sampark Abhiyan* (GSA) in 2001 was 'Village Health'. This presented a unique opportunity to diagnose new cases and disseminate information on leprosy. The District Leprosy Officer (DLO) can train the GSA teams on diagnosing and disseminating information. Also, general information on leprosy can be included in health related training programmes for the village *sarpanch* and *panch*. Under the provision of the *Gram Swaraj* declaration in Madhya Pradesh, village health committees have been formed in every village. The presidents of these committees are to be trained in issues of health and access to health services. Danish International Development Assistance (Danida) plans to support this training. Ensuring that this training module also includes a small session on leprosy would result in at least one person per village being aware of the general information available on leprosy.

The study revealed that for every one visit to a government health institution, a Gond makes at least six visits to private doctors. Therefore, a pilot project can be launched to experiment with training private medical practitioners to diagnose leprosy and counsel patients. Another related strategy might be to monetarily award the private practitioner for every confirmed case referred by her/him. The quantum of the award could be anything between Rs.50 and-Rs.75. In addition the Gonds prefer to visit the non-formal medical system, viz., *Parihar, Guniya, Jankar, Bhumka* or *Bhagat* before they decide to approach the formal medical system. It is

thus suggested that the non-formal healers are sensitised to leprosy, its symptoms and identification. This is expected to increase the detection rate and reduce the time lag between the onset of the disease and the treatment.

In addition to wall posters, which have been commonly used in these areas, there is a need to use popular venues such as *haats* (weekly markets and *madais*, the annual fair) as communication platforms. *Haats* are an indispensable part of the life of a Gond. Most of their work outside the village is done on the day of the *haat*. Thus it is suggested to have an information kiosk on leprosy in the *haat*. In order to attract the villager, the information kiosk can play popular songs interspersed with messages on leprosy, preferably in Gondi (the Gond language). Another popular event is the annual *madai*. Besides being a mega *haat*, the *madai* lasts for 3-4 days. The average number of visitors to a *madai* ranges from 6,000-8,000 as compared to 1,000-2,000 at a *haat*. The main attraction at the *madai* is the many cultural and sporting events that are popular with the Gonds. A radical proposition for NLEP or DANLEP is to sponsor prizes for select cultural events at the *madai*. The occasion can be used to disseminate general information about leprosy. In addition, local folk theatre like the *Ram satta* can be tapped to increase awareness and knowledge.