Leprosy in Tribal Madhya Pradesh

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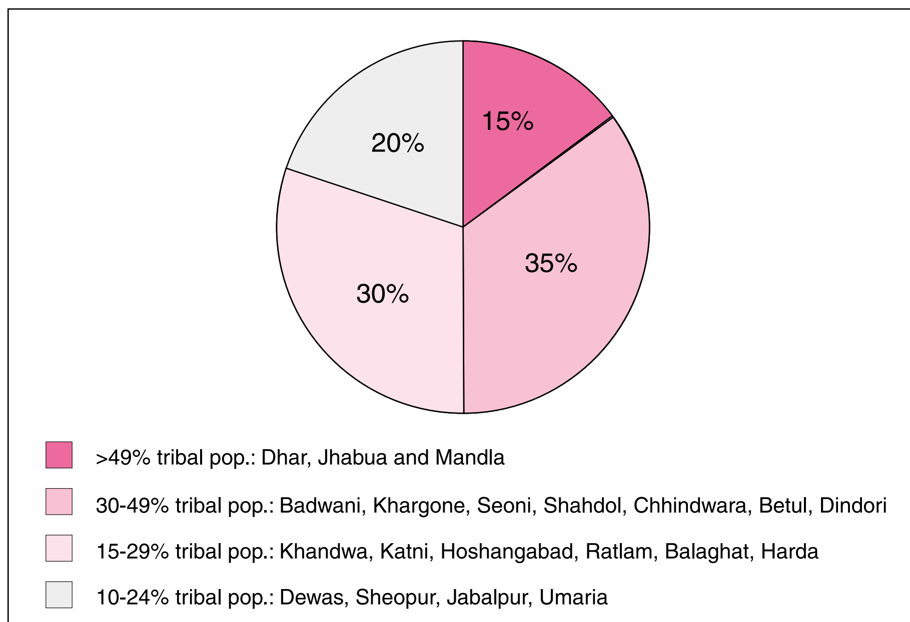
Background

The tribal population of Madhya Pradesh is 10,281,532, constituting 22% of the state's total population. It is mainly spread over 21 tribal districts. There are 92 tribal blocks, and 33 partially tribal blocks.

The main tribal groups in the state are the Bhil, Gond Sahariya, Baiga, Halba, Bahariya, Kol, Korku, Oroan and Saura. Together, the Gonds and Bhils constitute 75% of the tribal population of Madhya Pradesh.

Figure 1: Tribal districts of Madhya Pradesh, grouped by proportion (%) of tribal population to total population



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A total of 66 SAPELs have been conducted in 15 districts covering 2,784 villages in Madhya Pradesh. The effectiveness of this approach in detecting hidden cases is illustrated by an increase in NCDR and PR after the SAPEL. For instance, during a SAPEL conducted in 1998 in Rama block of Jhabua district, out of a total of 146 suspected cases, 82 were confirmed during a campaign period of one month. Prior to the SAPEL, there were only 18 registered cases in the block. While the pre-SAPEL PR was 2.1, the corresponding figure for the post-SAPEL period jumped to 11.6. More SAPELs are required in districts like Jhabua, Khargone, Shahdol, Umaria, Dindori and Sheopurkala, where the gap between registered and expected PR remains high.

DANLEP-facilitated activities in tribal areas of Madhya Pradesh

In addition to facilitating the SAPEL projects in the state, the DANLEP Madhya Pradesh unit has helped develop context specific IEC material for awareness-generation in tribal areas. Street Theatre or *kala pathaks* and interactive huts have been organised. With a strong focus on destigmatisation and social integration of leprosy-affected persons, several Care and Concern camps have been organised in interior villages. One such POD camp was organised in Heedli village in Betul district on 7-13 February 2003. In addition to these camps, attempts have been made to bring providers, patients and communities together on a common platform in response to specific circumstances. For instance, when the body of an inmate of Karuna Sadan, a leprosy mission hospital in Jhabua, was sent back to her village for burial, her family refused to perform the last rites. Due to the on-going association between the DANLEP zonal co-ordinator and the missionary hospital, a trialogue was organised in

A tribal woman sharing her story as a leprosy patient at a POD camp.

the deceased inmate's village to increase people's awareness about leprosy with the hope of diminishing stigma in the village community.

Attempts have also been made by DANLEP, Madhya Pradesh, to spread the message of leprosy elimination through advocacy with the tribal welfare and forest revenue departments.

While the earlier focus in tribal areas in Madhya Pradesh was mainly on IEC activities, more recently concerted efforts have been made to develop link workers (one male and one female for each village) using the networks of the Gayatri Pariwar, a socio-religious organisation that has become a major partner in leprosy elimination activities in Madhya Pradesh and Chhattisgarh. In Betul district, DANLEP has established links with World Vision, a Christian relief and development organisation mainly working for the well-being of children. Its activities include emergency relief, education, health care, economic development and promotion of justice. The Betul unit of World Vision is working in a number of villages on these issues. During October 2002, it provided material assistance for the organisation of a POD camp in Betul town. More recently, a house-to-house survey was conducted in Kholgaon village with the help of the *panchayat* members and local volunteers.

Partnership with the Gayatri Pariwar

The Gayatri Pariwar is a socio-religious organisation that seeks to promote traditional Hindu values. DANLEP, Madhya Pradesh, has collaborated with the Gayatri Pariwar for leprosy elimination activities in a partnership that was publicly announced in February 2003 at a public meeting in Bhopal, when the International General Secretary of the organisation declared the incorporation of leprosy in its health agenda in Madhya Pradesh. The organisation, in fact, pledged to make Madhya Pradesh leprosy-free in the presence of the Chief Minister. This was in line with earlier contributions, as for example the first Care and Concern camp was organised by the Gayatri Pariwar as far back as in 1988 in a temple in Bhillai (now in Durg district of Chhattisgarh). Subsequently, similar camps were organised in Balaghat, Jabalpur and other districts in undivided Madhya Pradesh.

The Gayatri Pariwar works through local units at village, block and district-levels to promote vegetarianism, anti-alcoholism, literacy, youth welfare, and

women's empowerment. In the tribal areas of Jhabua and Badwani districts, it regularly organises public functions called "*Vaishno Mukti Samaroh*" aimed at making the participants adopt a Hindu way of life. In the given context, this primarily means giving up the consumption of meat and alcohol. For instance, during April 2003 one such event was organised by Damania Baba in the Salli Tanda village of Rajpur block in Badwani district. Over 200,000 tribal persons participated in the three-day camp, which was inaugurated by the Chief Minister of Madhya Pradesh. Damania Baba, himself a tribal, is a direct disciple of the founder of Gayatri Pariwar, the Late Sriram Sharma Acharya. The theme of leprosy was woven into the main agenda of the camp.

Subsequent to the formal pledge to make Madhya Pradesh leprosy-free by the Gayatri Pariwar Madhya Pradesh unit, the activities to this end have become more structured. DANLEP has facilitated the collaboration between the local Gayatri Pariwar units and the NLEP and general health care system functionaries. In order to increase awareness about leprosy in the general public, the theme of leprosy elimination is also mentioned in the regular prayers. Indeed, the organisation of POD camps in temples links the themes of destigmatisation and religious worship.

Health seeking behaviour among two major tribes of Madhya Pradesh

In order to gain a more comprehensive understanding of people's perceptions of leprosy and their health-seeking behaviour among different tribal groups, DANLEP Madhya Pradesh has contracted NGOs like Vimarsh in Bhopal and Sambhav in Gwalior to undertake studies on specific tribal communities such as the Bhils in Jhabua district, the Gonds in Hoshangabad, Chhindwara and Betul districts and the Sahariyas in Sheopur, Shivpuri, Gwalior and Guna districts.

The health-seeking behaviour of individuals and communities are embedded in their socio-cultural context. It is, hence, important to take cognizance of the distinctive, socio-cultural and linguistic characteristics of the local communities when focusing on leprosy elimination campaigns in tribal areas. In view of the demographic preponderance of the Gond and Bhil tribes in Madhya Pradesh, the DANLEP unit of Madhya Pradesh, as part of its tribal strategy initiative, commissioned two studies on the understanding,

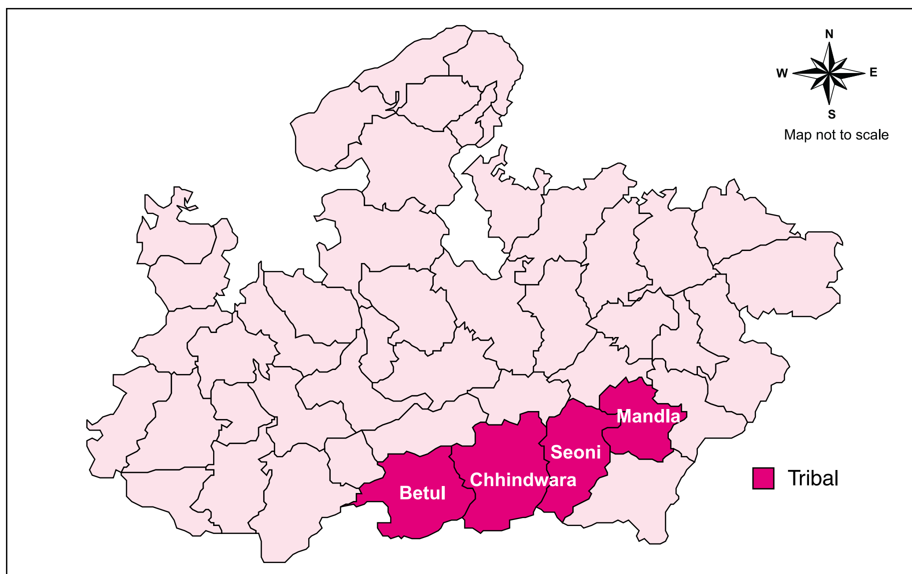
perceptions and treatment behaviour with regard to leprosy at the individual and community-levels.[2] In addition, an important aim of these studies was to recommend context-specific communicative strategies to enhance awareness about leprosy and MDT acceptance among the tribal communities.

Leprosy among the Gonds[3]

The Gonds are the single largest tribal group both in Madhya Pradesh and in India. In Madhya Pradesh, they mainly reside on the Satpura Plateau stretching across the districts of Chhindwara, Betul, Seoni and Mandla.

The incidence of leprosy is not high among the Gonds. The statistics suggest an inverse relationship between leprosy prevalence and the concentration of tribal population in the blocks. Higher numbers of leprosy cases are found in villages with larger number of non-tribals situated near markets and railway stations. The observed lower prevalence rate among the Gonds could either

Figure 2: Districts in Madhya Pradesh with a concentration of the Gond Tribe



[2] *See Leprosy: Perceptions and Practices of Gond in Betul, Chhindwara and Hoshangabad*. Vimarsh/DANLEP (2002). And *"Leprosy: Perception and Practices of Bhil in Jhabua"*. Centre for Advanced Research and Development/DANLEP (2002).

[3] Adapted from *Leprosy: Perceptions and Practices of Gond in Betul, Chhindwara and Hoshangabad*. Vimarsh, Bhopal. New Delhi, 2002: DANLEP

be due to an actual difference in epidemiology between tribal and non-tribal populations, or it could be a result of higher levels of awareness about leprosy and its treatment in villages more exposed to the outside world.

In the catalogue of skin afflictions in Gond society, leprosy or *kushta* is often identified in its later manifestations in the form of disfigurements and deformities. It is distinguished from *korh* (leucoderma), which is considered a more serious disease as it is not curable. The believed etiological factors leading to the onset of *kushta* range from contaminated water to consumption of meat and liquor. The belief in the infective potential of the disease is often linked to the pattern of its local occurrence, that is, if a large number of persons are affected in the village, especially if there is familial clustering of cases, it is considered contagious.

Generally, leprosy-affected persons among the Gonds are not isolated or stigmatised. The pattern of seeking treatment depends on the course of the disease. In the early stages when it appears as a painless patch, the traditional healer might be consulted. However, with progressive deterioration, the patient would move closer towards accessing allopathic government services. Thus at the level of advanced disfigurement of limbs and loss of sensation, the patient would make the journey to the district or missionary hospitals for treatment. This treatment seeking pathway is only broken, if the patient is identified through a survey or referred to the NLEP by a doctor.

The reported absence of stigmatisation of leprosy patients among the Gonds was confirmed by the accounts of health workers in Betul and Hoshangabad districts. Although the patients might not be allowed to participate in religious functions, there was no physical isolation or social discrimination against them.

Leprosy among the Bhils[4]

The Bhils are concentrated in Western Madhya Pradesh, mainly in the districts of Jhabua, Khargone, Dhar, Khandwa and Dewas. They also live in the neighbouring states of Rajasthan and Gujarat.

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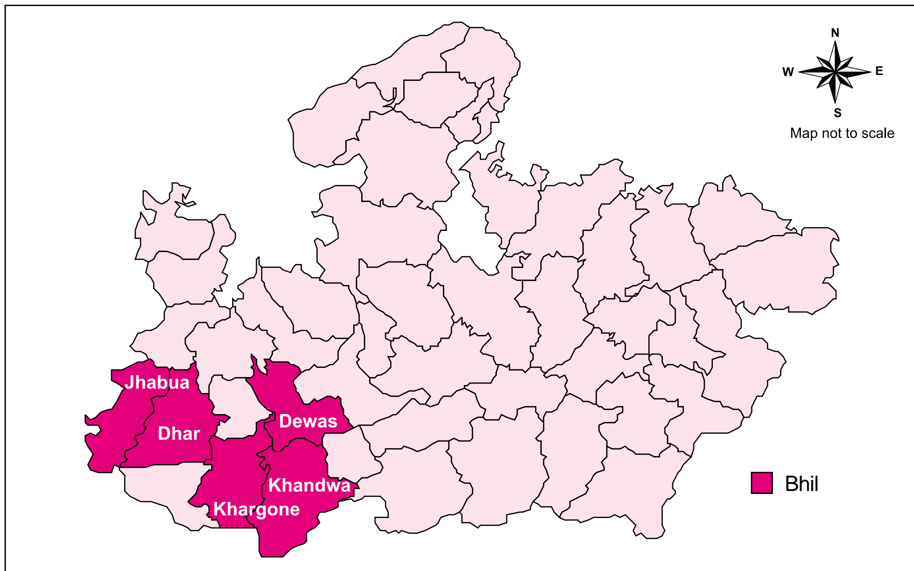
[4] Adapted from *Leprosy: Perception and Practices of Bhil in Jhabua*. Centre for Advanced Research and Development. New Delhi, 2002: DANLEP.

Figure 3: Districts with a concentration of the Bhil Tribe in Madhya Pradesh



The Bhils have a distinct culture in which the status distinctions and purity-pollution concepts of mainstream Hinduism have been adopted.

There are several terms referring to leprosy among the Bhils like *Korh, Vaabi, korh vaabi, motala, motali mata, patbala* and *bada dukh*. While *motali mata* and *bada dukh* are most commonly used in Jobut block of Jhabua district, *patbala* is most often used in Sondwa block and *korh* and *kala vaabi* in Thandla Block of Jhabua district. As in the case of the Gonds, the early stages of the disease in the form of skin patches or spots were categorised as simple skin problems for which local doctors would be consulted. It is only in the later stages when ulcers, deformities and large-scale loss of sensation set in, is it labelled as leprosy. The disease is then perceived as a punishment for sins, ranging from consumption of meat and alcohol to theft and murder. It is considered an incurable affliction, which runs in families.

Due to the perception that leprosy is incurable and to the stigma associated with it, leprosy workers often do not give the diagnosis to the patient for fear of causing further distress and treatment default. Although well-intentioned in the short run, this approach may in the long term diminish the urgency to access timely and affective treatment.

The pattern of treatment often involves consultation of a range of practitioners with the government health facility being the last pattern of resort. *Jadi butti* (herbal treatment) and *badavi* (black magic) may be followed by visits to 'Bengali' doctors at the village-level.[5] Other private doctors may be consulted in the larger towns. The financial costs of this doctor-shopping are an additional burden to patients and families already entrenched in poverty.

The irregularity of survey work in far flung villages by NLEP workers means that many patients would not be picked up through routine surveillance. Due to basic mistrust of the government system and lack of knowledge about the curability of the disease and the availability of free treatment in government hospitals and dispensaries, most patients are started on MDT at a late stage of leprosy. The study in Jhabua showed that 90% of patients started MDT at an advanced stage of the disease marked by loss of sensation in limbs, clawing of fingers and bleeding in toes.

Under such circumstances, the temporary side-effects of MDT, the long duration of treatment and the partially irreversible nature of existing disfigurements and deformities are frustrating experiences leading in many cases to treatment discontinuation and further deterioration. The perceived absence of symptomatic relief and persistence of disabilities, even after the full course of medication has been completed, has resulted in a strengthening of the belief that leprosy is incurable. Routine counselling by health workers, explaining the process of long-term treatment under MDT, would go a long way in changing the low treatment completion rates among leprosy-affected persons, since treatment default is correlated with a negative perception of treatment outcome.

Unlike the Gonds, leprosy is highly stigmatised among the Bhils. It is regarded as a highly infectious disease which can be contracted by merely sitting, eating or talking to a leprosy-affected person. Leprosy-affected persons try to hide the tell-tale signs of the disease, shy away from social gatherings for fear of being discovered and ostracised. Families of leprosy-affected persons may also discriminate against them by keeping their clothes

[5] A generic term referring to all kinds of unregistered medical practitioners and quacks.

and utensils separate. A separate hut might be built a little away from the village for the patient to stay in. The marriage prospects of leprosy patients and their children may be compromised on account of the disease. Leprosy patients often lose their basic right to a normal life in the community.

The severity of stigmatisation is reflected in such practices as burying leprosy-affected persons alive, so that their soul cannot return to the same family and village to afflict others. It is believed that this practice will actually ensure the salvation of the affected person. The corpse of a leprosy patient is not cremated because it is believed the germs will spread through the fumes of the funeral pyre. Residents of a leprosy mission in Jhabua district could not return home for fear of being killed by their immediate family members.

The strong social taboos and prejudice associated with leprosy are reflected in the treatment process as well. In order to avoid being found out, leprosy patients and their families do not want the health worker to come to their home to dispense medicines, preferring instead to collect the drugs themselves from the health facility. But due to the long distances and difficult terrain, there are often disruptions in the treatment regimen.

Conclusion

In all its tribal activities, DANLEP, Madhya Pradesh, has attempted to promote internalisation of leprosy through the involvement of a range of CBOs and NGOs. This has been done with the aim of ensuring continuity of ongoing activities in a situation where DANLEP is phasing out and the NLEP will be merged with the general health system. In tribal areas such as Jhabua and Badwani, the grass-root networks of the Gayatri Pariwar are being channelled to promote leprosy work at the village and block-levels. In addition to providing direct services through skin and POD camps, the main objective is the establishment of strong linkages between the local-level functionaries of the Gayatri Pariwar and the health system in the training of link workers to carry back knowledge about leprosy to their respective villages.

In the case of Betul, advocacy by the Madhya Pradesh unit has resulted in World Vision, an international NGO, incorporating leprosy work in its local agenda of action. This kind of networking is one way of working towards local ownership of the programme.

Interviews conducted with representatives of both the Gayatri Pariwar and World Vision at the time of documentation revealed a high level of commitment to leprosy elimination. The Gayatri Pariwar units in Jhabua and Badwani have chalked out a calendar of activities in the form of training workshops, and skin and POD camps. World Vision is a good candidate for carrying on leprosy work. In addition to being a well-resourced NGO with an international standing, it also undertakes developmental work in a number of tribal villages. With proper orientation, it can organise surveys and ensure follow-up of identified cases in these areas. Dovetailing leprosy with other developmental activities is likely to be the best way of sustaining the momentum towards elimination.