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Knowledge, Attitude and Practice

The health seeking behaviour of any community is a result of the knowledge, attitude and practices (KAP) prevalent in that community. The dimensions of KAP act as key determinants of any health seeking behaviour and are mutually dependent and embedded in the social and cultural milieu of that particular community. While this is true in all health related issues, it is specially so in a disease such as leprosy, which besides being a physical affliction, also has a social stigma attached to it.

During the course of the study, special emphasis was on understanding the KAP of the Gonds with respect to leprosy. It was expected that this will help in understanding the prevalent health seeking behaviour and in determining the nature of and the cause of differentials between the ideal behaviour and the prevalent behaviour.

The following text tries to analyse the KAP dimensions of leprosy among Gonds. While the analysis has been categorised under the three dimensions, it should be appreciated that knowledge, attitude and behaviour are not mutually exclusive categories. In fact, one determinant leads to and is influenced by the other. As a result, the boundaries between these dimensions are often blurred.

Knowledge

Occurrence/Existence of the Disease

During the course of the study, more than 30 LAPs were interviewed in detail, in addition to the FGDs conducted in the villages. In more than 20 cases, leprosy was reported as a new occurrence. In about 20 cases, the

villagers were unaware of the prevalence of such a disease. This perception is corroborated by the observation during the PRA exercises. In every village, mapping of KAP was attempted for the most common diseases. For this as the first step, a list of common diseases prevalent in the field was drawn up in the PRA group. Almost always, leprosy never featured in the list. The most common diseases/ailments that featured were fever, cold, diarrhoea, malaria, skin ailments and asthma. Then leprosy was introduced as an external item into this list. The listed diseases were then prioritised and ranked by the community based on their occurrence and importance. In this ranking exercise, leprosy always ranked the last in terms of its importance *as perceived by the community*. (As an example, the KAP matrix output for village Chhatribad (Shahpur block, Betul) has been attached.

In addition, the Gonds believed that leprosy or *kushth* was a more recent introduction into their society. During the PRA exercises, an attempt was made in every village to chronologically elicit the disease prevalence between 1960 and 2000. In this, it was almost always seen that leprosy featured as a disease only in more recent years.

Recognition of the Disease/Symptoms

It was observed that depending upon the physical manifestation of the disease, leprosy was understood (mis-understood!) and confused with different ailments. Among all the persons interviewed and interacted with, the degree of awareness about the symptoms of leprosy was found to be negligible. Interestingly, even in households where one member is already suffering from the disease, the ability to detect the symptoms in other members of the household was very low. This particular observation is grounded in the fact that the physical manifestation of the disease varies from person to person and from case to case, even within the same family.

KAP Matrix for Common Diseases, Chhatribad

	बहुत लोगों को होता है क्या?	जान लेवा	[illegible]	[illegible]	[illegible]	[illegible]
[illegible]	●●●●●●	●●●●●	●●●●●●	[illegible]	[illegible]	[illegible]
[illegible]	●●●●●	●●●●●●	●●●●●●	〃	[illegible]	〃
[illegible]	●●●●	●●●●	●●●●●	[illegible]	[illegible]	〃
[illegible]	●●●●●●●	●●●●●●●	●●●●●●●	[illegible]	[illegible]	[illegible]
[illegible]	●●●	●●	●●●●	[illegible]	[illegible]	[illegible]
[illegible]	●●	●	●●●	[illegible]	〃	〃
[illegible]	●	●	●●	[illegible]	〃	〃

Venn Diagram: Health Providers, Chhatribad

Traditional knowledge: Boon or bane?

During the Focus Group Discussion at village Aamdhana, Dr. Gupta from DANLEP explained the initial symptoms of leprosy and demonstrated the identification process with the help of leprosy affected persons of Aamdhana. However, the group of villagers having patiently listened to Dr. Gupta, reiterated that the explanation of Dr. Gupta as to what was the symptom of leprosy was wrong. This went on for hours. Even as the focus group discussion concluded, the villagers were not fully convinced.

In the case of Suresh (Barbatpur, Betul), the manifestation of the disease was in the form of numbness, whereas in the case of his father who contracted leprosy at a much later date, the symptoms were that of pale patches. It should be mentioned here that despite suffering from leprosy, Suresh could not identify the symptoms in his father and recognise them as symptoms of leprosy.

In addition to this, the repertoire of existing knowledge among the Gonds also acts as a barrier in identifying the symptoms and associating them with leprosy. During the course of the study, it was found that the Gonds confused and associated the initial symptoms of leprosy with different types of skin ailments.

The Gonds identified leprosy only with its terminal stage manifestations, namely disfigurement of limbs.

Another omnipresent confusion noticed was between the terms *korh* and *kushth*. While technically and linguistically, these words have the same meaning, they are understood differently at the village level among the Gonds. By *korh*, the Gonds referred to leucoderma, whereas by *kushth*, they referred to leprosy. According to them, *korh* was incurable, whereas *kushth* was curable. Thus Gonds ranked leucoderma (*korh*) as a far more serious affliction than Leprosy (*kushth*).

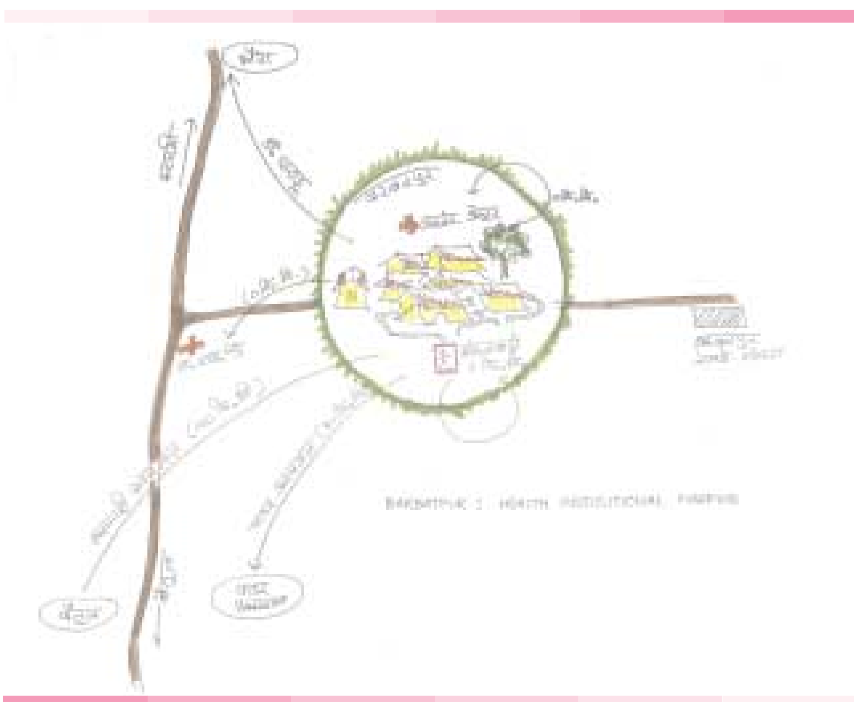
A case in point is that of Malti (village Kala Akhar, Kesla). Malti is suffering from leucoderma. While some refer to her ailment as *korh*, others believe that it is *kushth*. As a result, she is confused and is not sure of her disease. When the study team interviewed her, it was found that she took medicines for both the ailments.

No.	Manifestation	Understood as	Remarks
1	Pale patches	Sheeva, Vahi, Chatta	This was found to be the principal category of symptoms (50-60%)
2	Numbness	Weakness (*kamzori*)	This was a less common initial symptom (20-25%)
3	Blisters	Skin allergy	This again was a less common initial symptom (20-25%)

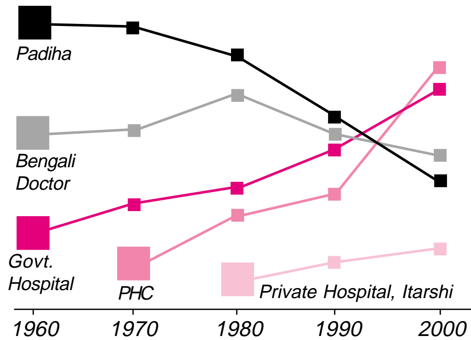
The association of the symptoms of leprosy with the local ailments was found to be very strong.

Cause of Leprosy

As to the knowledge base on the cause of leprosy, the respondents, both LAPs and FGD participants, scored feebly. However, there were exceptions. The people of Kala Akhar (Kesla block) believed that impure water caused leprosy. The family of late Puniya Saharey (village Ulhawadi, Chhindwara) believed that wrong food habits like intake of non-vegetarian



Junkar: Popularity of Health Service Providers



food and consumption of alcohol had a major role to play in the cause of the disease and its perpetuation. In the case of village Jaatasemar, the villagers believed that leprosy came to their village from outside. They believed that the villagers of Jaatasemar contracted leprosy when they went out of the village to big cities such as Nagpur.

The PRA process in these three villages (Kala Akhar, Ulhawadi, Jaatasemar) showed an interesting correlation. It was found that inadequate availability of safe drinking water was a major problem for the residents of Kala Akhar. Hence, the villagers of Kala Akhar saw every health issue as an outcome of this problem. In the case of Puniya Saharey, it came out that he consumed alcohol in excess. This was a major cause of worry for Puniya's family, especially his wife, Shantibai. Thus, she attributed the cause of leprosy to alcohol and food habits.

Jagram: Trust betrayed

When Jagram visited the private 'Doctor' at Shahpur with his initial symptoms of leprosy, the 'Doctor' advised him to discontinue the consumption of tea and assured him that this would cure him. Jagram, trusting by nature, followed the *diktat* of the doctor for 14 years, only to end up in an advanced stage of leprosy that left him with permanent disfigurement of limbs even after the infection was cured by MDT. Thanks to NLEP and the local NMA, he was diagnosed and further disfigurement could be avoided.

In the case of Jaatasemar, the village was a homogenous settlement of Gonds living in harmony since decades. However, recently, the youth of the village had started migrating out of the village in search of better livelihood opportunities. The village elders did not look upon this transition process kindly. They believed that the external world polluted their children. Thus, it can be seen that the causes attributed to leprosy were principally controversial issues for which the village community had not yet arrived at a solution.

Dr. H.R. Paul at his clinic: Khamarpani, Block Bichhua

How it Spreads?

Regarding the process of spread of leprosy, a very clear pattern emerged from the focus group discussions (FGDs). In all those villages where

A list of villages visited and their brief opinions on how the disease spreads.

S.No.	Village	Disease occurrence pattern	Perceived spreading of the disease
1	Kala Akhar	Diffused	Non Contagious
2	Khasda Kurd	Concentrated in a few families	Contagious
3	Palaspani	Diffused	Non Contagious
4	Jhunkar	Concentrated in a few families	Contagious
5	Aamdhana	Diffused but many patients	Contagious
6	Barbatpur	Diffused	Non Contagious
7	Shahpur	Diffused	Non Contagious
8	Badosa	Concentrated in one family	Contagious
9	Ulhawadi	Concentrated in one or two families	Contagious
10	Jaatasemar	Diffused	Non Contagious
11	Kanhargaon	Diffused	Non Contagious
12	Chhattribad	Diffused	Non Contagious

A Non-functional 'Bengali' Clinic at Badosa

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.

Knowledge Base of Alternative Service Providers

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*, local healers, and '*Bengali*' doctors. Hence the knowledge base of these alternative service providers is very important as the faith of the Gonds in alternative systems of medicine is stronger than in the formal system. This is especially so in the case of skin ailments, with which the initial manifestation of the disease is often confused. The knowledge base of these alternative service providers on leprosy was found to be grossly inadequate and minimal at best.

Dr. Patankar (Pandu), a very famous private doctor in Bhoura, claimed to the study team that he had a sure cure for leprosy which required only three doses to treat the disease. It was seen that more than 95 percent of the leprosy patients interviewed had visited one or other type of alternative health providers. In almost all of these cases, no patient was diagnosed correctly. Nor was any patient referred by them to the appropriate leprosy health service provider as there is fierce competition between the different systems of medicine and referral to another service provider amounts to promoting the competitor.

Despite the functioning of National Leprosy Eradication Programme (NLEP) for a decade or so, more than 90 percent of the alternative service providers were not aware of its existence.

Thus, in addition to the knowledge set of the Gonds, the inadequacy of knowledge and information on the part of the alternative service providers, is another key deterrent to the success of the NLEP.

Attitude

Attitudes are an outcome of understanding of a given quantum of knowledge in a particular social/cultural milieu in the light of past experiences. In the KAP continuum, attitude plays a pivotal role in linking knowledge to action. It should be appreciated that correct knowledge in the absence of right attitude will yet result in unfavourable action. In order to understand the attitude of the target community towards leprosy, it was attempted to understand the perception of the Gonds on what they construe as health, disease, medicine/treatment and cure. The FGDs highlighted a number of interesting opinions.

Attitude towards Health

It is important to note that the Gonds understand and regard health in economic terms. To them better health meant less expenditure on health related issues. Also, a Gond considers him/herself healthy as long as his/her economic productivity i.e. ability to earn was not impaired. Thus, it can be seen that among Gonds, health is not considered important *per se*, but as a determinant of economic productivity.

The Government is trying to push cheap medicines onto us!

In village Kala Akhar, during the FGD, while the NMA was explaining the treatment process for LAPs, Amrit Lal (panchayat member) opined that the medicine must be very cheap and ineffective as it took such a long time to cure the disease. He was also very disappointed when he learnt that the treatment consisted of only tablets and no injectables. He accused the government machinery of having sold off the injections and of distributing only cheap tablets to the patients.

This attitude towards health 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 of the patient, 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 he is not convinced of his affliction. This is another reason that during the entire gamut of PRA exercises, leprosy was accorded the least importance/priority.

A classic example of this is the story of Mamta and Meena (case study — *A tale of two sisters*). The central theme of the case is the reluctance on the part of the patient to consume the medicine regularly as there is no immediately apparent adverse effect when the patient discontinues the intake of medicine.

> Every time a villager looked at him, Suresh felt that the villager was searching for tell-tale symptoms of leprosy on his body.
>
> *(Suresh, Barbatpur, Betul)*

Attitude towards Disease

Among the Gonds, a disease is something that sets in immediate physical discomfort often leading to loss in economic productivity. According to the Gonds, a disease exists only when accompanied by symptoms such as fever, vomiting or diarrhoea. Thus, the Gonds find it difficult to believe that discolouration of skin in patches can ever be the forerunner to a disease as grave as leprosy.

The inability of a Gond to accept the symptoms of leprosy as that of the grave disease, is best captured by the words of Somji Saryam (Kala Akhar, Kesla). *Na bukhar, na ulti aur na hi dard. Phir isko bimari kaise maanen*? (*No fever. No vomiting. Nor pain too. Then how am I to accept it as a disease?*)

Attitude towards Medicine/Treatment

During the course of fieldwork, it was found that an average Gond believes that injectables are the best form of treatment. He swears by injections

and intravenous treatment. He does not have faith in tablets as he thinks that tablets, being cheaper than injectables, are less effective. In addition, a Gond does not expect an average treatment to exceed three days. Thus, he is not able to accept the idea that the treatment (Multi Drug Therapy) for leprosy can stretch for months and years.

Testing for Leprosy

Also, 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, he immediately loses faith in the medicine and discontinues the treatment.

Attitude towards Cure

The Gonds are once again very clear about what constitutes a cure and what does not. According to them, a cure should be fast and must be symptomatic. Thus if MDT cures them of the infection, but does not cure them of symptoms such as loss of sensation and discolouration of skin, they do not accept it as cure. Almost always, symptoms such as pale patches, loss of sensation in limbs and clawing of hands are irreversible. Thus, though technically cured, the Gonds do not accept this as cure and hence spread the word around that the particular medicine is ineffective, as it does not cure fully.

Attitude towards Leprosy Affected Person (LAP)

The attitudes towards the LAP can be classified into three broad categories:

a. Attitude of the LAP towards self
b. Attitude of the family members towards the LAP
c. Attitude of the community towards LAP

Attitude of the LAP towards Self

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 on the disease. Of course in addition to this, there is the set of attitudes inherited from one's social and cultural environment. The attitude of the afflicted towards one's self ranged from self-pity on one end (Kaliram Uike, Shahpur) to indomitable spirit on the other end (Balia Bai, village Aamdhana).

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. This was because, people associated leprosy with its terminal stage of physical manifestation, that of disfigurement of limbs.

However, the ability of coping with the disease was found better in the older generation than in the younger generation. During interviews with LAPs of various age groups, it was found that patients who were afflicted by the disease about 15 years ago had fewer problems at the individual level in accepting their affliction compared to the younger generation. The social stigma attached to the disease is more among the new generation of Gonds than in the old generation.

Bengali doctors vs government doctors

The team interviewed 11 private doctors who practiced in the villages being studied. While some of the old '*Bengali*' practitioners were Registered Medical Practitioners having cleared exams and having received their registration from Calcutta, most others had only some diploma in Ayurveda, Unani, Homeopathy or even at times uncommon subjects like a Diploma in Iridology. Most of them acquired knowledge of allopathic medicine either from their father/brother who were into similar practice or by working as assistants or compounders to MBBS doctors.

From the discussion with the villagers, it was amply clear that the villages preferred the *Bengali* doctors to the government doctors. Their faith in the '(*Bengali*) doctors' is a result of a number of factors. Firstly, there is a personal touch in the behaviour of the private practitioner towards the patient, which unfortunately is absent in the government hospitals. Villagers said that they felt alienated in the environs of the government hospitals. Also, the villagers have a weakness for treatment that gives symptomatic relief. The *Bengali* doctors have understood this psyche of the average villager. The added attraction in approaching the private doctors is that they give treatment on credit and also arrange for credit for the purchasing medicine. Also, the villagers have the option of paying in kind (such as with agricultural produce, vegetables, goat and chicken). Then there is also the practice of differential billing, where the villager might be asked to pay less than the usual fees if he is financially very poor. It should be noted that the average tribal in these areas is not even aware that they are not qualified doctors. This is clearly reflected when they go to PHCs and are not able to differentiate between the doctors and compounders. Many PHC compounders exploit this ignorance and charge them in return for a prescription and some medicines.

This is because of the increasing urban linkages in the Gond society. With increasing urban contacts, the society was found to be more biased against the disease and the LAP. Thus the younger generations, who are decidedly more 'urban' than the older generation, discriminate against the disease and disease affected persons and in turn feel discriminated against, in case they themselves are affected by the disease.

Attitude of Family Members towards LAP

The attitude is a result of the knowledge base acquired by the family from the elders in the society and alternative health providers/local healers.

Thus often the physical isolation of the LAP within the family is because 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 a spouse does not lead to his/her estrangement or isolation.

Attitude of Village Community towards LAP

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 was contagious and often took strict measures like the physical isolation of the patient. (Puniya Saharey of village Ulhawadi, Chhindwara.) While leprosy does not constitute a reason for bias if it occurs after marriage, the Gonds prefer not to bring in brides/grooms who are known to be suffering from the disease. There is absolutely no bias against the LAP at social events. It is important to mention here the case of Jaatasemar (Chhindwara). In this village everybody believed that leprosy has spread in the village from Sabulal. However, they were all warm about their relationship with Sabulal. Their feelings are best expressed by Bisan.

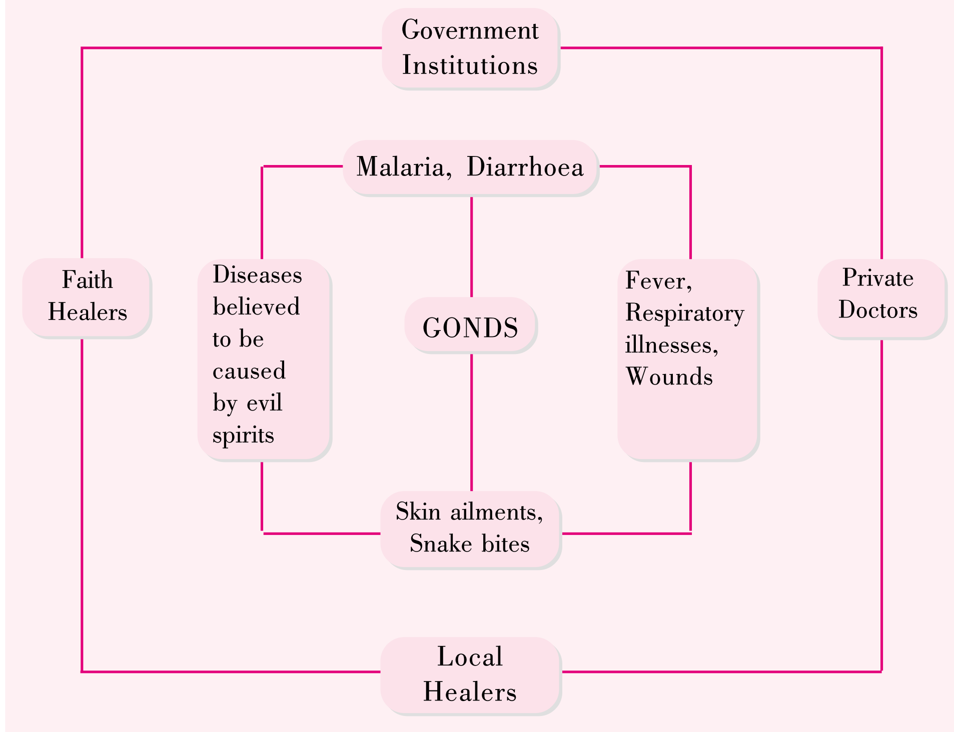
> *We know Sir, that the root of the disease in our village is Sabu. We also know Sir, that not only we, even his daughters and son got the disease from him only...but it is not his*

fault…even if it is…so what…shall we stop sharing our beedi, our Mahua with him…shall we stop sharing these small pleasures of our lives with him…

Attitude towards Health Service Providers: Government vs Non-Government Institutions

It was seen during the focus group discussions that the Gonds' faith in the different health institutions, formal as well as non-formal, varies according to the health problem. The degree of trust is undoubtedly influenced by how the disease has been classified. General ailments that are more likely to be classified as caused by evil spirits are treated by the *Parihar* or *Bhumka*. Ailments such as skin diseases are treated by local healers who rely on herbal medicines. Diseases like malaria, diarrhoea, cases of accident-related trauma, and flesh wounds are treated at modern medical institutions. The villagers turn to government-run institutions only in case of malaria and diarrhoea. Their preferences can be seen in the health institution mapping exercise of the health service provider vs the disease.

Recourse to the formal system of medicine is their last resort. Even here, they prefer the private health service provider who may be registered (RMP) or non registered (*Bengali* doctor). There is a general distrust of government service providers, which has only been amplified by the casual



attitude of government health functionaries towards the Gonds. They feel that the government health institutions are totally impersonal, unlike the *Bengali* doctors, who according to them remember their personal histories. Also, their services are more dependable – government doctors are often not available – and they give both treatment and medicine on credit, which is very important for these poor tribals. In general, the Gonds take the following route in the referral process: from faith healer to local healer, then to private doctor and finally to government institution. The disease is usually cured at one of these stages. When it does not happen, the cycle is reversed with the Gonds turning to the less recognised forms of treatment.

Practice

The health seeking practices among the Gonds in the case of leprosy can be discussed under two broad categories, *referral* and *treatment*.

The Referral Process

The stages in the referral process can be classified according to the manifestation of symptoms. The symptoms in the first stage are patches, an initial numbness or slight swelling. A characteristic of this stage is the absence of active health seeking behaviour. Even families with members who were previously treated for leprosy were found to be apathetic. However, in case the symptom was manifested in the form of blisters and boils, the patient sought 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 were characteristics of the second stage. At this stage, the patients or their guardians discuss the condition among themselves or with close acquaintances. In the case of blisters, they are likely to consult a local healer or a non-registered allopathic practitioner. In case these symptoms are accompanied by a number of misfortunes, the family may consult a faith healer.

The third stage is usually when the fingers/toes start disintegrating or get clawed or the patient loses total control over a limb. The desperate family then takes the patient to private doctors or, in rare cases, to government doctors.

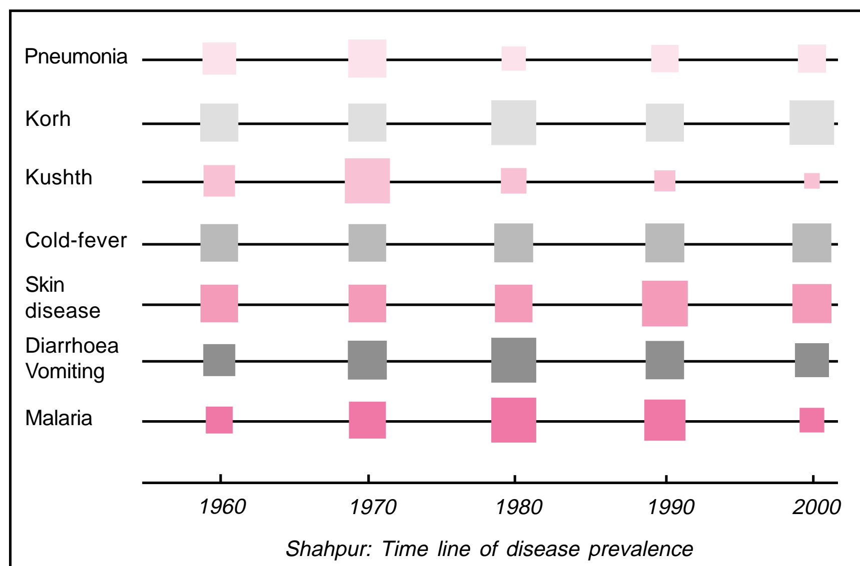
The fourth stage is characterised by advanced disfigurement of limbs and total loss of sensation. At this stage, patients seek redressal at the district hospitals or the missionary hospitals at either Padhar or Kothara, depending upon their economic status.

This chain in the referral/treatment process is broken only on the intervention of the NLEP functionary who has identified the patient either through a survey or another doctor has referred the patient.

The main reasons for the delay in seeking treatment by LAPs in the first stage is because they are not inconvenienced by leprosy in the initial stage and because their most preferred service provider – the non medical practitioner – is unable to diagnose the disease.

The Treatment Process

One of the major hindrances to effective treatment is the frequent discontinuation of medication. About 40 percent of the LAPs studied, had at some point or the other stopped medication. Lack of symptomatic relief combined with the patients not feeling any discomfort were the chief reasons although in some cases the patients expressed doubts about the efficacy of the treatment because it did not contain injectables. Other reasons noted were the long period of treatment or a break in the drug delivery cycle by the NMA.



Shahpur: Time line of disease prevalence

Another factor noticed was that the patients were often not convinced that MDT was a sure cure. They said they knew others in their villages who still have ulcers or distorted limbs that should have disappeared had the medicines been effective. In the three districts covered, very little post-cure counselling (POD Camps) has been initiated. As a result patients even after they were cured continued to show deterioration in the condition of the affected limbs, perhaps because they had not been taught self-care practices to prevent worsening of disability.