CHAPTER NINE

PERCEPTION TOWARDS LEPROSY BY THE PEOPLE, PATIENTS AND HEALTH-PROVIDERS: AT GHUMKA (AN ANALYSIS OF EXPLANATORY MODELS)

Perception studies in Social Science Research have a vital importance, as such studies bring out an understanding of human behavior towards a particular social problem in the context of the cultural framework.

The present study has aimed towards analyzing the Explanatory Models of the 3 P's, namely, the people, the leprosy persons / patients and the providers of health (in leprosy), with regards to their perceptions toward leprosy.

The Chapter first analyzes the differential explanations the people, patients and providers of health services have given toward the early signs and symptoms, disease etiology, deformity and ulcer aspects and their attitude towards leprosy persons. The set of explanations given by each category of people constitute the Explanatory Model.

At the end of the Chapter, a comparative table is formulated comprising all the three Explanatory Models corresponding to the people, patients and providers of health services.

This Chapter attempts to prove the hypothesis that, change in perception towards leprosy has resulted in changes in Explanatory Models of the people, patients and providers of health.
I. Analysis of Community Members’ Explanatory Model:

(Refer to Appendix no. 3 for all the tables)

(A) IDENTIFICATION OF A LEPROSY PERSON

The table indicates that a high percentage of people identify a leprosy person by ulcers and deformities (76%).

1. Deformities in leprosy are identified by

   - Shortened digits, referred to as “Thuthuwa”
   - Contractured fingers - “Terga-Merga Anguli”
   - Deformities of hands and feet - “Kokran-Kokran”
   - Disfigurement - “Akriti-Vikriti”
   - Absorption of fingers and toes - “Gallen-Shedan”

A leprosy ulcer is distinguished from other ulcers in its tendency to result in deformities of limbs and wasting of flesh.

An ulcer is referred to as “Ghao-Gondar” in Chattisgarhi.

2. About 49% of the community members are aware of patch as a sign of leprosy. Different types of skin ailments associated with skin patch are not uncommon experience among the community members. Both children and adults are exposed to skin ailments like scabies, rashes, ring-worms patches, leucoderma, vitamin-D deficiency etc. A skin patch which appears to be unlike the common skin ailments are identified as a leprosy patch. Patch is referred to as “Chakta”, “Daagi”, “Daag”, “Dhabbah”, etc. A leprosy skin patch is identified, based on;
(i) Colour
White - "Pandra"
Pale - "Badami or Badrang"
Yellow - "Pela"
Red - "Lal or Laluwa"
Black - "Karia"
Mixture of two pigments like normal skin colour and hypo pigmented - "Kabra -Kabra" (or infiltrations)

(ii) Size
Small white spots - "Chanda or Tipka"
Broad and wide - "Chaker or Chappa"

(iii) Nature
Raised Patch - "Ubhara daggi"
Patch with anesthesia - "daagi mei sunnapan"
Patch with smooth oily surface - "Chikni daag"

Although, a patch is not a visible sign of identification as deformities or ulcers, yet a high percentage of community members have identified patch as a sign (rather an early sign) of leprosy.

3. Swollen Conditions: Puffiness of face and swollen body was another category of signs and symptoms by which about 43% of community members could identify a leprosy person. In the pre-MDT era, leprosy was often referred to as "Pani ki bemari" or "Pani rog" (disease of watery discharge) by the health-workers (as an effort to reduce stigma associated with the word leprosy, that is "Kodh"). People perceive the swollenness of body as being filled with water or fluids. Swollen body condition are also seen in other common physical complaints associated with the digestive and excretory system like "unclean bowls", indigestion due to consumption of certain toxic food items, etc.
But swollenness in leprosy is distinguished from other conditions with its association with puffiness of face and watery discharges or pus discharges from the ulcers present in the person’s hands or feet which gives it a wet appearance, "Pichpicha or filled with pus.

Swollen body condition is referred as "Pasia dhar liya" meaning filled with excessive water of fluids. "Pasia" in Chhattisgarhi literally means rice-water.

Swollen conditions in the local language is labeled as following:
- Puffed up face "Chehra Phulphula" or Muhbhobraha"
- Swollen hands and legs - "Haath-per pholphola"
"Pholphola also refers to blisters due to burns

4. Cracks and fissures: About 23% associated leprosy with cracks and fissure in hands and feet in addition to other signs and symptoms like patch, ulcers and deformities.

The terminology used to describe cracks and fissures is "Chirra-darrah"," Chatkan" "Phatan" etc.

5. Anesthesia: Anesthesia and tingling sensation is rather a subjective symptoms and not easily observed. Yet, about, 16% attributed it to leprosy, again in combination with other signs and symptoms, particularly with patch, cracks and fissures and ulcers.

Anesthesia is commonly termed as "Sunnapan". community members generally talk of anesthesia of the skin and do not refer to anesthesia in the limbs.
6. Other signs and symptoms include:

(a) Oily shiny skin: (16%) referred to as "Chiknapan" of the skin or "Telia chamak" on the affected persons face.

(b) Boils and blisters (10%) are also associated with leprosy. All ailments occurring on the superficial portion of the skin are believed to be caused due to impurity of the blood. Hence, as leprosy is believed to be caused by impure blood, boils and blisters (skin ailments) are also associated with leprosy (Sharing a common causal factor). But boils and blisters are distinguished from other common boils and blisters caused due to burns or body heat, in that, it leads to ulcers and finally to deformities.

Boils and blisters are commonly referred to as "Phodaphunsi" (Boils and rashes) and "Phophola" blisters.

(c) Face and skin reddish colour: (8%)

Changes in the skin colour has also been identified as a sign of leprosy. Person with reddish colour in the face and body are believed to be affected by leprosy. "Lalima" or "Lalipan" refers to reddish skin colour. However, further analysis indicates that MB patients under MDT treatment acquire reddish skin colour due to the drug rifampicin. This could be one of the reason for people identifying patients on the basis of their skin colour.
(d) Lethargy, Body weakness and Sagging skin: (4%)  

People perceive lethargy and body weakness as outcomes of the disease body conditions

Terminologies associated with the above symptoms are:

"Ubasaha" - Slackness in the body parts  
"Jhulsapan" - Sagging of skin, particularly of the face  
"Bhasbosaha" - Weakened muscles

(B) CAUSATION OF LEPROSY:

Multiple factors are responsible for the causation of leprosy according to the community members perception.  

Their concepts about causative factors is guided by their experience with other chronic diseases like, tuberculosis, asthma, cancer, gastro enteric conditions etc.

1. Deviation from norms: Unhygienic conditions, wrong combination of food items, contaminated or stale food, deviant sexual behaviour were considered by people as major causative factor for leprosy (41%)

People had always repulsed from the sight of uncleanliness projected by a leprosy person on account of the oozing ulcers, wasting and rotting of flesh and bones. Though, they might not have had a close encounter with such a case but a mental image of the leprosy person was instilled in their minds by the older folks of the community.

Thus, anyone following unhygienic health, habits not conforming to the norms of rightful eating habits and
balancing the diet, uncleanliness of body parts, indulging in wrong sexual behaviour, etc were regarded as deviants of the norms. Such individuals were charged with the curse of leprosy such as "Rogaha" (one infected with the dreadful disease i.e. leprosy)

Unhygienic condition include: Uncleanliness of body parts and environments.

Wrong combination of food items: Causes various conditions of ill-health, like indigestion, vomiting and nausea, swelling of limbs etc, but leprosy is predominant among all. For example, a kind of porridge is prepared out of rice and gram flour (Besan) along with "Lakri" dal. Consumption of this preparation in excessive quantity causes leprosy, or rather, the deformities of the limbs. (However, scientific studies have proven the harmful effect of "Lakri" i.e. Kesari in crippling the limbs leading to paralysis. This has no relevance to leprosy.

Another example is that of consuming Yoghurt after being kept in a brass container for an overnight. This too, is believed to cause leprosy, or rather, rotting of flesh and bones.

There is a common practice in the village to consume rice (baasi) of the previous night, soaked in water, as the morning meal. Consumption of such putrid food, is regarded to causes leprosy. leprosy. (This view is held by upper community who do not follow the above food-habit, like the Brahmins, Kausle, Jains).
2. Germs:

The entry of micro-scopic germs into the body is a causative factor for most of the disease. According to one view leprosy is caused due to the attack of germs in the body. The raise in the body temperature favours the breeding of the germs in the body.

People refer to germs as "Kida" an insect-like crawling organisms.

Another view supplies that the germs present in the blood vessels causes impurity of blood, which leads to leprosy.

According to Surajbai, the disease causing germs (Kira) eats away the blood. This causes the ulcers to appear on the fingers and toes resulting in rotting away of the flesh.

The concept of germs is related with the impurity of blood, entry of germs causes impurity of blood. Secondly, germs present in the ulcers are also believed to be the causative agents for the disease. The presence of germs or rather micro-scopic worm-like organisms in the ulcers are responsible for the pus formation and watery discharges.

However, people who have undergone health-education in leprosy, participated in leprosy control programmes or attended a skin diagnosis or ulcer care camps perceive that specific bacili or leprae bacili ("Kusht ki Kitanu") causes leprosy (figures shown in the table).

Thirdly certain worm like insects (Diyar) eats up the flesh and causes ulcers and absorption of the affected person's digits.
3. Impure Blood:

About 32% of people perceived leprosy to be caused due to the impurity of blood. (Khoon ki Kharabi). The above causative factors like germs, consumption of contaminated or spoilt food all lead to impurity of blood becomes an indirect causal factor for the disease.

The concept of impure blood as causative factor in leprosy and other skin ailments, too, have been installed in the minds of people by the traditional healers and private practitioners of the village. Thus, herbal or ayurvedic medicines are prescribed for cleansing the blood, such as intake of better herbs and leaves like that of neem (azardiracta indica) "Chiraita".

4. Body Weakness:

According to Urmilla bai (Ghumka) body weakness is due to less in-take of food and more work-load. Body weakness had been indicated by 27% of people to be the cause of leprosy.

Occurrences of most of the diseases have been attributed to body weakness and leprosy is inclusive among them.

According to Tarabai (Ghumka), oil and salt are commonly consumed by all, but not all contract diseases.

The pattern of food habits differs from culture to culture and individual to individual. Body weakness is dependent upon the right combination of food items, intake of food with vitamin and protein contents etc. Thus, a person with a weak body is prone to contract illness.
However, an educated class of people expressed the above concept as low immunity system of the body and inability to fight the germ-causing agents intruding the body.

5. Supernatural Causes:

In the pre-MDT era, leprosy was believed to be due to the "wrath of gods" or "stricken of god" (Devi-Dewtao ka Prakop"

However, this perception has been changing in the present day context. Only 2% have attributed leprosy to be caused due to "wrath of gods".

About 18% have expressed the cause of leprosy to have originated in oneself.

About 13% hold "Kismet" or ill-fate as the causative factors while 5% believe "one's fault" ("apni kartab") and result of past sins (Purawa janan ka paap) as the cause for leprosy.

6. Contact with affected person:

Only 4% have said the cause of leprosy to be through close contacts with affected persons either in the family or community.

(C) TRANSMISSION OF LEPROSY:

Majority of the community refute the belief that leprosy is communicable (60%) of these who believed leprosy to be communicable have stated the various communicable aspects of the disease (indicated in the table  

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Non-communicable aspects of the disease have been attributed to the fact that the disease is under control and thus, not communicable. Secondly, a common belief prevails that the disease is confined to the affected person alone and there is no fear of others contracting it. The person is diseased on account of his own fault and body weakness.

Agents of transmission were also believed to be urine and blood of the affected person. Water was also commonly believed to be the reservoir of infection. Leprosy was believed to spread through water contaminated by the affected person. This was one of the reasons why leprosy persons at some places were barred from taking bath at the village ponds.

(However, at village ponds, people follow a hygienic practice of first pouring water over the stone placed at different points for taking bath, thus cleansing it of all infection or pollution it might cause the person.)

(D) TREATMENT IN LEPROSY:

1. What kind of treatment was available in leprosy before MDT?
   People had vague ideas about the treatment aspects in leprosy prior to MDT era.

   About 30% expressed the notion that no treatment was available during the pre-MDT era. About 5% stated that some treatment was available, but was not effective and secondly it was costly and unaffordable.

   25% of people were aware of leprosy hospitals and colonies as centres for the treatment. Examples were given of leprosy hospitals at Raipur (60kms away) Betulpur (120 kms away) and Basantpur (30kms away).
10% knew about traditional and Ayurvedic treatment for leprosy, particularly for ulcers, wounds, boils and skin patches.

Partial or total isolation of leprosy victims as preventive measures against the spread of leprosy germs from the person's body clothes ulcers and wounds were expressed by 12% of the community, members.

Only 20% had knowledge about the monodrug therapy. Though they were not aware of the name of the drug but referred to it as "white tablets" given by the leprosy doctors in the village along with some injections (B-complex injection).

Neem and tomato leaves were tied for the healing of ulcers. A paste of neem leaves were also applied on the ulcers, to kill the germs and ensure fast healing.

2. What kind of treatment is available in leprosy at present?

Majority of the people were aware of the multi drug therapy administered to the leprosy patients (93%).

Multi-drug was referred to as "new-medicines" for the treatment of leprosy.

The knowledge about MDT had been gained during the Intensive phase of MDT implementation which involved participation of certain section of the community members like community leaders, teachers, members of youth clubs, farmer's clubs and ladies clubs, etc.

Opening up of service delivery points at five different villages of Ghumka sector is another source of information
about MDT. Skin diagnosis camps and ulcer-care camps have also made people aware of the new drug in leprosy. Moreover, stickers and posters painted on walls at public places advertising early signs and symptoms and of early treatment and cure have further enriched their knowledge about the treatment aspects.

3. How effective is MDT treatment?

They are also aware of the effectiveness of the new drugs in leprosy.

20% believe that MDT kills or destroys the leprosy germs. Majority of them perceive that it prevents the disease from spreading i.e., control and arrest of the disease has been possible (37%) This has been supported by the fact that people have not seen deformity cases anymore in the present day situation. Only 9% have perceived that MDT has prevented ulcers and deformities. Whereas, 17% have stated that MDT has brought physical relief to the patients, has cleansed the body and blood of infectious germs and restored new life and strength to the affected persons. Their concepts about treatment extended to treatment of ulcers and deformities, cleaning of blood, regain of body strength and destruction of bacilli.

(E) CONCEPT OF CURE IN LEPROSY:

1. Is leprosy Curable?

About 61% of the community members believed that leprosy was curable and 28% believed that leprosy was curable but that marks of the disease remained.
2. If no, what makes leprosy incurable?

Those who expressed notions about the incurability of the disease (11%), listed the incurable aspects of the disease (table 7).

3. What is your concept of cure in leprosy?

The people's main concern in leprosy have been ulcers, deformities and disabilities. Thus, cure in leprosy would imply relief from the above signs and symptoms. 46% have stated healing of ulcers and correction of deformities as signs of cure in leprosy, 34% accepted the disappearance of patch as cure. 12% felt that relief from physical discomfort, return of body strength and healthy glow in the person's face were significant indicators for cure. 4% expressed that they would be convinced of cure after observing the patients condition for 10-15 years, if the complete course of treatment is undertaken, if patient is accepted in the community despite the deformities and ulcers. About 2% would accept cure of leprosy persons only on the basis of medical doctors certificate of fitness.

(See Table-EM18 p 372)

According to Kartikram, a healthy or a cured person is the one who is able to walk about in a normal way and perform his own tasks.

According to Galiram Banjare (Ghumka) the concept of cure is associated with the person's cleanliness. In the presence of deformities and ulcers, cure relates to no further absorption of fingers and toes, limbs having a clean appearance with no sign of oozing ulcers or ulcerated boils.
The terminology "clean" refers to:
- Absence of oozing ulcers
- Fingers and toes having smooth and dry appearance.
- Oiled body and hair well-groomed.
- Person neatly cheased with clean clothes.
- Healthy glow in the face.

Cure may be possible on the exterior, but the effects of the disease lingers in one's soul and mind, which is difficult to erase.

On account of deformities, people's attitude towards an affected person has driven him to maintain a low profile of himself and a very low self-estimation. Thus cure under such circumstances is possible through the restoration of self-confidence and self-estimation in the affected persons.

According to Abhayram (Rraikhurd) deformities cannot be corrected. It is like a bent branch of a tree which cannot be straightened. However, if the body is having a clean appearance, it indicates cure.

Another view states that deformity and regeneration of limbs are irreversible. It is compared to a tried-up tree whose roots are eaten up by ants, and never blossoms again.

4. In leprosy, is medicine the only means through which the patient recovers from his disease? (Refer to table.) If no, what factors contribute to recovery?

Factors for Patient's Recovery:

Majority of the community members have stated the cleanliness of body parts' as an important factor for patient's recovery (52%)
whereas 29% have indicated that medicine is the only means for recovery.

About 15% have given importance to dietary restrictions and remaining 4% perceive care and support from family members as essential factor for the recovery of patients' ill-health. (Table-EM10 p.373)

Deformation Prevention and Ulcer Management:

1. Is deformity in leprosy different from other deformities?

About 82% of community members felt that deformities in leprosy is different from other deformity conditions on account of paralysis, accidents, congenital defects, polio etc. 16% stated that deformities were present only in leprosy. The differences between deformities and leprosy and other deformity conditions are highlighted in the table -

2. What causes deformity in leprosy?

The major cause for the occurrence of deformity in leprosy has been attributed to the disease itself or it erupts from within the body (38%). (Table-EM11 p.373)

About 15% had knowledge about the "nerve damage" ("Nes ki Kharabi" or "Nes khich gaya hai") leading to deformity of the limbs, particularly, contractures of fingers.

According to this view, due to nerve damage there is sensation loss in the affected area resulting in muscle-weakening and crippling of the limbs leading to deformity. Nerve-damage also blocks proper circulation of blood and this again results in weakening of the affected parts.
10% stated that long duration ulcers or recurring ulcers cause wasting of bones and flesh, resulting in deformity.

7% agreed that lack of early treatment or irregular treatment has lead to progression of disease to the deformity stage. 6% attribute the causation of deformity as one's own carelessness and lack of personal hygiene.

What causes ulcers and wounds?

With regards to ulcers in leprosy, about 77% thought it to be distinct from other ordinary ulcers caused due to injuries, burns and accidents, ulcers in skin ailments and allergies, ulcers present in certain diseases like diabetes etc.

The causative factors for wounds and ulcers in leprosy are represented in table - $E_{M1}^2, P = 3.74$.

Community Members' attitudes toward leprosy affected persons:

A three-point attitude scale was developed for analyzing the community members attitudes toward leprosy affected persons. The responses which did not coincide with the three-point attitude scale were categorized in separate columns and analyzed in relation to the responses accommodated in the attitude scale. (see appendix for the Table $AT-I$ on attitude scale) $P = 0.296$.

1.a) You would allow your son / daughter to marry a Leprosy cured person.

b) Tie a marital bond with the family members of the affected person.

a) A low percentage of the community members expressed their consent towards their daughter or son marrying a leprosy cured person.
person (24%). Majority expressed a negative view to marriage with leprosy affected persons (43%). About 25% of them agreed to tying marital bonds if the person was cured of disease and had a clean appearance (referring to absence of deformities or oozing ulcers). About 6% advocated marriage only within one’s own Samaj (caste-group)

b) With regards to tying marital bonds with the family members of the affected person, about 44% agreed and 56% disagreed.

2. They can be allowed to carry out / participate in religious functions / enter a temple / offer food-grains and offering to the deities:

About 58% of the respondents had no objection towards leprosy affected persons entering into sacred premises of the temple, offering food-grains or participating in any religious functions. Around 23% said that such persons participating in religious activities should be cured and have a clean appearance.

Only one opposed the idea of leprosy persons with deformity and ulcers participating in the religious functions.

3. a) You would avoid touching the person with leprosy / b) you would tie a bandage or apply medicine to the wounds and ulcers of the affected person:

About 37% of the respondents said that they would avoid touching the affected person 6% responded that they would maintain physical contact only if the persons are cured, have clean appearance and if ulcers are dried and healed up. Rest 57% had no objection to having physical contact with the affected persons.
3.b) About 57% of the respondents said that they would tie bandages or apply medicines to the wounds and ulcers of the leprosy affected persons whereas, 39% opposed to such a step. 4% expressed that they would only render services if the affected person is a family member, a close friend or a relative.

4.a) You would travel with him / her in the bus / b) You would sit near him / her and have your meals.

About 62% of the respondents did not mind traveling with the affected person in a bus whereas, 18% objected to it. About 20% expressed favorable attitude to traveling with affected person if he / she exhibited clean appearance. With regards to having meals with affected persons, 45% had favorable attitude. About 19% of them said that such persons should be cured or under treatment and have clean appearance, so as to participate with them in meals.

4.b) About 36% harbored an unfavorable attitude to participating in meals with the leprosy affected persons.

5. You will accept a glass of water from a leprosy person :

About 28% of the respondent opposed the idea of accepting a glass of water from the affected person, whereas, 57% had affirmative attitude towards it. However, 16% advocated that the affected persons should be devoid of ulcers and deformity so that the above suggestion could be acceptable.

6. You would allow an affected person to carry your children :

About 49% of the respondents had no qualms about the leprosy affected persons carrying their children. 18% said that they would allow carrying of their children if the persons are under
treatment or cured. About 4% approved the above suggestion only if the person's ulcers were healed and dried up (in case of any ulcers being present).

Rest 28% of the respondents opposed the above suggestion.

7. You would employ a leprosy person at your house / fields:

Majority of the respondents (58%) agreed to employing leprosy affected persons at their homes and fields. About 19% said that they would employ them only if they are cured and have clean appearance (even if there are deformities present). In case of ulcers it should be healed and dried up.

About 12% responded that the leprosy affected persons should be physically fit, even if deformities are present. The remaining 8% expressed unfavorable attitude to employing leprosy affected persons in their household or fields.

8. You would motivate the patient to take regular treatment:

A significant number of respondents (90%) said that they would motivate the leprosy patients for regular treatment. About 2% were negative and 8% were neutral in their response towards the above statement.

9.a) He / she should be allowed to mix freely in the community / leprosy affected persons' should participate in festive occasions like Holi, Ram-leela, other cultural programmes:

About 56% of the respondents expressed a positive view towards leprosy affected persons' free intermingling in the community and their participation in the festive occasions. About, 22% of them favored the above view, but regarded clean appearance (i.e.
absence of oozing ulcers or ulcers healed and dried up) of the affected persons in their free movement and participation within the community. Another 22% of the respondents held a negative view towards the above statement.

10. You would invite the patient for functions or ceremonies at your house / you would visit his / her house on any occasion:

About 56% of the respondents said that they would extend invitation to leprosy affected persons for attending any functions or ceremonies held at their house and would visit the affected person's house on any occasion.

About 12% of the respondents favored the above statement on condition that the affected persons were cured and exhibited clean appearance. 26% of the total respondents expressed a negative view.

About 4% of the total respondents said that they would invite affected persons to their house for any occasion, but would not visit the persons house.

11. There is no problem of leprosy affected persons using common well, ponds, etc. :

About 67% of the respondents expressed that there was no problem regarding leprosy affected persons using the common wells and village ponds for washing or bathing purposes. Around 16% favored the above statement, on the basis, that the affected persons should not have ulcers with pus formation or the ulcers present on their limbs should be healed up. Only 17% held an unfavorable view towards the above statement.
The Guttman Scalogram method has been utilized for scaling the attitudes of the community members toward the leprosy affected persons. The responses to the statements have been graded as affirmative or negative. Within the above gradings, sub-gradings have been included to incorporate varying degree of responses in each. (see the Table no. AT-1 on Attitude Scale).
TABLE ON ATTITUDE SCALE

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Responses are recorded in percentage. In this table the percentage of responses to each statement are converted into code numbers ranging from 1 - 10. Affirmative responses ranges from 1 - 7. Use no. 8 is Negative. Use no. 9 is Neutral. Score is computed from substracting the total number of affirmative responses from the negative neutral responses for each statement.
The percentage-wise responses:

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Attitudinal Responses:

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<td>2</td>
<td>If family member or friends</td>
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<td>3</td>
<td>Only within one's samaj (community)</td>
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<td>4</td>
<td>If physically fit</td>
</tr>
<tr>
<td>5</td>
<td>Under treatment or cured</td>
</tr>
<tr>
<td>6</td>
<td>If cured and clean appearance (i.e. absence of oozing ulcers)</td>
</tr>
<tr>
<td>7</td>
<td>Devoid of ulcers or deformity</td>
</tr>
<tr>
<td>8</td>
<td>No</td>
</tr>
<tr>
<td>9</td>
<td>Neutral</td>
</tr>
</tbody>
</table>
II. Analysis of Patients’ Explanatory Model:

(A) HEALTH-SEEKING BEHAVIOR:

1. When did you first come to know you had some symptoms of leprosy (period from the date of interview)?: (Refer to table EMP 12 p. 379)

2. Who suspected your disease first?

A total of 20 patients had self-suspected their own disease conditions out of which 11 voluntarily reported to leprosy health-workers, 4 to Medical doctors at PHC and community Health-Volunteers. Of the remaining 5 patients 3 were detected by leprosy workers and 2 by Janbhagidars.

Those who had voluntarily reported their cases to leprosy workers, 6 were aware of their disease as leprosy while 5 had gone to consult the leprosy worker for other complaints whereby they were detected as leprosy cases. The other complaints included Vitamin D - deficiency (chikni daad), small white spots (sila), skin rashes (prasod), tingling sensation (Jhunjuni) and blisters and itching (Phoda-punsi) see table EMP 10 p. 379.

2. Who was consulted first for the treatment?

The first person consulted by the patients after knowing some signs and symptoms of the disease is represented in table. They have consulted the above category of people for various ailments ranging from ordinary skin patches (Daagi), boils, rashes blisters, ulcers, tingling sensation to asthama and arthritic pain and swelling in the hands and legs.
A pattern of leprosy patients' health-seeking behaviour could be understood from the following case-studies:

(1) Fulubai (Age-55 yrs, Female, Type - MB-RFT Village - Gkumka) had first consulted a medical officer at the leprosy hospital Basantpur (60 kms. away). The doctor examined her for signs of any loss of sensation with a "cotton-touch" method and found her limbs having anesthetic condition. Her face was puffed up. Though he informed her about the disease as "kusht" she could not understand the terminology. She was under Monodrug Therapy for three months, whereby the puffiness of face disappeared.

Two years prior to this, in 1970s, she had first taken treatment at Kharakpur (Bihar) for blisters ("phoda") and tingling sensation ("Jhunjun") in her limbs. She had paid a total sum of Rs. 2000/- for the medicines and injections but it had brought no relief to her condition.

About three years later, she returned back to the PHC (Ghumka) and consulted Rathore Babu (Nurses' Supervisor). He, too, charged a large sum of money for treating her.

In 1977, she was detected in a survey by the newly appointed Non-medical Assistant (NMA) Mr. R.K. Soni and brought under Monodrug once again. The blisters cleared up. Though he continued treating her disease, he had never disclosed the reality of the disease. Furthermore, he never talked about self-help or deformity to her, due to which her disease progressed and deformities set in. She laments as she relates the above experience, that had the doctor told her about deformity prevention through HOPE, such a condition would not have occurred.
(2) Rembhagas (Age - 32, Male, Type - MB-RFT, Village - Eraikhurd) At first had applied home remedy for the small whitish skin rashes. ("Prasod"). Mehendi's ( ) fruit was crushed, mixed in water and taken orally. But, it brought no relief. After 2-3 years, the skin formed dry scales, and cracks and fissures appeared on his palms and soles. There was a pale patch on his left hand.

He, then went to Khairagarh (40 kms. away) and took treatment for 2 years under monodrug therapy. Yet no relief was experienced from his diseased condition. No one at the PHC (Khairagarh) told him about the name of the disease.

In 1978, he was detected by the NMA Mr. Soni and brought under Monodrug therapy. The NMA told him about his disease. Prior to this, he had already suspected his disease as leprosy (kodh") when cracks and fissure had appeared on his palms and soles.

At the beginning of the Monodrug, there was loss of sensation in the limbs (a feeling of thickened skin), puffed up face and tingling sensation on his limbs, which was also covered by skin rashes ("prasod"). After three years of treatment, puffiness and rashes subsided. After the introduction of MDT, he had underwent treatment for two years. Under this regimen, tingling sensation disappeared.

(3) Hirondi (Age - 50 yrs. Female, Type - MB-RFT, Village - Eraikhurd) had first consulted a "Baiga" (Village medicine man), when pain and swelling began on her right leg. The baiga declared the symptom to be "baat" (arthritis) and advised dry fomentation by placing a cloth pad on the heated frying pan and pressing it against the areas of intense...
pain. As the result the skin was scorched and left a white scar.

Next, she had consulted Dr. Sadani (M.D. at the PHC, Khairagarh) who gave about 200 white tablets and charged for it. Four years later she was detected by NMA Mr. Soni who detected a leprosy patch within the scorched burnt mark. After undertaking Monodrug for a year she was shifted to MDT for two years and declared as RFT.

(4) Mongaldas (Age - 62 yrs. Male Type - PB-VT. Village - Eraikhurd) had self detected a patch on his body as big as the size of a beanseed about three years prior to a skin Diagnosis camp held at his village during the year 1988. At first he had shown it to the NMA, Mr. Soni and an ANM of the village. Both denied it to be a leprosy patch. Later he showed it to the CHV (community health volunteer) of the village who referred him to the present NMA, Ms Usha Sinha. This indicates that Mongaldas had suspected his disease as leprosy and pursued consultation of health workers till he was brought under proper treatments.

(5) Genda (Age - 60 yrs, Male, Type - MB-RET, Village - Botepar) had first consulted the private practitioner at a village called Pipariya. He had gone with the complaint of tingling sensation (Jhunjuni) on his hands and feet. The doctor had given him some injections, but felt no relief. Later blisters had appeared on his hands when he had poured hot water over it. He consulted the "Baiga" of the village (a distant relative) who directed him to consult the leprosy worker at Ghumka. A village baiga, too, can play an important role in the detection of cases and directing them to proper source of treatment.
(B) DISEASE IDENTIFICATION:

1. How was your disease noticed?

Majority of the patients were identified on the basis of the patch (66%). This indicates that the health-workers and community members were aware of the early signs and symptoms of leprosy. (see table EMP 11 p. 349)

(C) DURATION OF DISEASE:

About 29 cases (58%) have had a long history of leprosy ranging between five to twenty years. Out of those having leprosy for five years and above, 20 were of MB type and 13 belonged to deformity grades II and III. (Table - EMP 4 p. 377)

1. After knowing the disease, when was a doctor or any practitioner consulted?

Time period between the occurrence of disease and contact with health services:

A high number of patients (20%) consulted some practitioner whether traditional or medical, immediately for their disease condition and about 15 patients (30%) consulted within one year after the occurrence of some signs and symptoms of the disease. As mentioned earlier, all were not aware of their disease as leprosy at the beginning. This health-seeking behavior of patients reveal that they harbored a general awareness towards any disease condition and adopted immediate steps to treatment and prevention of the conditions. (Table - EMP 17 and EMP 18 p. 381)
2. When did you know about the availability of proper treatment?

Knowledge about the availability of proper treatment (Mono/MDT) period after the beginning of the disease-symptom:

Those who came in contact with the proper health services within the short span of time (23 = 46%) were satisfied with the health services and experienced complete cure from the signs and symptoms of the disease (about 17 out of 23 = 73.9%)

About 23 patients (46%) came under monodrug or MDT within a year's period i.e. from less than a month to one year.

15 patients (30%) knew about the proper treatment after the elapse of three to five years and above. (see table $\text{Table 8.3}$)

8 out of 11 patients who disbelieved in curability of disease (72.7%), had deformities and recurring ulcers. They showed dissatisfaction with the health-services and believed their condition was incurable or curable but marks remain.

(D) BELIEF IN THE SUGGESTION ABOUT THE DISEASE:

1. Did you believe in the suggestion about disease?

Only 13 believed that they were suffering from leprosy (26%) while 22 did not accept their disease as leprosy (44%). About 4 did not understand the term "kusht" used by the health-workers or understood their disease as ordinary skin ailment. For 11 patients (22%) no one disclosed to them that they were suffering from leprosy. The health-workers in the pre-MDT era used to maintain secrecy while treating leprosy patients to avoid creating fear in the minds of the patients and secondly to avoid
any discriminatory measure taken by community members against the affected persons.

It took about one month to more than two years for patients to accept their disease condition as leprosy. (for those who rejected the diagnosis of their disease as leprosy or were not aware of their disease) See table - E\textsuperscript{14} and E\textsuperscript{15}.

Presence of case in the family, health-worker’s assurance of cure, viewing their disease as an ordinary ailment were some of the factors for accepting the diagnosis of the disease.

In cases where no one suggested about the disease, patients suspected it as leprosy when contracture of fingers, ulcers, cracks and fissures began to appear on their hands and feet and secondly, when the neighbors and the community members began talking about their conditions as "kodh".

Those who rejected the diagnosis were motivated to comply to treatment when in their mental agony their physical condition deteriorated, when the effects of medicine in other patients were seen, when explained about facts in leprosy under MDT.

(E) COMPLIANCE TO TREATMENT:

Majority of the patients (52%) had directly contacted the proper source of treatment for their disease condition and 74% complied to the treatment without discontinuing it in between.

However, the information taken from the patients’ record card indicate the following pattern of treatment compliance. Table E\textsuperscript{16}.

About 90% of them felt that they needed more medicines and dosages to cure lethargy, tingling sensation, patch, blisters and
recurring ulcers.

The following are some case-studies to illustrate patients' compliance to treatment:

(1) Ghanshyam (Age - 60 yrs. Male, Type - PB/RFC Village - Eraikhurd) was brought under monodrug therapy for one year. During that time, he used to consume half of the total medicine and throw away the remaining. The NMA had not disclosed about the disease name to him so he never thought it as a serious or a stigmatized one. However, upon meeting a friend from the village Patwewah (2 kms. away), he discovered that the person was undergoing treatment for the same type of ailment. His friend motivated him to be regular. Ghanshyam had white ("Pandra") patches on his left elbow. He complied to the treatment till the patches disappeared. After 5 years he was declared as relieved from contact (RFC) under Monodrug Therapy.

(2) Phulbatti (Age - 53 yrs., Female type - MB-RFT, Village - Eraikhurd) was detected as a case by one of her colleague (an ex-patient) while working in the fields together. She detected a pale patch on Phulpatti's back and asked her to consult the NMA at Ghumka. She was confirmed as an MB case and put under MDT. After an year of treatment, she felt that her condition was improving and discontinued the treatment. When the NMA visited her following her absence during the pulse day, she discovered that only half of the medicines had been consumed by her from the blister pack. (Blister packs are convenient for patients to follow the sequence of drug-consumption for each day. If consumed regularly, the last tablet consumed would point to the fact that the following day is the drug-delivery day). As for Phulbatti, due to irregular in-take of drugs she missed her pulse date.
To avoid confusion, the NMA took away the unfinished blister pack and gave her a new one, so that proper track of days could be kept before the next pulse-day arrived. For village people, days and dates are easily forgotten thus, blister pack in one way ensures proper compliance to drugs.

(3) Amroutinbai (Age 40 yrs, Female, Type PB-RFT village-Botepar) initially was overcome by fear when she knew about her disease to be leprosy (Kodh). She had a patch which was detected by her nephew (ex-patient). She had refused to accept the diagnosis or the treatment. The anxiety about her having contracted a dreaded disease, led to the deterioration of her health. Thus, to regain the normal health, she complied to the treatment. To prevent further progression of disease or deformity, she regularly attended pulse-days irrespective of the adverse weather conditions like heat or rain. The SDP was about 3kms away from their village. To attain a healthy life, she felt that compliance to treatment is essential.

(F) KNOWLEDGE ABOUT CAUSATION OF THE DISEASE:

Patients' perception about the different aspects of the disease have been shaped on the basis of their own personal experience with the disease.

A significant number of patients believed that the bacilli, germs or biting of insects have been the major cause of the disease. (22=44%) \(\text{Table- EN12 p 371}\)

About 8 of them attributed the causation of leprosy to Kismat, God's will and ones own fault (16%) Impurity of blood as causative agent was held by 11 of the patients (22%) and defect in one's system, body weakness was viewed by 6 of them (12%).
Only one supported the idea of contaminated food or wrong kind of diet and 3 of them (6%) thought that leprosy occurred by itself, without one’s knowledge.

A significant number of patients perceived that leprosy was caused through close contacts with affected persons (5.10%)

Out of those who believed leprosy was caused due to germs, bacilli and biting of insects, about 16 of them (32%) had knowledge about the leprosy bacilli ("Kusht ka Kitanu") The factors responsible for their knowledge about this fact was their participation in leprosy camps, health-education received. Through camps and health-workers, video shows, posters and stickers on facts in leprosy, exhibited in public places, etc.

The remaining 6 patients (12%) explained that the causation of leprosy was due to entry of germs into the blood-stream which results in the impurity of blood. Another view was that crawling of insects in the blood stream caused the disease.

According to Hirondibai, leprosy occurs by itself. It originates in one’s body like rashes, initially.

Chaitibai supplied that the impurity of blood within the blood stream causes the disease to be expressed on the exterior.

(G) TRANSMISSION OF LEPROSY :

Majority of the patients believed that leprosy is not transmitted, but occurs by itself. It originates in the body. (17=34%). *(Table - EM3 p. 371*)

About 16 patients (32%) perceived germs in the atmosphere, soil and food as agents of transmission of disease and 11 of them
(22%) held affected persons as potential agents of transmission.

With regards to communicability of the disease, 14 patients (28%) stated that leprosy is communicable, while 36 (72%) refuted that it was communicable.

Of those who believed in communicability of the disease, the following aspects were noted as communicable. (Table EM5 p. 371)

(H) CONCEPT OF CURE:

Majority of the patients (39=78%) stated that leprosy is curable, while 3 of them (6%) did not accept the disease as curable. 7 of them (14%) were not convinced of complete cure in leprosy.

Of those who were convinced of cure, expressed the following aspects in the curability of the disease. See Table EM8 p. 372.

However, on further analysis, it was found that out of those who were convinced of complete cure, 19 of them still harboured doubts. (48.7%) Comparative Tables.

(I) FACTORS THAT CONTRIBUTE TO PATIENTS RECOVERY:

About 17 of them (34%) stated that medicine is the only means of recovery. This category of respondents belonged to PB type of disease, which did not involve ulcer care or deformity prevention aspects. (Table EM9 p. 372).

Out of 30 patients who advocated other means of recovery apart from medicines, 18 of them (60%) said that HOPE (Hydro-oleo-Physiotherapeutic-exercise) were essential for healing of ulcers, cracks and fissures and regain of sensation.
Cleanliness of body parts was felt important for patient-recovery by 6 of them (20%). Dietary restrictions were put forth by 3 (10%) and right life style and acceptance within the community circles were felt by another 3 of them (10%) (Table - EM 10 p.373)

(J) TREATMENT IN LEPROSY :

Majority of the patients felt that MDT was effective in curing the disease (43=86%), 5 of them (10%) had doubts about it and two of them (4%) had taken treatment under monodrug. See Table.

Certain side effects of the drugs were experienced by the patients. See Table

Most of the side-effects were experienced by the patients belonging to MB type.

(K) COMPLIANCE TO TREATMENT :

On analyzing the data on patients clinic attendance, it was found that irregularity in clinic attendance was more in MB type (15 out of 19=75.7%) than PB type of patients. About 7 out of 19 irregular patients were of deformity grades II and III and having a long duration history of leprosy (36.8%).

(L) AWARENESS ABOUT EARLY SIGNS AND SYMPTOMS :

About 34 patients (68%) were aware of a patch as early sign and symptom of the disease. (Table - EM 12 p.370)

Different type skin patches identified by them are as follows:

- Smooth patch, as big as fish eye
- Raised patch "Ukhara daagi"
- "Firki-firki daad". Reddish colour patch
- Reddish Black Patch : "Laluwa - Karia"
- Patch with whitish rashes, "Prasod"
- Vitamin-D Deficiency patch "Chikni daad"
- Wide patches - "Chappa-Chappa"
- White round patches that occur during the harvest time "Navve junni sila"
- Infiltration- "Kabra - Kabra"
- No sensation in the patch and itching, smooth and oily, no pain when pinched in the area. " Chamari mein mota pan"

Tingling sensation was experienced by 8 of the patients (16%) tingling sensation was described as:

- "Koot-Koot" feeling as if some insects are crawling and biting within the body, or ants crawling on the skin of the affected area.

- "Junjuni" : Tingling sensation
- "Taru-Taru" sensation like crawling of ants

About 4 of them (8%) identified puffed up face ("Muh Bhoboraha") and swollen of the limbs ("Soojan") as early signs of their disease conditions. Whereas, 3 of them (6%) were aware of pain ("Pira") and swelling ("soojan") as the beginning of the disease. Patients described pain, particularly, of the nerves ("Nes") as : "Tur-Tur pira" on hand and legs. These were referred to as neuritic pain by the health-workers.

Patients suffering from such neuritic pain and burning sensation ("Aagi Barti hai") thought that they were suffering from "Baat" (Arthritis) initially.

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Three of the patients (6%) observed blisters ("Phoda") and itchings ("Khajuwata") on hands and feet as early signs of the disease whereas, only one (2%) noticed cracks and fissures ("Katan-Phatan") as the beginning stages of the disease.

A significant number of patients (18-36%) were not aware of any early signs and symptoms of the disease.

(M) SELF-CARE AND DEFORMITY PREVENTION ASPECTS:

The figures for deformity cases from the patients record cards show the following status. (Table EMP5 p. 377 and EMP8 p. 378)

About 29 MB type belonged to different deformity grades

11 belonged to grade I
10 belonged to grade II
7 belonged to grade III
One MB type belonged to grade 0

Out of 21 PB type of leprosy cases
12 belonged to grade 0
5 belonged to grade I
2 belonged to grade II
2 belonged to grade III

It is evident from the above figures that 73.8% of total deformity cases were MB and 42.1% belonged to PB type, (Total deformity cases = 38)

Year of detection, age at detection, disease duration, and time elapse between occurrence of disease and contact with proper health services are some of the factors responsible for high number of deformities in both categories of leprosy.
(N) KNOWLEDGE ABOUT CAUSATION OF ULCER AND DEFORMITIES:

Majority of the patients believed ulcers and deformities were due to the disease itself (17=34%) while a significant number of them perceived irregular or delayed treatment (9=18%) and nerve damage resulting in loss of sensation (7=14%) as causative factors. (See Table EM1 p 34)

Patients, in the course of interview, had cited various incidence were they attributed loss of sensation as major reason for ulcers and deformities.

According to Gitabai (Ghumka) due to the insensitivity in her foot, a stone had lodged under the big toe and caused a big ulcer. Through hydro-oleo therapy (advised by the health-worker) the ulcer healed.

Fulubai (Ghumka) had perceived the occurrence of blisters when the steam of boiling rice had burnt her.

Another case, Genda (Botepar village) had been burning thorns and thistles in the field. Due to the heat of fire, blisters occurred on his hands and feet which later developed into ulcers.

Jagturam (Ghumka) relates that initially he had an "Agiya" like ulcer in his right foot. He had applied ash-water to it and tied up a bandage. The ulcer was due to prickling of the thorn which had caused a septic. Later due to drying up the ulcer, a hollow was formed. Due to loss of sensation, a pebble had got lodged in the hollow and for many days it had gone unnoticed. It was only when the big toe began to swell and his slippers would not fit that the pebble was noticed. He believes that as long as he kept consuming medicines, ulcer did not occur. But once this continued, it recurred.
According to Hirondi (Eyraikhurd), swelling of face, ear-lobes, hand and feet lead to deformity. Ulcerated boils caused ulcers. Bursting of blisters also was believed to have resulted bleeding ulcers.

With regards to prevention of deformities and ulcers, 18 of them believed Hydro-oleo-therapy as effective method for preventions while 15 (30%) perceived early treatment. About 8 (16%) of them stated the use of cloth-pad for hot objects avoiding sharp tools and wearing proper foot wear.

Majority of them stated that the source for the above knowledge was through health-workers (20=40%) 12 of them based their knowledge upon their own personal experiences and observations whereas, 9 (18%) gained knowledge through witnessing demonstrations in ulcer care camps.

A significant number of patients were benefitted from Hydro-oleo-physio-therapeutic exercises (HOPE) (25=50%) : Only one did not gain any advantage from HOPE. For the remaining it was not applicable as they included PB cases and non-deformity cases. However, analysis show that three of the deformity cases had no knowledge about HOPE.

(O) PARTICIAPTION IN LEPROSY CONTROL PROGRAMMES :

Patients scientific knowledge about leprosy, disseminations of fear and misconceptions, deformity prevention and ulcer care aspects can be attributed to their participation or non-participation in the control programme.
A high percentage of patients had participated in various leprosy control programme (27=54%). (See Table )

Majority of them participated as patients (9=18%), observers (7=14%) and as demonstrators for HOPE (5=10%).

Many of them had participated on being motivated by the health-workers (8=16%) either for being declared as RFT in an RFT camp (5=10%) or brought forward by the health-workers for treatment at a skin diagnosis camps (2=4%).

About seven of them (14%) had gone to witness a camp out of their own curiosity and personal interest in the NLCP. Seven had gone to show suspected signs to health-workers at a skin diagnosis or ulcer case camps (14%).

About 38 patients (76%) differentiated between a leprosy control programme and other health programmes like, Malaria control programme, Family planning, immunization, Mother and child health (MCH) etc.

35 patients were satisfied with the health services rendered under NLEP. Satisfaction towards health services was influenced by their experience in cure, compliance to treatment experience with long duration disease and infirmities cases etc. (Refer to the cross-tabulation charts).

About 28 could recall health-workers talk to them about early signs and symptoms, causation and infectiousness in leprosy (56%). 13 could remember health-worker talk about HOPE and cure of limbs (26%) while about 10 of them 20% could not recall the Health-Education given to them about facts in leprosy.
III. Analysis of Health-Workers' Explanatory Model:

The table on personal data reveal that majority of the respondents belonged to age-group 20-40 years (27.4%) out of which about 23 belonged to Non-medical assistant category (65.7%). About 6 of them have put in 21-35 years of service in the leprosy field alone and about 13 (37%) have contributed 10-20 years of service for the same. 18 (51%) of the leprosy workers had relatives engaged in social work, leprosy and other health departments as medical doctors and health-workers and 2 (5.7%) of them had leprosy persons in their families. But only 8 (22.8%) of were influenced by the above categories of people for joining leprosy work.

About 8 (22.8%) of the leprosy workers did not have any personal hobbies, while remaining had interests in games and Sports, literature, music and dramas, photography and painting, letter and diary-writing, social work and political issues.

(A) Knowledge, Attitude and Practice towards leprosy:

About 10 of the leprosy workers did not fear any diseases. However, 4 of them feared general diseases, 5 feared AIDS and 6 feared cancer.

1. Perception towards leprosy prior to joining the leprosy work:

The table shows that majority of them (10=29%) had no prior knowledge about leprosy. A significant number thought leprosy to be incurable (6=14%), communicable (4=11%), leads to deformities and result of one's misdeeds (6=14%). About 10 of them (29%) sympathized with
2. Perception towards leprosy after joining the LCP:

The figures show that 11 of the workers gained knowledge about leprosy, after joining the leprosy work. This infers that there has been 100% gain of knowledge on leprosy by the health-workers. This is logical as all had to undergo training programmes before joining the leprosy work. About 10 (29%) of them believed in curability of leprosy through MDT and 5 of them felt motivated to restore self-respect of the patients. 3 of them underwent change in their former notions and misconceptions in leprosy. However, 1 continued to harbour fear towards communicable aspect of leprosy through physical contact (like touch).

3. Present Attitude towards leprosy:

Apart from being convinced about the curability of leprosy (expressed by the majority of them) 5 of them viewed community participation as necessary in LCP, 4 of them perceived early case-detection as important for deformity prevention. Patients' restoration of self-respect was a priority for 6 of them and community awareness campaigns were advocated by 7 (20%).

No fear towards being in close contact with leprosy persons was expressed by all. (including the one who had continued to harbour fear, indicated in the table E315 p. 375)
4. Fear-removal:

About \( \frac{3}{4} \) of them (57%) had harboured fear and held misconceptions towards leprosy and leprosy affected persons, prior to joining the leprosy work.

Factors leading to fear-removal from the minds of the workers have been presented in table 16 p. 375.

5. Transmission and Infectivity:

Health-workers had expressed critical views regarding the transmission and infectivity of the disease. Out of 35 respondents 4 had supported the idea that leprosy was communicable. 2 of them had stated that leprosy is communicable if early treatment is not taken by the patients, while other 2 had attributed close-contacts with affected persons as the mode for disease transmission.

According to one of the respondent, their medical officers do not talk about infectivity in leprosy, while the medical scientists engaged in the field of research state that leprosy is communicable and low immunity system of the body is host-factor for the disease.

"Leprosy is communicable when the person is not under treatment. We, as leprosy workers are engaged in destroying the bacilli which have emerged out of a big pit. Strategies should be directed towards the destruction of bacilli within the pit. Even if the pit is covered, the bacilli would dig out other openings for its exit".

A question was been raised as to how to increase the immunity of the body, if low immunity is the reason for the
occurrence of disease. The health-workers have suggested that all should be vaccinated for strengthening the body immunity systems.

Another issue which perplexes most of the leprosy-workers engaged in field-work and health-education, is the difficulty in explaining about the body immunity system as cause for the entry of bacilli into one’s body. Questions are asked by the community as to how they should know the level of immunity system, whether it is weak or strong. The scientists should device an instrument for measuring the different levels of immunity system of the people and protect the persons with low immunity system against a leprosy bacilli.

6. Concept about Cure:

All of the leprosy-workers were convinced about the curability of leprosy. Unlike the community members and the patients, leprosy workers had been personally involved in providing health-facilities to patients, motivating them for treatment compliance, advising and administering HOPE for ulcer and deformity cases, etc. Their experience of seeing patients being cured of disease symptoms have boosted their self-confidence in both medical and social therapy administered to patients. The patients give credit to the workers for curing their disease. (Table EMT p. 372)

Compare with Table EMHW3 p. 384.

According to Dr. G.P. Mishra (DLO), the patient’s concept of cure is very high in leprosy, unlike the medical concept of cure which is based on the bacteriological status of the disease. Where the bacteriological index is negative, the patient is declared as cured.
But in leprosy, it is only when a deformed person is accepted within the community circles that he is said to be cured.

All the respondents agreed to the care of patients after being declared as RFT. They felt that it was their responsibility to extend care and support to the cured leprosy persons. The following table indicates the reasons for health-workers maintaining social relationships with cured persons.

7. Deformity Prevention and Ulcer Care:

About 29 of the respondents stated that they were benefited from an ulcer-care camps. All of them agreed that patients had benefitted from the above camps, except one who had not answered. Similarly, all the respondents agreed that community members were also benefitted. (except 3 who had not answered) see table.

Majority of the health-workers had differentiated between an ulcer in leprosy and ulcers in other disease conditions (like diabetes, ulcers due to cuts and burns, accidents, ulcers as result of skin diseases, etc.) The reasons for the differentiation has been present in the table.