

CHAPTER-XII

CHAPTER XII PROBLEMS RELATED TO LEPROSY

12.1 Diagnosis of Psycho - Social Problems :

Contemporary developments in social science revealed that the health is not a bio-medical phenomenon but is also influenced by social, psychological, cultural, economic and political factors of the concerned people.

In case of leprosy, the moment a person is correctly diagnosed as a leprosy patient, clouding of mind starts. The stigmatized experience among the family members, colleagues and in the community tend to make the leprosy patient lose his social values, self concept and homeostatis. Such clouding of mind, psychological trauma along with ignorance about the trouble - free early symptoms of the disease contribute towards non-reporting, non-acceptance of diagnosis and non-compliance to treatment.

During the present study, in order to know psycho-social problems associated with a leprosy patient, detailed discussions were done with 177 active leprosy cases who are undertaking treatment. Each problem was awarded one point in order to judge the mental status of the sufferers. Later these problems were broadly categorized

into four groups, viz., Perceptual, Psychological, Social and Treatment Compliance, and individually each problems frequency were calculated under these sub-headings as shown in table 12.1

TABLE 12.1 : Type of problems associated with active leprosy cases.

SR. NO.	RESPONSES TO PROBLEMS ASSOCIATED WITH LEPROSY ACTIVE CASES	FREQ.	%
A. PRECEPTUAL PROBLEMS			
1.	No idea about the cause of leprosy	148	83.6
2.	No idea about the infection of leprosy	152	85.8
3.	No idea about effect of leprosy	132	74.5
4.	No idea about physical manifestation of disease	162	91.5
5.	No idea about cure of this disease	138	78.0
6.	No idea that deformity will affect the personality	168	95.0
AVERAGE		150	85.0

SR. NO.	RESPONSES TO PROBLEMS ASSOCIATED WITH LEPROSY ACTIVE CASES	FREQ.	%
B. PSYCHOLOGICAL PROBLEMS.			
7.	Depression	19	10.7
8.	Anxiety : Curability	173	97.7
9.	Anxiety : Future of the family.	157	88.7
10.	Anxiety : Economic loss.	143	80.7
11.	Anxiety : Future of the children	101	57.0
12.	Anxiety : Complete cure.	98	55.3
13.	Fear : Disability.	42	23.7
14.	Fear : Divorce.	52	29.3
15.	Fear : To lose job.	87	49.1
16.	Fear : To get married / For marriage	89	50.2
17.	Fear : Discarded / Acceptance	143	80.7
Average		116	66.0

SR. NO.	RESPONSES TO PROBLEMS ASSOCIATED WITH LEPROSY ACTIVE CASES	FREQ.	%
C. PROBLEM OF TREATMENT COMPLIANCE			
18.	Delay in collecting drugs.	82	46.3
19.	Prolonged treatment	27	15.2
20.	Irregular in taking medicine	67	37.8
21.	Irregular visit to hospital	54	30.5

SR. NO.	RESPONSES TO PROBLEMS ASSOCIATED WITH LEPROSY ACTIVE CASES	FREQ.	%
22.	Pregnancy	9	5.0
23.	Poor Co-operation from doctors	1	0.55
24.	Poor co-operation from health worker	12	6.7
25.	Treatment facility is quite far	60	33.8
26.	Treatment is quite costly	17	9.6
Average		37	21.0

SR. NO.	RESPONSES TO PROBLEMS ASSOCIATED WITH LEPROSY ACTIVE CASES	FREQ.	%
D	SOCIAL PROBLEMS		
27.	Abuse from spouse	54	30.5
28.	Abuse from in-laws	20	11.2
29.	Driven out from home.	21	11.8
30.	Isolation at home.	47	26.5
31.	Threatned to get divorce.	28	15.8
32.	Consipracy to murder	2	1.1
33.	Jail term in hospital	2	1.1
34.	Retirement.	40	22.6
35.	Sex difficulties.	62	35.0
36.	Change in financial status	84	47.4

SR. NO.	RESPONSES TO PROBLEMS ASSOCIATED WITH LEPROSY ACTIVE CASES	FREQ.	%
37.	Change in different type of work	74	41.8
38.	Change in working hours.	25	14.1
39.	Change in eating habits.	123	69.4
40.	Problem of school admission for children	9	5.0
Average		42	24.0
Overall Average		73	41.0

Table 12.1 indicates that the patient may be suffering from one or more of the problems mentioned. This table shows that at least 85% of the patients had suffered from perceptual problems, 66% from psychological problems, 41% from social problems and 21% from problems related to treatment compliance.

Figure 12.1 gives the decreasing pattern of the problems associated with leprosy patient with in increasing months or years of suffering.

Table 12.2 : Cross examination of the total of score of problems associated with leprosy patient with duration of suffering of leprosy patient each group.

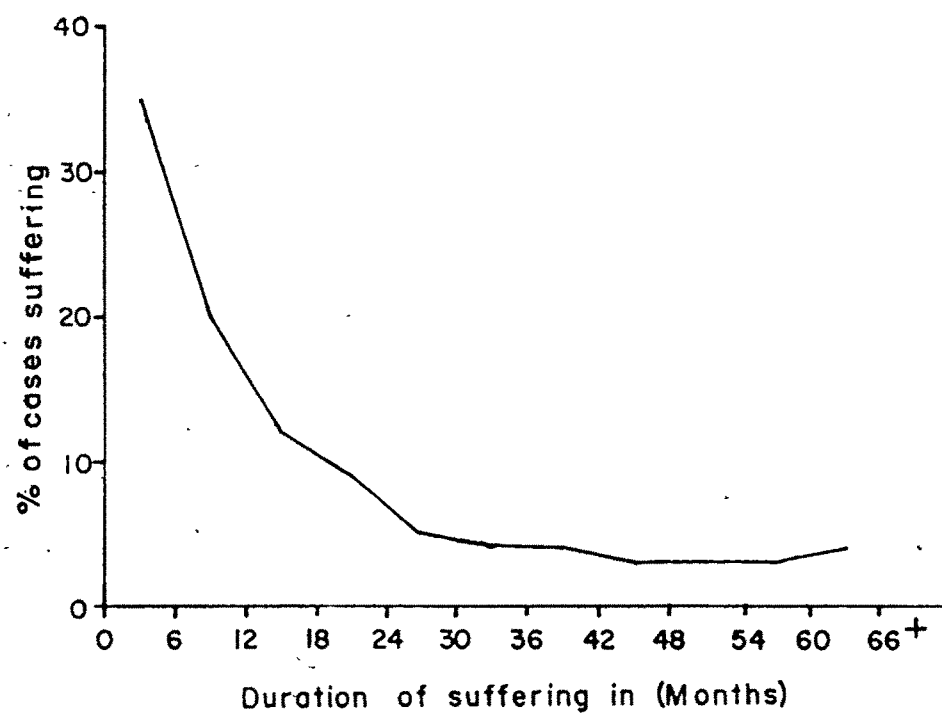


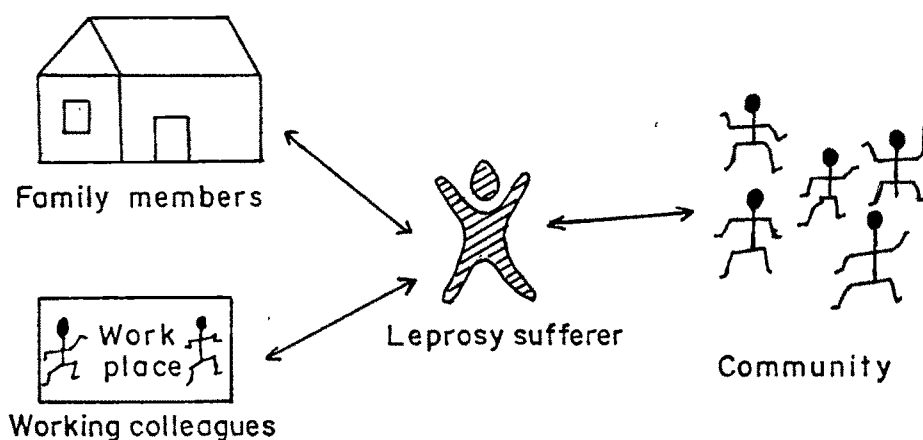
Fig.12-1

Years of suffering (Months)	Score of the problems of leprosy patient							Total Cases
	1-5	6-10	11-15	16-20	21-25	26-30	31-35	(%)
0-6	4	12	18	21	4	3	-	62(35)
7-12	2	8	9	10	6	-	-	35(20)
13-18	1	4	5	6	3	1	-	20(11)
19-24	1	3	4	5	2	1	-	16(9)
25-30	-	1	3	3	1	-	-	8(4.6)
31-36	-	1	3	2	1	-	-	7(4)
37-42	-	1	3	2	1	-	-	7(4)
43-48	-	-	1	2	1	-	1	5(2.8)
49-54	-	-	2	1	2	-	-	5(2.8)
55-60	-	-	1	2	1	-	1	5(2.8)
Above 60	-	-	2	3	1	-	1	7(4)
Total	8(4.5)	30(17)	51(29)	57(32)	23(13)	5(2.8)	3(1.7)	177(100)

In general, it was noted that the onset of the disease gives rise to greater psychological problems. The trauma is enhanced due to the lack of knowledge about the disease. The fact that psychological problems are less among those suffering over a prolonged period is due to increasing knowledge with experience and a gradual state of acceptance of facts. This analysis further emphasizes the need for spread of education among the masses so that no person need face the trauma that largely results from ignorance.

12.2 Attitude :

Seeing the stigma associated with this disease, attitude is an important factor in the study. Attitude can be judged in two ways, i.e. the attitude of the sufferer towards his family / colleagues / community and vice versa as shown in figure 12.2 below.



Thus one can say that attitude is a reciprocal process in between the sufferer and non-sufferer either at their home, or at their work place or within their community. Thus, for discarding or accepting, one cannot blame either society or community or family or working colleagues because the sufferer has an equal and shared responsibility in reinforcing the negative attitude of others towards him. A look at the attitudes of sufferers towards others and vice versa reveals interesting results.

TABLE 12.3 : Details sufferers' attitude towards persons
in the family or community etc. & vice versa.

SR. NO.	TYPE OF PATIENT	DID NOT RESPOND	AVOID PEOPLE	MIX FREELY	TOTAL
1.	Active cases (Adult)	102	63	12	177
2.	RFT Cases (Adult)	219	189	36	444
3.	Relapse cases (Adult)	3	27	6	36
TOTAL		324 (49)	279 (42)	54 (9)	657

From the total only 9% of cases mix freely with others while 42% try to avoid people owing to the stigma associated with the disease. Apart from this 49% were not willing to disclose their attitude either due to shame or due to social prejudice against them. The reasons for not mixing with others are as follows :

REASONS FOR NOT MIXING	ACTIVE CASES	RELAPSE CASES	RFT CASES	TOTAL CASES	(%)
- Unable to say/don't want to disclose	102	3	219	324	(55)
- It may affect others since it is infectious	30	16	78	124	(20)
- Out of shame	16	5	65	86	(14)

Cont...

REASONS FOR NOT MIXING	ACTIVE CASES	RELAPSE CASES	RFT CASES	TOTAL CASES	(%)
- Out of frustration	6	2	5	13	(2)
- Other people tend to avoid	11	4	41	56	(9)
TOTAL	165	30	408	603	(100)
REASONS FOR MIXING					
- It is a normal disease	4	1	13	18	(34)
- Believe that medicine will cure	3	1	5	9	(17)
- Other people not aware of the patient's condition	3	3	4	10	(18)
- People didn't know much about this disease	2	1	14	17	(31)
TOTAL	12	6	36	54	(100)

12.2.1 Family Attitude:

In order to know about the stigma within the family,
the sufferer responded hesitantly to the following :

REASONS FOR NOT MIXING	ACTIVE CASES	RELAPSE CASES	RFT CASES	TOTAL CASES	(%)
- They think it as normal diseases	16	5	42	63	(10)
- They did not know much about the infectivity of this diseases	30	10	54	94	(14)

REASONS FOR NOT MIXING	ACTIVE CASES	RELAPSE CASES	RFT CASES	TOTAL CASES	(%)
- Seeing the social custom and tradition they did not accept it.	69	17	68	154	(23)
- Do not want to disclose their family attitude / unable to say	62	4	280	346	(53)
TOTAL	177	36	444	657	(100)

Out of total case nearly 53% of the cases did not want to disclose their family attitude towards them. It not only shows the negative attitude of the family towards the sufferer but also the sufferer's responsibility in creating such attitude towards him. Seeing the social custom and tradition, 23% of cases have been neglected or discarded or suffer from negative attitude within their family while 14% cases had reported that their family did not have much knowledge about the infectivity of the disease. Only 10% of case had reported saying that their family members take it as a normal disease because by taking medicine regularly it can be cured. Thus 24% (14 + 10) can be considered to have positive attitude towards the sufferers within their family while the rest 76% can

be considered to have negative attitude.

For knowing sex attitude of the active cases within the family or, in other words, whether the stigma associated with disease had any effect on their physical relationships, the indirect information was asked with the help of leprosy health workers. The following results were obtained.

-	Did not respond	63 cases	-	36%
-	No difficulties	72 cases	-	41%
-	Had difficulties	42 cases	-	23%
	TOTAL	177 cases		

36% of cases kept silent or did not responded possibly because they do not want to expose their private life. Of the 41% who had reported to have no difficulties had mentioned that their did not know much about the infectivity of this disease. Only 23% had reported to have difficulties with their partner either because their partner knew about the infectivity of the disease or due to social custom and tradition they usually kept themselves away from each other.

12.2.2 Attitude of Colleagues :

Attitude of colleagues working with sufferers also plays an important role in creating negative or positive image of the sufferer. Out of total only 8% of sufferers are not working while rest 92% are engaged in earning their livelihood through various professions. The following responses were given by the sufferers regarding the attitudes they encountered at their work place.

RESPONSES	CHILD	RELAPSE	ACTIVE	RFT	TOTAL	(%)
-Not working	56	1	8	0	65	(8)
-Unable to say	26	5	44	124	199	(26)
-Colleagues not aware of respondent's diseases suffering	16	14	52	83	165	(21)
-Colleagues keep distance from respondent	4	10	18	76	108	(14)
-Colleagues do not know much about the infectivity of this disease	5	-	17	42	64	(8)
-Maintain normal attitude	-	-	16	31	47	(6)
-Adopt discarded attitude	6	6	22	88	122	(23)
TOTAL	113	36	177	444	770	(100)

It appears that the number of colleagues who do not adopt a negative ^{attitude} towards the sufferers^{es} is about 28%. So the

majority have reasons to feel discarded since those who have not responded may be unwilling to reveal the negative attitudes.

12.2.3 Attitude of the Community :

It is an important factor to visualize the stigma within the society in which the sufferer lives. The following experiences within their community have been narrated by the sufferers.

COMMUNITY EXPERIENCE	ADULT CASES	RELAPSE CASES	RFT CASES	TOTAL CASES	(%)
-Unable to say/reluctant to speak.	37	6	109	152	(23)
-Discarded attitude / social boycott	82	22	203	307	(46)
-Normal attitude because it is curable by taking regular medicine	24	2	52	78	(12)
-Others are unaware of the suffering	15	3	32	50	(8)
-Others don't have much knowledge about the infectivity	19	3	48	70	(11)
TOTAL	177	36	444	657	(100)

In these cases too, about 1/3rd of the sufferers have

experineced a positive attitude. But majority of cases had experienced negative attitude towards them due to this disease.

By taking into consideration the experiences at all the three levels (family members, friends and colleagues and community), the overall picture of the district that emerges is that 50% had experienced negative attitudes. Nearly 15% of cases are unable to say or are not willing to disclose their experience due to social prejudice and only 10% of cases had experienced a normal attitude because of the belief that medicine can cure that disease and hence they consider this disease as normal and also behave normally towards the sufferers of this disease.

Further details as to what type of custom and tradition are associated with this disease are revealed in the following analysis :

CUSTOM AND TRADITION	NOS. OF CASES	(%)

- Unable to say / reluctant to speak	116	15
- Total social boycott at any occassion	354	46

CUSTOM AND TRADITION	NOS. OF CASES	(%)
- Sufferer should be kept in Isolation	98	13
- The entire family is boycotted	126	16
- Only formal relations are maintained	70	9
- Formerly such persons were buried alive in the community	10	1
TOTAL	770	100

On classifying the above customs and tradition according to community the following results are obtained.

CUSTOM AND TRADITION	SC	ST	OTHERS	TOTAL
- Unable to say / reluctant to speak	37	50	29	116
- Total social boycott at any occassion	113	152	89	354
- Sufferer should be kept in Isolation	31	42	25	98
- The entire family is boycotted	40	54	32	126
- Only formal relations are maintained	25	28	17	70
- Formerly such persons were buried alive in the community	-	10	-	10
TOTAL	246	332	192	770

Maximum problems arising out of primitive social customs and tradition appear to be associated with tribal communities. However as is already seen, such customs and traditions are also prevalent among other communities.

12.2.4 Marriage Attitude :

In order to know the attitude of marriage among the active leprosy cases the following queries were made.

Q. Did you get this disease before or after marriage ?

- Before marriage	28 cases	17%
- After marriage	109 cases	61%
- Bachelor	40 cases	22%

Q. Does your husband / wife accept you ?

a. Reasons for positive response :

	No. of cases	(%)
- He/she does not know much about this diseases	43	31
- He/She thinks it as normal disease	19	14
- He/She had hope that it will be cured	14	10

b. Reasons for negative response :

- Because of this disease	32	23
- Due to social customs	18	13

- He/She is no more

11

9

Q. Why are you not married ? (For Bachelors)

- All of them stated that they were worried about this disease and all had hope for cure which will enable them to marry later. But most of these respondents tended to conceal their disease.

12.2.5 Treatment Compliance :

As regards treatment compliance attained through medicine the following answers were given by the sufferers.

	TREATMENT COMPLIANCE ATTITUDE	NO. OF CASES (%)

-	Unable to answer	128 17
-	Seeing other cases cured, had faith on medicine	384 50
-	Medicine cannot cure deformity	48 6
-	The main advantage is that medicine is free	198 26
-	Till now no improvement was found	12 1

	TOTAL	770 100

Out of total cases nearly 17% of them were unable to answer. Almost 50% of cases had a positive attitude towards the treatment given to them for their suffering

for this disease, and 26% of them are feeling relaxed that medicine is free. But 1% of cases had complained about no improvement in the suffering till date, while 6% of them had complaint that medicine cannot improve deformity.

12.2.6 Negligence :

Negligency of leprosy sufferers shows the ignorance about knowledge of the disease. The time delay towards the treatment or delay in early detection of leprosy can increase the case load of the disease. On asking as to how long after they first noticed the symptoms they went for their first treatment for this disease, the responses were as follows :

RESPONSES		FREQUENCY	(%)
-	Unable to answer	62	35
-	Within a Month	46	26
-	After 1 - 2 Months	24	13
-	After 2 - 3 Months	16	9
-	After 3 - 6 Months	12	7
-	After 6 - 12 Months	17	10
TOTAL		177	100

Nearly 35% of the respondents were unable to recollect as

to when they went for their first treatment after they came to know about their suffering. Only 26% of the respondents went within a month to take their treatment, while the remaining 39% took longer time to go for their treatment. The following are the reasons mentioned by these respondents for their delay in taking treatment against leprosy.

REASONS	FREQUENCY	PERCENTAGE
- Confused as a patch of leucoderma	14	20
- Due to economic reasons	39	57
- Consider as normal patch	16	23
TOTAL	69	100

12.3 Leprosy Stigma :

As already noted leprosy is a painless disease because of the anaesthetic condition of the affected parts of the body. At the same time the sufferers of leprosy are subjected to the most painful experience of life owing to the social stigma attached to the disease.

The moment a person is correctly diagnosed as a leprosy patient, his role in the society will be restricted and

constrained in view of the cultural norms of society. This tends to isolate him mentally and later physically, when advanced symptoms of the disease, like deformity sets in. Thus he is subjected to an "exile" into a leprosy colony and completely separated from ordinary social activities. In his new role he will soon become a "nonperson" thus starting his own premature "social death" and become an "out caste". Besides he will also be blamed for his own sickness. However, in spite of his willingness to assume a sick role, he may not always be willing to accept the prescribed drug regimen, thus posing dilemmas to medical profession and the healthy society. This behaviour pattern of non-compliance to treatment may end up with wrong perceptions on the part of the health giver (educator) and resulting in a hostile attitude towards the patient. So, as in all clinical practices, when the patient shows no will to be well, the importances of medicine will be reduced or totally abolished. At the same time, the health provider loses the motivation to cure along with whatever compassion and drive to help he might have had. Instead cynicism becomes part of the professional stock.

Traditionally, stigma is considered as a phenomenon out of the perception of the healthy society. According to this theory, as propounded by Goffman (1991) the stigmatised individual will define himself as not different from other human beings of his group, but those around, will identify him as someone set apart. This clash of perception of the patient and the beholder leads to the impression that the former's identity and images is vitiated by the community which is mainly responsible for the community's general reaction towards the leprosy patients.

This view - point swayed for a long time. However, empirical studies by Valencia in the Philippines and by A.M. Kurup in Wardha, indicate a contrary trend. According to them, the patient has an equal and shared responsibility in reinforcing the negative attitude of others towards him. In other words patients themselves contributes towards spoiling their self - image. Self - familial and community affairs which is the consequence of his blurred and lowered self - image. This lowered self - image is the result of his perception about the disease that it is likely to persist for long and that the

therapy offered to him may not control or reverse his disfigurement. This dilemma of stigma, arising out of contradictory perceptions, is an important point for the leprosy control programmes.

The factors associated with stigma, when examined in the study area, reveals certain interesting features, some of which are already revealed through the preceeding discussions on attitudes and the rest will be apparent in the following analyses of knowledge, awareness and perception of both sufferers and non-sufferers, and the health workers.

12.4 Knowledge, Awareness & Perception (KAP) :

The secondary data reveals excellent efforts made by the health educators in imparting health education to the suffers and non-sufferes at various places (Home / School / Villages / City areas) by using posters, slide shows, booklet / verbal instructions, etc. Since it was very difficult to judge KAP in 770 cases on the field, it was decided to take only adult active cases in order to judge their knowledge, Awareness and perception. Also, KAP among non-sufferers and leprosy medical and para-medical

personnel was also judged. Each answer, which matches the criteria laid down by the National Leprosy Eradication programme (NLEP), is awarded **one** point.

TABLE 12.4 Criteria for Judging KAP

Q. What is your belief about this disease ?	POINTS
- Hereditary disease	0
- Punishment from god	0
- Contact disease	1
- Just like other disease / Normal disease	1
- Untouchable type of disease	0
- Skin disease	1
Q. In your opinion how does this disease spread ?	
- Close contact with infectious person	1
- Spreads through cough, sneezing, sputum	1
- Nasal droplets	1
- Through breathing	1
- Environmental factors, viz., overcrowding, unhygeinc surroundings, etc.	1
- By biting insect / mosquitoes / cockroach etc.	0

Q. What are the early signs of leprosy ? Points

- A pale / red patch on the skin and change in texture 1
- A raised or flat patch - dry, shiny or smooth... 1
- Loss of anaesthesia on the patch site 1
- Loss of anaesthesia on hand & feet 1
- Swelling of nerves 1
- Bending of fingers / wrist drop and others 0

Q. Is leprosy curable ? YES NO
1 0

Q. Does leprosy effect everyone ? 0 1

Q. Is it necessary to isolate leprosy sufferer ? 0 1

Q. Is leprosy infectious ? 1 1

Q. Can deformities be prevented ? Yes No
1 0

Q. What can you do for leprosy sufferers ? Points

- Educate them about this disease. 1
- Make them go for early treatment 1
- Give them equal opportunities in all respects 1
- Do not neglect them 1
- Boost up their morale 1
- Give them proper advice about the treatment 1

12.4.1. KAP Among Sufferers and Non-sufferers :

When each question was analysed among sufferers, non-sufferers the following results are obtained :

Table 12.5 : Details of responses of KAP among sufferers and non - sufferers.

SR. NO.	SCORE GROUP OF BELIEFS	SUFFERERS	NON-SUFFERERS	TOTAL (%)
1.	Unable to say.	98	12	110 (38)
2.	One point* only	52	65	117 (41)
3.	Two point only.	5	4	9 (3)
4.	Wrong Belief.	22	29	51 (18)
TOTAL		177	110	287 (100)

The above table indicates that 38% were unable to answer while 18% had wrong belief about the disease. Majority, i.e., 41% believed the disease to be a contact disease or normal disease or skin disease, thereby scoring only one point while only three percent firmly believed the disease was not only normal disease or skin disease but also infectious and thus scored two points.

SR. NO.	BELIEF ABOUT THE DISEASES	SUFFERERS	NON-SUFFERERS	TOTAL (%)
1.	Hereditary	5	6	11 (3.8)
2.	Punishment from god	12	10	22 (8.0)
3.	Contact disease	32	48	80 (28)
4.	Just like other disease/Normal disease	7	5	12 (4.0)
5.	Untouchable type disease	5	13	18 (6)
6.	Skin disease	8	8	16 (5.5)
7.	1 & 3 Belief	2	1	3 (1)
8.	2 & 3 Belief	1	1	2 (0.7)
9.	3 & 5 Belief	2	2	4 (1.6)
10.	4 & 6 Belief	2	2	4 (1.6)
11.	2 & 3 & 4 Belief	3	2	5 (1.8)
12.	Unable to say	98	12	110 (38)
TOTAL		177	110	287 (100)

The above table shows that out of total cases nearly 38% were unable to answer while 17.8% had wrong notion about the disease. Majority, i.e. 28%, believed the disease to be infectious.

SR. NO.	SCORE OF EARLY CARDINAL SIGNS	SUFFERERS	NON-SUFFERERS	TOTAL (%)
1.	Unable to answer	27	52	79 (28)
2.	One point only	126	46	172 (60)
3.	Two point only.	8	-	8 (2)
4.	Wrong Answers	16	12	28 (10)
TOTAL		177	110	287 (100)

The above table indicates that nearly 28% were unable to answer while 10% had given wrong answer. Among those who responded, the majority believed that loss of sensation on patch site was the only early cardinal sign for leprosy.

SR. NO.	KNOWLEDGE OF EARLY CARDINAL SIGNS	SUFFERERS	NON-SUFFERERS	TOTAL (%)
1.	A pale red patch	18	0	18 (6)
2.	A raised patch	20	18	38 (13)
3.	Loss of sensation at patch site	58	28	86 (30)
4.	Loss of sensation on hands and feet	18	-	18 (6)
5.	Bending / claw of finger hand/ feet	16	12	28 (10)

SR. NO.	KNOWLEDGE OF EARLY CARDINAL SIGNS	SUFFERERS	NON-SUFFERERS	TOTAL (%)
6.	Swelling of nerve	8	-	8 (6)
7.	1 & 2 Cardinal sign	2	-	2 (0.28)
8.	3 & 4 Cardinal sign	2	-	2 (0.28)
9.	5 & 6 Cardinal sign	2	-	2 (0.28)
10.	1 & 3 Cardinal sign	2	-	2 (0.28)
11.	3 & 5 Cardinal sign	2	-	2 (0.28)
12.	3,5 & 6 cardinal sign	1	-	1 (0.3)
13.	2,3 & 6 cardinal sign	1	-	1 (0.3)
14.	Unable to say	27	52	79 (27)
TOTAL		177	110	287 (100)

The utter ignorance of people regarding the early symptoms not only reveals their lack of knowledge and awareness about the disease, but also explains one of the main reasons for the low percentage of self-reporting of cases.

Q. Is leprosy curable ?

SR. NO.	OPINION ABOUT CURABILITY	SUFFERERS	NON-SUFFERERS	TOTAL	(%)
1.	Unable to say	98	54	152	(53)
2.	Yes	52	32	84	(29)
3.	No	27	24	51	(18)
TOTAL		177	110	287	(100)

As regards curability nearly 53% were unable to answer, while only 29% answered in the affirmative and 18% had responded negatively. overall, it apperas that the sufferers are more sceptical about their chances of recovery. The number of respondents giving how, why and why not they believed, the disease can be cured are shown below.

Q. How the disease can be cured :

OPINIONS	SUFFERERS	NON-SUFFERERS	TOTAL
- If medicines are taken regularly.	47	-	47
- If detection and reporting is early	-	2	2

Q.	Why the disease is considered curable :			
		Sufferers	Non-Sufferers	Total
-	Many people in the village have cured.	4	30	34
-	Respondent himself already been cured.	1	-	1
Q.	Why the disease is considered incurable :			
-	Without any reasons	11	24	35
-	No improvement is observed so far	27	24	51

It is evident that almost one-third of the respondents believed that the disease is incurable. More than 50% of the sufferers have realised that cure is possible through regular intake of medicine. The attitude of the non-sufferers is largely guided by their observation of the number of people cured. The implications of these findings is the urgent need for adequate health education and erasing the misconceptions regarding the disease from the minds of the people. The fact that 53% of the respondents (including sufferers and non-sufferer) were unable to comment at all, further strengthens this necessity.

SR. NO.	OPINION ABOUT AFFLICTION OF LEPROSY	SUFFERERS	NON-SUFFERERS	TOTAL	(%)
1.	Unable to say	102	78	180	(63)
2.	Yes	18	27	45	(15)
3.	No	57	5	62	(22)
TOTAL		177	110	287	(100)

As regards whether leprosy affects all people, 63% of the respondents were unable to answer, 22% felt it could not affect everybody and 15% accepted the occurrence of the disease among all people. The reasons cited for these responses are as follow.

REASONS	SUFFERERS	NON-SUFFERERS	TOTAL
- Without any reason	14	16	30
- Because it is contagious	4	11	15
- Affects only persons living with patient	17	5	22
- Affects only poor people	26	-	26
- Affects only slum dwellers	14	-	14

Q. Is it necessary to isolate leprosy sufferers ?

SR. NO.	OPINION ABOUT ISOLATION	SUFFERERS	NON-SUFFERERS	TOTAL	(%)
1.	Unable to answer	52	62	114	(40)
2.	Yes	93	38	131	(46)
3.	No	32	10	42	(14)
TOTAL		177	110	287	(100)

As regard isolation of leprosy patients, about 46% of respondents expressed the need for isolation. The reasons for the need for isolation, evoked responses in the following manner:

REASONS	SUFFERERS	NON-SUFFERERS	TOTAL
- Others in the family may get infected	34	32	66
- Because of social stigma associated with it.	40	-	62
- It is infectious disease	19	6	25

Reasons why isolation was not necessary are seen in the following responses :

REASONS	SUFFERERS	NON-SUFFERERS	TOTAL
- Economic support to family will be affected	10	10	20
- Increase mental worries	5	-	5
- Health workers provide treatment at home	3	-	3
- It is normal disease	14	-	14

Q. Is leprosy infectious ?

SR. NO.	OPINION ABOUT INFECTION OF LEPROSY	SUFFERERS	NON-SUFFERERS	TOTAL	(%)
1.	Unable to Say	42	22	64	(22)
2.	Yes	92	62	154	(54)
3.	No	43	26	69	(24)
TOTAL		177	110	287	(100)

As regard infectivity more than 50% have accepted, the fact that the disease is infectious while of the rest either do not consider it as infectious or have no knowledge in this matter. The reasons why the disease is considered infectious are as follow :

REASONS	SUFFERERS	NON-SUFFERERS	TOTAL
- Becasue of social stigma associated with it	14	30	44
- Persons living with them also have it.	38	-	38

The reasons why the disease is considered not infectious are :

REASONS	SUFFERERS	NON-SUFFERERS	TOTAL
- Just like other disease	11	-	11
- Unable to give reasons	32	26	58

Q. Can deformity be prevented ?

SR. NO.	OPINION ABOUT PREVENTION OF DEFORMITY	SUFFERERS	NON-SUFFERERS	TOTAL	(%)
1.	Unable to answer	170	107	277	(96)
2.	Yes	-	-	-	(00)
3.	No	7	3	10	(04)
	TOTAL	177	110	287	(100)

Knowledge regarding the occurrence of deformity seems to be very poor among both sufferers and non-sufferers as 96% of them were unable to answer it. Only about 4% were able to express their opinion and that too, was a wrong notion. The reasons why deformity cannot be prevented showed the following responses.

REASONS	SUFFERERS	NON-SUFFERERS	TOTAL
- Deformity is bound to occur in this disease	6	3	9
- Unable to give reasons	1	-	1

Q. What can you do about leprosy ?

SR. NO.	RESPONSE FOR GIVING THE SERVICE TO THIS DISEASE	SUFFERERS	NON-SUFFERERS	TOTAL (%)
1.	Unable to say	132	22	154 (54)
2.	Educate others about this disease.	8	-	8 (3)
3.	Make others go for early treatment	22	58	84 (28)
4.	Take medicines regularly	2	-	2 (0.65)

Cont...

SR. NO.	RESPONSE FOR GIVING THE SERVICE TO THIS DISEASE	SUFFERERS	NON-SUFFERERS	TOTAL (%)
5.	Do not neglect the patients 2	-	-	2 (0.65)
6.	Response number 2 & 3	5	-	5 (1.7)
7.	Response number 3 & 4	6	30	36 (12)
TOTAL		177	110	287 (100)

To judge the initiative taken by the respondents towards this disease, questions asked showed that 54% were unable to answer or were not willing to take any initiatives in this regard. Majority of those willing render some service would only recommend early treatment.

The maximum score a sufferer or non-sufferers could have was 25 points from the questions as stated above. The maximum score of sufferer was 24 and non-sufferer 21 and the minimum score among sufferers was 1 and non-sufferers was 3. The scoring groups were made seeing the maximum and minimum scores found among sufferers and non-sufferers and the results of the final score regarding knowledge and awareness, were as follows :

TABLE 12.6 : Final KAP scores among sufferers and non-sufferers :

SR. NO.	SCORE GROUP	SCORE CLASS	SUFFERERS	(%)	NON-SUFFERERS	(%)
1.	No Score	Zero	36	(20)	7	(6)
2.	Poor	1 - 6	44	(25)	44	(40)
3.	Average	7 - 12	52	(30)	24	(22)
4.	Good	13 - 18	38	(21)	27	(25)
5.	Excellent	19 - 24	7	(4)	8	(7)
TOTAL			177	(100)	110	(100)

It is evident that nearly 45% of the sufferers have practically nil to very little knowledge and awareness about the disease, while only about 25% have good understanding.

The trend among non-sufferers is very similar to that of the sufferers. All these point to the inadequacy of the health education programme of the NLEP. One reason for this could be that the health workers visit the village during the day when most of the people are at work. So the education programme of NLEP should be extended to

evening hours when all the village folk are available.

12.4.2 KAP Among Medical and Para-Medical Staff :

Besides sufferers and non-sufferers, leprosy medical and para-medical staff were also evaluated. Among these were 5 medical officers (M.O.) 13 leprosy supervisors (L.S.), 3 health educators, 3 Physiotherapists (Phy) and 54 leprosy para-medical workers. The questions asked are as shown in **appendix 5.6** along with the answers. Each correct answer (as shown in **appendix-5.6**) was rewarded one point. The point classification of each answer was as follow.

Table 12.7 : Responses Regarding KAP Among Medical and Para-Medical Staff (Note for details answers refer Appendix 4.6)

SR. NO.	RESPONSES REGARDING THE BELIEFS ABOUT DISEASES	MO	LS	HE	PHY	PMW	TOTAL	(%)
1.	Contact disease	1	3	1	-	25	30	(38)
2.	Just like other disease/ Normal disease	3	6	2	-	13	24	(31)
3.	Skin disease	1	4	-	3	16	24	(31)
TOTAL		5	13	3	3	54	78	(100)

Among leprosy medical and para-medical staff 38% belived leprosy to be an infectious disease while 31% belived it is as a normal disease. An equal percentage believed it as a skin disease.

Q. How does this disease spread ?

SR. NO.	OPINION ABOUT THE SPREAD OF DISEASE	MO	LS	HE	PHY	PMW	TOTAL (%)
1.	Close contact	1	2	-	1	11	15 (19)
2.	Through Sputum	2	3	1	1	8	15 (19)
3.	Nasal Droplet	-	4	2	1	1	8 (11)
4.	Through breathing	-	-	-	-	11	11 (14)
5.	Opinion 2 & 3	1	2	-	-	8	11 (14)
6.	Opinion 2,3, & 4	1	2	-	-	15	18 (23)
TOTAL		5	13	3	3	54	78 (100)

Only 23% of the respondents were able to give all the three causes of spread of the disease. Thus 23% of the respondents scored 3 points, while 14% scored 2 points, and the majority of them i.e., 63% scored only one point.

Q. What are the early cardinal signs of the leprosy ?

SR. NO.	RESPONSES TOWARDS EARLY CARDINAL SIGNS	MO	LS	HE	PHY	PMW	TOTAL	(%)
1.	A pale red patch	-	-	-	-	-	-	-
2.	A raised patch	-	-	-	-	-	-	-
3.	Loss of sensation at patch site	-	-	-	-	-	-	-
4.	Loss of sensation at hands and feet	-	-	-	-	-	-	-
5.	Swelling of nerve	-	-	-	-	-	-	-
6.	1 3 & 5 Cardinal sign	-	3	1	1	11	16	(20)
7.	2 3 & 5 Cardinal sign	1	3	-	1	27	32	(41)
8.	1,2,3 & 4 Cardinal sign	1	5	1	1	10	18	(23)
9.	1, 2, 3, 4 & 5 Cardinal sign	3	2	1	-	6	12	(16)
TOTAL		5	13	3	3	54	78	(100)

Only 16% of the respondents had correctly answered the early cardinal signs of leprosy but majority of them (41%) were able to give correctly atleast three cardinal signs, viz., a raised patch, with or without anesthesia and swelling of nerve and anesthesia of hand and feet, as early cardinal signs.

Among these respondents only 16% have scored 5 points 23%

have scored 4 points while majority of them (61%) had scored three points.

Q. Is leprosy is curable ?

Almost all the respondents agreed that it can be cured if medicine is taken regularly and through early detection or reporting. Besides this, they also admitted that many people had been cured when these points were followed strictly.

Q. Dose leprosy affect every one ?

Nearly 6% PMW agreed that it affects everyone because it is a contagious type of disease while 94% did not agreed that it affects everyone becasue according to them this disease is found to be among slum dwellers.

RESPONSES	MO	LS	HE	PHY	PMW	TOTAL	(%)
YES	1	6	-	1	30	38	(49)
NO	4	7	3	2	24	40	(51)
TOTAL	5	13	3	3	54	78	(100)

Almost half of the respondents agreed to isolate leprosy sufferers while rest did not agree to this. The reasons for supporting isolation were (a) it may affect other family members (20%) and (b) because of the stigma associated with it (29%). Those who did not support isolation gave two main reasons (a) it is a normal disease (23%) and (b) the economic problems faced by the sufferer's family if the suffer was forced into isolation (28%).

Q. Is leprosy infectious ?

RESPONSES	MO	LS	HE	PHY	PMW	TOTAL	(%)
YES	2	6	-	1	30	39	(50)
NO	3	7	3	2	24	39	(50)
TOTAL	5	13	3	3	54	78	(100)

Here almost 50% considered it as infectious disease while remaining 50% did not agree with this. The reasons why the disease is considered to be infectious are :

RESPONSES	MO	LS	PHY	PMW	TOTAL
- because of social stigma associated with it	1	2	-	17	20
- because it spread through contact.	1	3	1	-	5

Cont...

RESPONSES	MO	LS	PHY	PMW	TOTAL
- person living with them also have it.	-	1	-	13	14
TOTAL	2	6	1	30	39

Q. Can deformity be prevented ?

Almost all staff agreed that early reporting and early diagnosis of the disease helps in preventing deformities among sufferers.

Q. What can you do about leprosy ?

RESPONSES	MO	LS	HE	PHY	PMW	TOTAL	(%)
1. Educate others about this disease.	-	-	-	-	-	-	-
2. Make them go for early treatment	-	-	-	-	-	-	-
3. Take medicines regularly	-	-	-	-	-	-	-
4. Do not neglect the patients	-	-	-	-	-	-	-
5. Responded to 1 and 2 services	1	4	2	-	7	14	(18)
6. Responded to 2 and 3 services	1	5	-	2	4	12	(15)
7. Responded to 1, 2, 3 and 4 services	3	4	1	1	43	52	(67)
TOTAL	5	13	3	3	54	78	(100)

Majority (67%) of the respondents agreed to give their services for leprosy by making them go for early treatment, educating people about the disease, advice patients to take medicines regularly, and do not discard them.

Q. When did NLEP start ?

RESPONSES	MO	LS	HE	PHY	PMW	TOTAL (%)
- unable to answer	-	1	-	1	12	14 (18)
- In 1955	5	12	3	2	42	64 (82)
TOTAL	5	13	3	3	54	78 (100)

It is seen that at least 18% of the respondents were unaware as to when the NLEP came into existence. The majority of such respondents were para-medical workers.

Q. In which year Vadodara district had come under MDT scheme ?

RESPONSES	MO	LS	HE	PHY	PMW	TOTAL (%)
- In 1984	5	13	3	2	44	67 (86)
- unable to answer	-	-	-	1	10	11 (14)
TOTAL	5	13	3	3	54	78 (100)

Q. Do you know what are the reasons why Vadodara district was put under MDT scheme ?

RESPONSES	MO	LS	HE	PHY	PMW	TOTAL (%)
- unable to answer	1	3	1	1	18	24 (31)
- Because the district has P.R. more than 5 cases per 1000 population	4	10	2	2	36	54 (69)
TOTAL	5	13	3	3	54	78 (100)

Q. What are the main objectives of NLEP or MDT ?

OJECTIVES	MO	LS	HE	PHY	PMW	TOTAL (%)
- To render all infectious cases non-infectious	-	1	-	-	3	4 (06)
- To give adequate and regular treatment	-	-	-	-	5	5 (07)
- To prevent the emergence of of drug resistance	-	-	-	-	-	- (00)

OJECTIVES	MO	LS	HE	PHY	PMW	TOTAL (%)
- To ensure early detection and treatment	-	1	-	-	18	19 (22)
- To carry out systematic health education	-	-	-	-	-	- (00)

Cont...

OJECTIVES	MO	LS	HE	PHY	PMW	TOTAL (%)
- To prevent the spread of leprosy	-	-	-	-	-	- (00)
- To eradicate leprosy	-	-	-	-	-	- (00)
- Objectives 1 and 2	1	-	-	-	2	3 (05)
- Objectives 1, 2, and 3	-	3	2	2	3	10 (13)
- Objectives 1, 2, 3 and 4	2	2	1	-	6	11 (14)
- All objectives from 1 to 7	2	4	-	-	2	8 (10)
- unable to answer	-	2	-	1	15	18 (23)
TOTAL	5	13	3	3	54	78 (100)

Note : For detail answers refer appendix 5.6.

Nearly 23% of the respondents were unable to respond while only 10% were fully aware of the all the objectives of NLEP. Maximum lack of knowledge was amongst the para-medical workers.

Q. In how many stages was the multidrug treatment project implemented ?

RESPONSES	MO	LS	HE	PHY	PMW	TOTAL (%)
- Unable to say	-	1	-	1	8	10 (13)
- Four phases	5	12	3	2	46	68 (87)
TOTAL	5	13	3	3	54	78 (100)

Q. What do you mean by active case finding ? (For answer please refer appendix- 5.6)

RESPONSES	MO	LS	HE	PHY	PMW	TOTAL (%)
- Unable to answer	-	8	1	1	42	52 (67)
- Correct answer	5	5	2	2	12	26 (33)
TOTAL	5	13	3	3	54	78 (100)

Q. What is passive case finding ? (For answer see appendix - 5.6)

RESPONSES	MO	LS	HE	PHY	PMW	TOTAL (%)
- Unable to answer	1	9	1	1	44	56 (72)
- Correct answer	4	4	2	2	10	22 (28)
TOTAL	5	13	3	3	54	78 (100)

Q. What are relapse cases ?

- All answered correctly.

Q. What are the early cardinal signs of leprosy to identify persons suffering from leprosy ?

RESPONSES	MO	LS	HE	PHY	PMW	TOTAL (%)
1. Characterstic of skin lesion	-	-	-	-	-	-
2. Anaesthesia either partial or complete	-	-	-	-	-	-
3. Thickened nerves	-	-	-	-	-	-

RESPONSES	MO	LS	HE	PHY	PMW	TOTAL (%)
4. Demonstration of M. leprae in skin smear.	-	-	-	-	-	-
5. 2 and 3 Cardinal sign	-	-	-	1	34	35 (45)
6. 1, 2, and 3 cardinal sign	-	9	-	2	6	17 (23)
7. All four cardinal sign	4	4	3	-	14	28 (32)
TOTAL	4	13	3	3	54	78 (100)

Only 32% had responed correctly to all the four cardinal signs while 23% had given three cardinal signs and rest 45% ha mentioned only two cardinal signs.

Q. How many types of nerves are known to be involved in leprosy? What are the sites of predilection and signs elicited ?

RESPONSES	MO	LS	HE	PHY	PMW	TOTAL (%)
- unable to answer	-	-	-	1	-	1
- name of the nerve stated correctly	5	13	3	2	54	78 (100)
- site of predilection stated correctly	5	13	3	2	52	75 (96)
- sign elicited stated correctly	5	13	2	2	36	58 (74)

Except for one newly recruited physiotherapist who was yet to undergo training, all the staff were able to name all the nerves which are involved in leprosy. Among these 96% were able to explain their site of predilection correctly and only 74% were able to give all signs elicited with it. Hence, overall, 74% of the staff had given the correct responses of the nerves involvement.

Q. Give the classification of MB and PB type of cases ?

RESPONSES	MO	LS	HE	PHY	PMW	TOTAL (%)
- unable to answer fully	-	2	2	1	35	40 (51)
- Gave right classification (For MB - BB, BL, & LL) (For PB - I, PN, TT & BL)	5	11	1	2	19	38 (49)
TOTAL	5	13	3	3	54	78(100)

50% of the respondents were able to respond about classification of MB & PB type of cases and rest of them were unable answer fully. Among these the percentage of PMW is more.

Q. What is the treatment regime for MB & PB cases in adult & child leprosy cases ?

RESPONSES	MO	LS	HE	PHY	PMW	TOTAL (%)
- Unable to answer fully	-	-	-	1	2	3 (4)
- Answered correctly	5	13	3	2	52	75 (96)
TOTAL	5	13	3	3	54	78(100)

Q. What are clinical characteristics of MB & PB cases ?

RESPONSES	MO	LS	HE	PHY	PMW	TOTAL (%)
- Unable to answer fully	1	5	2	3	51	62 (80)
- Answered correctly	4	8	1	-	3	16 (20)
TOTAL	5	13	3	3	54	78(100)

The fact that 80% of the respondents were unable to answer fully the clinical characteristics of MB & PB cases, highlights the urgency for more training to be given for

differential diagnosis to both medical and para-medical leprosy workers.

Q. What is reaction in leprosy ? Mention its types also.

RESPONSES	MO	LS	HE	PHY	PMW	TOTAL (%)
- Unable to answer fully	1	10	2	3	49	65 (83)
- Answered correctly	4	3	1	-	5	13 (17)
TOTAL	5	13	3	3	54	78(100)

Q. What are the clinical features of both types of reaction ?

RESPONSES	MO	LS	HE	PHY	PMW	TOTAL (%)
- Unable to answer fully	3	9	2	3	49	66 (85)
- Answered correctly	2	4	1	-	5	12 (15)
TOTAL	5	13	3	3	54	78(100)

Almost 85% of the respondents were unable to answer correctly about clinical features of both types of reaction.

Q. How to give the grade to the deformed patients of Leprosy?

RESPONSES	MO	LS	HE	PHY	PMW	TOTAL (%)
- Unable to answer fully	-	-	-	-	7	7 (9)
- Answered correctly	5	13	3	3	47	71 (91)
TOTAL	5	13	3	3	54	78 (100)

Q. What are the side effects of the following drugs ?

RESPONSES	MO	LS	HE	PHY	PMW	TOTAL (%)
I. DAPSONE						
1. Unable to answer	-	-	-	3	6	9 (11)
2. Haemolytic Anaemia	-	1	-	-	18	19 (24)
3. Agranulocytosis	1	-	-	-	-	1 (1.5)
4. Dapsone sensitivity	1	5	-	-	-	6 (8)
5. Fixed drug eruption	-	1	-	-	-	1 (1.5)
6. Reaction 1 and 3	3	6	3	-	30	42 (54)
TOTAL	5	13	3	3	54	78 (100)

Cont...

II. CLOFAZIMINE	MO	LS	HE	PHY	PMW	TOTAL (%)
1. Unable to answer	-	-	-	3	9	12 (15)
2. Skin Change	-	3	-	-	8	11 (14)
3. Diarrhoea, Pain in abdomen	-	2	-	-	16	18 (23)
4. Change in the eye : conjunctial pigmentation	-	4	-	-	-	4 (6)
5. Reaction 2 and 3	-	2	1	-	14	17 (22)
6. Reaction 2, 3 and 4	5	2	2	-	7	16 (20)
TOTAL	5	13	3	3	54	78 (100)

III. RIFAMPICIN

1. Flushing or pruritis....	-	-	-	-	-	-	-
2. Pain in the abdomen....	-	1	-	-	4	5	(6)
3. Fever, chills, malaise.....	-	-	-	-	-	-	-
4. Shortness of breath.....	-	1	-	-	-	1	(1)
5. Purpure, acute.....	-	-	-	-	-	-	-
6. Liver failure, highrisk of...	-	1	-	-	-	1	(1)
7. Reddish colour urine.....	-	-	-	-	8	8	(10)
8. Reaction 1 and 2	1	-	-	-	10	11	(14)
9. Reaction 1, 2 and 4	-	2	1	-	5	8	(10)
10. Reaction 1, 2,3 and 4	2	2	2	-	7	13	(18)

Cont...

III. RIFAMPICIN	MO	LS	HE	PHY	PMW	TOTAL (%)
11. Reaction 1, 2, 3 ,4 and 5 .	-	3	-	-	6	9 (11)
12. Responded to all reactions	2	3	-	-	14	19 (25)
13. Unable to answer	-	-	-	3	-	3 (4)
TOTAL	5	13	3	3	54	78 (100)

Q. What is surveillance period ? Why is it done ?

- all answered this question correctly.

Q. What is the surveillance period of MB and PB cases ?

- All answered correctly.

The maximum points leprosy medical and para-medical staff could have was 70. Here the highest point was 64 and the lowest was 21. The score of medical and para-medical staff of leprosy had been divided into four groups on the basis of the points scored.

TABLE 12.8 : Final score of KAP among Medical and Para-Medical staff of leprosy.

SR. NO.	SCORE GROUP	GROUP CLASS	MO	LS	HE	PHY	PMW	TOTAL (%)
1.	Poor	1 - 16	-	-	-	1	19	20 25
2.	Average	17 - 32	3	5	2	-	11	21 26
3.	Good	33 - 48	1	6	1	2	18	28 36
4.	Excellent	49 - 64	1	2	-	-	6	9 13
	TOTAL		5	13	3	3	54	78 100

It is apparent from the above analysis that although the medical officers and leprosy supervisors have very good knowledge, awareness and perception of the disease, the same is not true for the health educators and para-medical workers most of whom have only poor to average understanding. Since it is the health educators and para-medical workers who are in constant touch with the people, creating awareness amongst the masses is their direct responsibility. The poor KAP score of the sufferers and non-sufferers already noted can therefore be partly explained by the state of knowledge prevailing among the health educators and para-medical workers.

Further intensive training of the staff should therefore be a priority. Another point to be noted is that the number of health educators in the entire district is only three. For the proper implementation of the education programme there should be at least one health educator for each taluka in order to allow maximum reach.

12.4.3 Spatial Analysis of KAP among Sufferers and Non-sufferers

The secondary source reveals that leprosy health educators of the district had done excellent work to impart health education among sufferers and non-suffers at schools, villages etc. Now, in order to know the spatial significance of KAP, the distance between the affected villages from the district headquarter (Vadodara city) was taken and related to the average KAP score of sufferers and non-suffers of these villages.

It was necessary to take district head quarter (Vadodara City) as nodal point because access to the treatment facilities and the awareness of the disease is found to be more among the urbanities compare to rural people. Though certain amount of stigma / mis-conception / wrong notion of the disease will always be there among the people living either in urban or rural areas, people of urban areas will have less misconception as compared to rural people.

On examination of the average KAP score respect to distance from district headquarter i.e., Vadodara city, it was found that with the increase of distance, the average score of KAP among sufferers starts decreasing as shown figure 12.3 a . However, there are some secondary peaks in the curve which coincide with the location of small towns or taluka headquarters. Thus one can say that health education among suffers living nearer to district or taluka headquarters (cases of district headquarter i.e., Vadodara city have been excluded) is good because it seems health educators are more interested in imparting health education in areas which are more easily accessible.

Thus in the remote parts of the district, misconceptions regarding the disease are more. Overall one can say that with the increase of spatial distance from the nodal centres, the knowledge, awareness and perception (KAP) among sufferers decrease which in turn helps to give rise to the stigamatized behaviour. Thus KAP is reciprocal to stigma with the increase of distance, giving rise to a distance - decay effect.

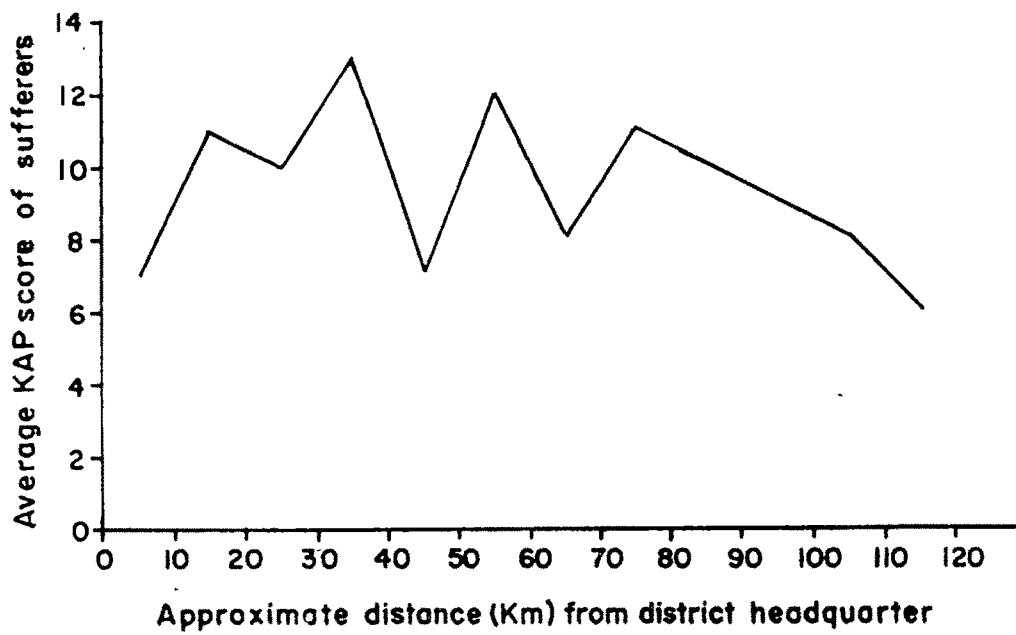


Fig.12-3a

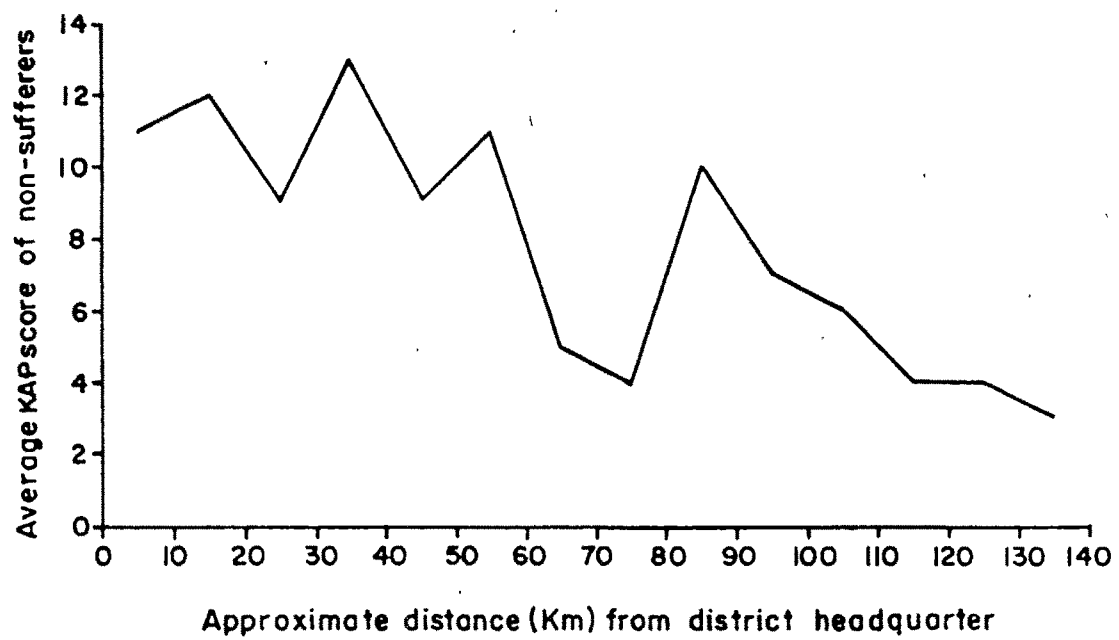


Fig.12-3b

A similar type of situation is also seen among non-sufferers as shown in figure 12.3 b.

TABLE 12.9 : The average score of the sufferers and non-sufferers in the various distance group from the district head quarter (DHQ).

APPROXIMATE DISTANCE FROM DHQ	AVERAGE SCORE	
	SUFFERERS	NON-SUFFERERS
0 - 10	7	11
11 - 20	11	12
21 - 30	10	9
31 - 40	13	13
41 - 50	7	9
51 - 60	12	11
61 - 70	8	5
71 - 80	11	4
81 - 90	10	10
91 - 100	9	7
101 - 110	8	6
111 - 120	6	4
121 - 130	-	4
131 - 140	-	3

12.5 Problems of Treatment Faced by Sufferers and
Leprosy Para-Medical Workers :

When asked what kind of difficulties they had faced during
treatment the following complaints were noted :

DIFFICULTIES OF SUFFERERS		FREQ.	%
1.	Unable to say	96	12
2.	No difficulties	308	40
3.	Felt loss of energy while working	107	14
4.	Itching sensation on patch site	20	3
5.	Since working on daily wages, unable to attend clinic	162	21
6.	No transport facilities	77	10
TOTAL		770	100

From the total 12 % of the cases were unable to narrate
their problems (these were mostly children and old people)
while only 3% complained about itching sensation on the
patch site. Beside this 14% also complained about loss of
energy while working. Nearly 21% reported their
unwillingness to attend clinic as they are working on
daily wages while 10% had highlighted the problem of

transportation. But the majority (40%) expressed that they have no difficulties during the course of treatment.

On asking para-medical workers as to what type of problems they face while imparting the treatment to the patients, almost all of them narrated the following difficulties encountered by them in the field which are as follows :

Health Worker's Difficulties

1. Individually unable to cover the area for survey.
2. Counselling difficulties, while imparting the treatment.
3. Difficulties in diagnosing the female patient.
4. Motivation techniques for deformity surgery and deformity casse.
5. Paper work load is more (filling reports).
6. Non-payment of TA and DA in right time.
7. Unable to perform the work during rainy seasons.
8. The local administration does not provide any encouragement while imparting health education in villages and in some urban areas.
9. Time bound promotions were not given by the district authorities.

10. Problems related to differential diagnosis among the leprosy sufferers.

Majority of the sufferers are worried about the deformity. Since, in the entire district, there are only two physiotherapists (one in the hospital and the other in the field). Thus it is impossible to provide assistance at every place at the same time. The sufferers are not willing to spare time to go to far - off places because their earnings are based on their daily labour. Secondly the accessibility to health centres is a problem in many rural areas. Thus larger number of physiotherapists need to be problem in many rural areas. Thus larger number of physiotherapists need to be posted in rural areas as field staff.

The suggestions put forward by the Medical and para-medical leprosy staff, regarding improvement in leprosy control work are as follows :-

1. Frequent refresher courses or training should be organised.
2. The teaching concept for all trainers should be common and common training materials should be prepared in order to avoid confusion.

3. In training more stress should be given on the motivation and counselling techniques.
4. More stress should be given for pre-and post-deformity care during the training sessions.
5. The allocation of villages in the endemic areas for each workers should be equal, i.e. division of work load should be shared equally.
6. In training, more stress must be given on differential diagnosis.
7. Frequent group survey should be allowed to be done.
8. Paper work load should be reduced in order to perform more field duties.
9. Each taluka must have one health educator and one physiotherapist.
10. The NLEP should be integrated with skin camp in order to detect more leprosy cases.
11. Payment of TA and DA and time bound promotion should be given in time.

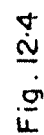
12.6 Spatial Distribution of Treatment Facilities :

The treatment facilities available for leprosy in Vadodara district consists of 17 sub centre and 50 SET centre (1992-93).

The spatial distribution of these centre (Fig. 12.4) reveals that these centres do not necessarily coincide with the high prevalence areas of leprosy. For example, the eastern talukas of Chhota Udepur, which is largely a hilly area having very few cases of leprosy, has as many as 9 sub centre, while Sankheda taluka, which has one of the highest prevalence rates in the district has only 6 SET centre. It is therefore apparent, that the prevalence pattern has not been taken into consideration when setting up these leprosy cure centre. Secondary source prevails that the district authority followed NLEP norms in setting these centre i.e., a leprosy para medical worker should at the most cover at least 25,000 thousand population.

It is thus essential to set up more units in the high prevalence zones in the Western part of the district as in Vadodara, Savli, Sankheda, Vaghodia talukas etc.. Another anomaly noted is that a number of centre have been set up in contiguous villages, while there are large areas with

Leprosy Sub Centre



no centre at all. These anomalies have resulted in inadequate and improper distribution of manpower and resources which could be more effectively utilised by better planning of location of the health care delivery system.
