

STUDY OF KNOWLEDGE, BELIEFS & ATTITUDES TOWARDS LEPROSY AMONG PATIENTS OF LEPROSY

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ABSTRACT:

Research Problem: What is the level of knowledge and attitudes of leprosy patients towards leprosy?

Objectives: To assess the knowledge, beliefs and attitude towards leprosy in leprosy patients.

Study Design: Hospital - based study by questionnaire method.

Setting and Participants: Leprosy patients attending Dermatology OPD, J.N. Medical College Hospital, A.M.U., Aligarh

Sample Size: 200 leprosy patients.

Study Variables: Knowledge, beliefs and attitudes regarding leprosy.

Outcome Variables: Percentage of patients having correct knowledge and positive attitude.

Statistical Analysis : By proportions.

Results: Ignorance about leprosy is still rampant. 81% of the patients were not aware of the cause of disease. 89.5% did not know whether the disease was preventable. 91% patients were optimistic that the disease was curable. 60% of the patients became anxious on learning the diagnosis of the disease. Relations were strained with spouse in 6% cases after learning the diagnosis of the disease.

Conclusions: Most of the patients had very little knowledge about leprosy, but they were optimistic about the cure of the disease. Interestingly, not much social stigma was encountered by the patients.

Recommendations : Raising the literacy status of the population

Key Words: Leprosy, Stigma, Knowledge, Relationships.

INTRODUCTION:

Leprosy is an ancient disease, probably the oldest known to mankind. It is a disease with a social stigma attached to it due to the deformi-

ties and disfigurements which it causes, leading to serious social and economic consequences.

'Stigma' has been defined by Goffman¹ as an attribute that is deeply discrediting and the stigmatized individual is one who is not accepted and not accorded the respect and regard of his peers, one who is disqualified from full social acceptances.

Stigma of leprosy is as old as the disease itself and is the major hindrance in the control of leprosy. It has been said "the problem with leprosy is not what the disease is, but what the people believe it to be." There is no other disease so associated with stigma and fear, and this seems to be related to the fact that leprosy deforms and disables but seldom kills, so that those it has crippled live on getting steadily worse, and yet for all to see².

Leprosy has for long remained a disease with a lot of misconceptions, erroneous ideas, superstitions and misrepresentations. In India, leprosy stigma has been very strong and deep. The disease was considered a punishment from God or a curse for the past sins of the sufferer. The disease was thought to be hereditary, highly infectious and incurable, frequently associated with beggars. In olden days, lepers were given bells to indicate their movements, and people used to move away from their path³. In Europe, in the Middle Ages, leprosy sufferers were declared unclean, they could not touch even their own children, and could not enter a house, an inn or a church, and were made to live in leprosy house/hospital, away from the city⁴.

Kant⁷ reported that due to the leprosy stigma, patients had to face a lot of problems.

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Education of student patients was disrupted, 16.7% patients had incurred debt for the diagnosis and treatment of the disease and 58.0% of the patients experienced difficulty in their work due to social ostracism. Tyagi and Jesupadam³ observed that it was next to impossible to get the children of leprosy patients married into healthy families.

MATERIAL AND METHODS:

The present study was conducted among the leprosy patients and their contacts attending Dermatology and Venereal Diseases Out Patient Department, Jawaharlal Nehru Medical College Hospital, Aligarh Muslim University, Aligarh, (U.P.) for a period of one year for a comprehensive knowledge and better understanding of the knowledge, beliefs, attitudes and practices regarding leprosy.

All patients attending the Dermatology OPD from Monday to Saturday were clinically looked for the signs of leprosy. The total number of patients who attended the OPD during the one year period was 16140. Out of these, 200 were provisionally diagnosed to be suffering from leprosy. All leprosy patients were asked questions regarding their knowledge, attitudes and beliefs about leprosy. Information included the patients' attitude and knowledge towards cause of the disease, cure, prevention and the affect of disease on relationships. Data was collected and recorded on a proforma, and later tabulated and analysed.

OBSERVATIONS AND DISCUSSION:

Knowledge and attitudes towards leprosy

From the study, it was found that a large majority of the patients (81%) were not aware of the cause of disease (Table - I). Even a higher percentage of patients (89.5%) did not know whether the disease could be prevented. However, 91% patients were optimistic that the disease was curable. There was no difference in the knowledge about cause, prevention and cure of leprosy between the sexes.

A substantial proportion (60%) of the patients became anxious on hearing the diagnosis

of the disease while 27% remained indifferent. 56.5% patients reported that others' attitudes towards them was indifferent, while 5% cases reported fear in other people on learning the diagnosis. 38.5% said others were tolerant of their condition. There was not much difference in attitudes among males and females. (Table - II)

Relation with family members remained normal in 94% cases. Relations were strained with the spouses in 6% cases after learning the diagnosis of the disease. There was no difference in the marital status between the sexes. (Table - III) None of the unmarried adults mentioned leprosy as a cause of their not being married. 8.5% married patients experienced marital disharmony which was due to leprosy.

Almost all the patients (97%) expected financial assistance for their treatment. 18% wanted special footwear to be made available to them free or at subsidised costs. None, however, wanted sheltered jobs, which were segregated from the society.

These observations on patients' attitudes are quite consistent with the findings of other workers. Pal and Girdhar⁸ reported that 25% of the patients knew the cause of the disease. Kasturi⁹ found that 42% of the cases knew of the contagious nature of the disease.

Kant⁷ reported that 10% of the patients could not marry due to leprosy, though they were of marriageable age. 5.2% had either separated or divorced only because they had this disease. 9.0% of the married patients had problems in their marital life, due to leprosy. Kaur and Dhar¹⁰ reported a high divorce rate due to leprosy in 44.4% cases. Thus, in this study, leprosy did not have much effect on the marital status of the patients, though it caused marital disharmony in 8.5% cases.

Pal and Girdhar⁸ reported that 75% of the patients did not encounter any adverse reaction from other family members and neighbours. Naik, et al¹¹ also reported that in 70% of the villages, people had adequate knowledge of the disease and not much social stigma against leprosy patients was prevalent among them.

RESULTS AND CONCLUSIONS:

Ignorance about the cause and prevention of leprosy is still rampant. 81% of the patients studied were not aware of the cause of disease, and even a higher percentage (89.5%) did not know whether the disease was preventable. However, 91% patients were optimistic that the disease was curable. A substantial proportion (60%) of the patients became anxious on learning the diagnosis of the disease. 56.5% of the patients reported that others' attitude towards them remained indifferent, while 5% of cases reported fear in other people on learning the diagnosis. Relations were strained with spouses in 6% cases after learning the diagnosis of the disease, while 8.5% of the married patients experienced marital disharmony due to leprosy.

97% of the patients expected financial assistance for their treatment while 18% wanted special footwear, grip aids, etc. made available to them free or at subsidised costs. None, however, wanted sheltered jobs, segregated from the society.

So, it can be concluded from the study that most of the patients had very little factual knowledge about the cause and prevention of leprosy, but they were optimistic about the cure of disease. Interestingly, not much stigma was encountered by the patients.

RECOMMENDATIONS:

- i. The help-aids like special footwear with microcellular rubber, grip-aids, etc. should be made easily available to the disabled persons.
- ii. Raising the literacy status of the population in general will help in better awareness of the disease and its implications and in removing the social stigma so closely associated with the disease.

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TABLE - I KNOWLEDGE ABOUT LEPROSY IN LEPROSY PATIENTS

Knowledge	Male		Female		Total	
	No.	%	No.	%	No.	%
Cause of disease						
Don't know	113	80.1	49	83.0	162	81
Infection	16	11.3	7	11.9	23	11.5
Malnutrition	12	8.5	3	5.1	15	7.5
Preventable						
Don't know	126	89.4	53	89.8	179	89.5
By isolation	6	4.2	4	6.8	10	5
By good nutrition	9	6.4	2	3.4	11	5.5
Curable						
Yes	129	91.5	53	89.5	182	91
No	12	8.5	6	10.2	18	9
Total	141	100	59	100	200	100

(n=200)

TABLE - II ATTITUDES INLEPROSY PATIENTS AND THEIR CONTACTS

Attitudes	Male		Female		Total	
	No.	%	No.	%	No.	%
Patients' attitudes						
Anxious	83	58.9	37	62.7	120	60
Depressed	18	12.7	4	6.8	22	11
Indifferent	40	28.4	18	30.5	58	29
Others' attitudes						
Tolerance/Acceptance	55	39.0	22	37.3	77	38.5
Indifferent	78	55.3	35	59.3	113	56.5
Fear	8	5.7	2	3.4	10	5
Total	141	100	59	100	200	100

(n=200)

TABLE - III MARITAL STATUS IN LEPROSY PATIENTS

Leprosy cases	Male		Female		Total	
	No.	%	No.	%	No.	%
Married	108	76.6	45	76.3	153	76.5
Unmarried	33	23.4	14	23.7	47	23.5
Total	141	100	59	100	200	100

(n=200)