

Assessment of Knowledge, Attitude and Practice about leprosy among patients and their families in a rural community in Tamil Nadu

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Received : 01.11.2012 Revised : 08.01.2014 Accepted : 11.01.2014

Leprosy as a social disease has been a major public health problem because of the social stigma and ignorance attached to it. This has made it difficult for our health care delivery system in their pursuit for early diagnosis and prompt treatment. This study was done with the objective of assessing the present knowledge, attitude and practice of leprosy affected persons and their family members in a rural setting. This cross sectional study was conducted by using a pre tested, structured questionnaire among 100 registered Leprosy patients and 100 adult members of patient's family in Thiruvallur district of Tamil Nadu. Data collected was analyzed and results were summarized in percentages and presented in tables. About 32% of the patients and 37% of family members were aware that leprosy is caused by a germ. Skin patches and loss of sensation as symptoms of Leprosy were known to 55% of patients and 73% of the family members. 84% of Patients and 64% family members said that leprosy was curable. About 90% of the patients and 82% of the family members stated that deformities can be prevented by early and regular treatment. The patients showed a negative attitude after contracting the disease. Most of the family members (73%) did not share articles used by patients. 91% of the family members felt leprosy patients can be employable. About 45% the family members opined that a cured leprosy patient can marry. About 90% of the patients participated in social functions and 64% didn't hesitate to take food along with others. All family members were found to be willing to support their leprosy affected relatives. This study revealed inconsistency and deficiencies in the knowledge, attitude and practice among the leprosy affected patients and their family members. The patients and family members had adequate average level of knowledge about leprosy, but their attitude toward the disease and their practices were not adequately favorable.

Keywords : Leprosy, Stigma, Knowledge, Attitude, Practice

Introduction

Leprosy is often referred to as the oldest disease known to man. Of all the communicable diseases,

leprosy is the most important for its potential to cause permanent and progressive physical disability. In addition the disease and its visible

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deformities in particular contribute to intense social stigma and social discrimination of the patients. Leprosy understood as God's retribution, has been present since the colonial times. Stigma attached to leprosy is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that result from experience, perception or reasonable anticipation of an adverse social judgment about a person or group (Scambler G 2009). The practice of isolating patients which was based on old religious traditions served the purpose of keeping leprosy sufferers part out of sight (Obregón D 2003).

While knowledge is an important factor, there are social and cultural pressures that have an impact on decision making and contribute to the delay in treatment seeking behavior of those affected. Even in situations where social pressures are minimal the individual's own perception of the risks involved in diagnosis is a further pressure on decision making. In his article on Health Related Stigma's, Graham Scambler describes about different forms of stigma especially about "enacted" and "felt stigma", the latter referring to fear of discrimination rather than to actual stigma (Scambler G 2009). As a result of perceived stigma, people may adopt a first choice strategy of non-disclosure and concealment. This had been a deterrent in the early diagnosis, prompt treatment and cure of leprosy in the earlier days.

Family is the source of social support to its members especially to those who are patients of chronic illness and more so stigmatized disease such as leprosy, which is as much a social problem as a medical problem. It was found that knowledge of the affected family about leprosy was significantly associated with their leprosy patient's attendance at treatment clinics. Lack of treatment compliance results in aggravation of the disease and manifestation of deformities

causing social, economic and psychological problems to the patients and their family (Linda M et al 2000, Raju MS 1995). With this background this study was planned with the main objective of assessing the knowledge, attitude and practice about leprosy among the patients and their family members in a rural community in Thiruvallur District of Tamil Nadu.

Methods

Study Design and Area

A population based cross sectional study was conducted in the Thiruvallur District of Tamil Nadu State. Most of the leprosy affected patients were residing in the rural villages of Nemam, Thiruniravur, Porur, Kadavur, Kollemedu, Redhills and Manali. This study area falls under the jurisdiction of Office of the Deputy Director, Leprosy Regional Centre, Ponamallee, Thiruvallur District of Tamil Nadu.

Sample Size and Sampling Technique

The list of leprosy patients were collected from the Office of the Deputy Director, Leprosy Regional Centre, The data collected were done from the leprosy affected patients residing in the 7 rural villages. From the available list of the leprosy patients, 100 patients were randomly identified from their address location registered with the Office and visited them according to their accessibility and availability. A convenient sample of 100 leprosy affected patients, who are living in these seven villages, and 100 available adult members of the patient's family who were present at their residence during the data collection had been selected for this study. Details of these patients and family members were collected by the investigators using the questionnaire visiting their homes to conduct this study.

Data Collection

The data collection was done by using a pre

tested, structured questionnaire for this study. The questionnaire was on responses to knowledge, attitude and practice about leprosy by the affected patient and the family members based on materials obtained from previous studies related to this study. Both the patients and the adult member of their family were interviewed by administering the questionnaire personally at their residence. They were briefed about the purpose, importance and usefulness of this study in assessing their understanding about its socio-cultural and medical implications. The informed consent was obtained from those who were willing to participate in the study.

Scoring of Knowledge, Attitude and Practice

Six questions with “yes” (for correct answers) or “no” (for incorrect answers) were presented to assess the knowledge of the patients and family members about leprosy and those responses with score greater than or equal to 70% were considered knowledgeable. A five item question was used to assess participants' attitude towards leprosy patients and those who score 70% and above were considered as having good attitude. To assess the practice of respondents, seven questions were prepared for the patients and three questions were for the family members and those who answered “Yes” to more than 70% of the questions were considered as if they are practicing correctly (Mathews B et al 2013).

Data Analysis

Basic demographic and morbidity details of the respondents such as age, sex, literacy, occupation and disease status etc were ascertained. Data was analyzed and the results were tabulated in the tabular form applying appropriate descriptive statistics.

Ethical Consideration

The study was carried out after securing the necessary ethical clearance from ethical committee of our Institution. The study populations

were the registered patients with the Regional Leprosy Centre and they were asked to participate in the study after they were explained about the objectives of the study and also after obtaining written consents from study participants. Confidentiality of the study subjects was maintained.

Results

Socio-demographic Characteristics of the Study Group

Out of the 100 Leprosy patients 64 were males and 36 were females. Among the family members 73 were females and 27 were males. Age group of leprosy patients ranged from 16 to 55 years. The age group of family members ranged from 20 to 50 years. In this study both the patients and family members were found to be literate. Majority of the family members completed high school. No patient has studied beyond higher secondary education. 36% of the female patient had high school level of education and 28 % of the male patients had primary school level of education. 55 % of males and 18 % of females were skilled workers (Table 1). According to B.G. Prasad Classification for socioeconomic status, 54% belonged to Class I, 28% to Class II and 18% from Class III.

Knowledge Level of the Study Group about Leprosy

Regarding the knowledge level of leprosy, about 32% of the patients and 37% of family members were aware that leprosy is due to infection caused by a germ. But many of these respondents also held other multiple beliefs regarding the causation of the disease like overwork, malnutrition, heredity, tiredness, insect bite, excess heat, sin, alcohol etc. Regarding the presenting symptoms, about 55% of patients and 73% of family members said that patches on the skin and loss of sensation were important symptoms of leprosy. Regarding the mode of

Table 1 : Distribution of the socio-demographic characteristics of the study group

Variables	Patients			Family Members		
	Male	Female	Total	Male	Female	Total
Total	64 (64)	36 (36)	100 (100)	27 (27)	73 (73)	100 (100)
Age (years)						
16-25	18 (18)	27 (27)	45 (45)	0 (0)	10 (10)	10 (10)
26-35	19 (19)	9 (9)	28 (28)	18 (18)	27 (27)	45 (45)
36-45	9 (9)	0 (0)	9 (9)	0 (0)	27 (27)	27 (27)
46-55	18 (18)	0 (0)	18 (18)	9 (9)	9 (9)	18 (18)
Education level						
Primary School	28 (28)	0 (0)	28 (28)	10 (10)	18 (18)	28 (28)
High School	18 (18)	36 (36)	54 (54)	18 (18)	36 (36)	54 (54)
Higher secondary	18 (18)	0 (0)	18 (18)	9 (9)	9 (9)	18 (18)
Occupational Status						
Skilled	55 (55)	18 (18)	73 (73)	27 (27)	27 (27)	54 (54)
Semi-skilled	1 (1)	8 (8)	9 (9)	0 (0)	0 (0)	0 (0)
Unskilled	8 (8)	10 (10)	18 (18)	0 (0)	46 (46)	46 (46)

(Figures in parenthesis are percentages) [Patients =100 Family members=100]

Table 2 : Knowledge about Leprosy among patients and Family members

Knowledge Variables	Correct Response (%)
Patients	
1. Causes of leprosy	32.0
2. Presenting Symptoms	55.0
3. Modes of Spread	91.0
4. Duration of treatment	82.0
5. Leprosy is curable	84.0
6. Deformities preventable	90.0
Average knowledge level	72.3
Family members	
1. Causes of leprosy	37.0
2. Presenting Symptoms	73.0
3. Modes of Spread	82.0
4. Duration of treatment	64.0
5. Leprosy is curable	64.0
6. Deformities preventable	82.0
Average knowledge level	67.0

spread, about 72% of the patients and 37% of family members said personal and close contact was the important mode of spread of leprosy, while 19% of the patients and 45% of the family member also said leprosy is spread through air. Thus a majority of 91% of the patients and 82% of family members answered correctly about the modes of Spread. 82% of the patients and 64% of family members responded correctly for duration of treatment of leprosy. Regarding cure of leprosy it was found that 84% of the patients and 64% of family members answered in the affirmative that leprosy is curable. 90% of the patients felt that the treatment of leprosy was too long. (Table 2)

Attitude of the Study Group towards Leprosy

The study shows that only about 9% of the patients felt like informing the family members immediately after making the diagnosis that they are suffering from leprosy. There was no change in the role the patient played in the family and only about 10% informed about any form of neglect

Table 3 : Attitude towards Leprosy among the study group

Attitude towards Leprosy	Yes % [favorable]	No % [unfavorable]
Patients		
1. Informing the family immediately after the diagnosis	9.0	91.0
2. Any form of neglect by family after the information	10.0	90.0
3. Any change in the 'Role' played in the family	0.0	100.0
4. Preference for discreet treatment	100.0	0.0
5. Feeling about duration of treatment considered too long	90.0	10.0
Average level of attitude	41.8	58.2
Family Members		
1. Staying of the patients in the family	82.0	18.0
2. Sharing of articles of the patient	27.0	73.0
3. Employment of the patient	91.0	9.0
4. Sitting beside a cured leprosy patient while traveling	91.0	9.0
5. Marriage of cured leprosy patient	45.0	55.0
Average level of attitude	67.2	32.8

Table 4 : Practices status of the study group about leprosy

Practice status	Yes %	No %
Practices of leprosy Patients		
1. Interruption in the treatment	18.0	82.0
2. Participation in Social Functions	90.0	10.0
3. Taking food along with others	64.0	36.0
4. Changes experienced in the ability to do work	18.0	82.0
5. Avoiding certain foods	18.0	82.0
6. Use of other systems of medicine for treatment	18.0	82.0
7. Difficulty in moving in public places	9.0	91.0
Average practice status	33.6	66.4
Practices Among family members		
1. Take food cooked by cured leprosy patient	09.0	91.0
2. Avoid cooking certain foods because of affected family member	10.0	90.0
3. Support throughout the duration of treatment of affected family member	100	0.0
Average practice status	39.7	60.3

after the information sharing. All the patients felt the need for discrete form of treatment [not revealing to others] and nearly 90% felt the

duration of treatment was too long. 82% of the family members said that a leprosy patient can stay with them in their house and 73% of them

hesitated to share articles of leprosy patient. 91% of the family members felt that leprosy patients can be employable and doesn't mind sitting beside them. About 45% the family members opined that a cured leprosy patient can marry. (Table 3) Regarding the right attitude, the average score was only about 41% favorable for the patients and 67% favorable for the family members towards the disease.

Practice status of the study group about leprosy

This study shows that nearly 82% were on regular treatment and 90 % of the patients had participated in social functions while 91 % did not find it difficult in moving in public places. Nearly 82% of the patients felt that they did not experience any changes in their ability to work during the illness duration. About 18% of the patients tried other systems of medicine for treatment in between. Nearly 91 % of the family members answered that they will not eat food cooked by a cured leprosy patient and an equal number of family members felt that there is no need to avoid cooking of any specific food items because there is a patient in their home. But surprisingly all the family members said that they will support the affected patient throughout the treatment period. (Table 4)

Discussion

This study which was conducted on leprosy patients and their family member in rural areas in Tamil Nadu on their knowledge, attitude and practice, shows interesting findings and also revealing a wide gap in their knowledge, attitude and practice levels. Most of the patients in the study group were males (64%) while 73% of the family members were. This male predominance among the patients is found to be comparable to similar studies conducted the patients in a leprosy colony in Mysore (Vasundhra MK et al 1983, Myint T et al 1992). Regarding the cause of leprosy about 32% of the patients and 37% of family members

informed that leprosy is due to an infection caused by a germ. But many of these respondents also held other multiple reasons contributing to the causation of the disease like overwork, malnutrition, heredity, tiredness, insect bite, excess heat, sin, alcohol consumption etc. In a study conducted in Mangalore, about 8 % among the community members knew that leprosy was caused by germs (Shetty JN 1985).

About 55% of the patients and 73% of the family members knew that skin patches with loss of sensation were the important symptoms of leprosy. This is in contrast to a study done at Palmoy where it was found that 90% of the community members stated correct symptoms of leprosy (Croft RA 1999). About 91% of the patients and 82% of the family members said personal and close contact and air were the important modes of spread of leprosy. A similar study regarding the knowledge about the mode of spread of leprosy found this knowledge was lacking in the majority of the patients (Raj V 1981). This study found that 64% of the family members and 84% of the patients said that leprosy was curable. In a study conducted by Shetty found that 86% of patients and 60% of the family members were of the opinion that leprosy is curable (Shetty JN 1985). A study conducted by Raj V in 1981 revealed that knowledge regarding the duration of treatment was lacking in a majority of patients, while this study showed that nearly 82% of the patients and 64% of family members stated correctly the duration of treatment of leprosy.

In this study 91% of the patients did not inform immediately their family members about them being diagnosed as suffering from Leprosy. In a study conducted by Kant VP revealed that 34.2% of the patient has hidden from their family the fact that they were taking treatment for leprosy (Kant VP (1984). About 82% of the family members stated that a family member affected

with leprosy can stay with them. The study conducted in Mangalore revealed that 60% of the patients felt it was necessary to segregate leprosy patients (Shetty JN 1985). Regarding continued staying of the patients in the family, it was found that 82% of the family members were in favor of the patients staying with them. In a study done by Raju MS found that 83% were in favor of retaining patients in their own homes (Raju MS1995).

Majority (90%) of the patients in this study participated freely in social functions. But 91% of the family members said they would not take food cooked by cured leprosy patient. As few as 25% of the respondents in a study done by Raju MS with high knowledge level were willing to accept food cooked by a cured leprosy patient whereas none of them were willing to do so from Orissa (Raju MS 1995, Myint T et al 1992). A study done at Palmoy by Croft RP found that 70 % of the community member said that a leprosy patient could eat with his or her family member. In this study 18% of the patients used other system of medicine for faster healing of leprosy but in a study conducted in Myanmar revealed that 31.5% of rural leprosy patient were taking other system of Medicine (Myint T et al 1992).

A similar study conducted among General Practitioners at Hyderabad in Pakistan showed that regarding stigma, a significant minority of doctors still felt such effects and was reluctant to mingle with patients, which shows that some prejudices and misconceptions still exist. Patients may be encouraged to form and join organizations that would allow them exchange their fears and discuss with each other the ways of coping with these stigma (Bajaj DR et al 2009, Heijnders M, 2006).

The study conducted by Madhavi JM (2011) found that there was a significant difference in physical domain in male leprosy patients and psychological domain in female leprosy patients as

compared with their respective gender controls in the community. The leprosy patients were more aware about the infectious nature of the disease, symptoms, transmission, and curability than the control group. But a negative attitude was seen towards the leprosy patients in the society (Madhavi JM et al 2011).

To sum up, this study clearly shows that an average score of about 70% was achieved by the respondents who had a satisfactory level of knowledge of the disease leprosy. But only one-third of the patients and family members were aware that leprosy was due to infection. Even though the overall average knowledge level was satisfactory among the patients as well as the family members, it was not sufficient enough as per the expectation of our National Program NLEP. A significant number of participants in this study had poor knowledge of the cause, mode of transmission, symptoms, referral pattern, cure and prognosis of leprosy.

Regarding the right attitude, the average score was only about 41% favorable for the patients and 67% favorable for the family members towards the disease. The stigmatized attitude towards leprosy such as difficulty in getting marriage proposal, staying away from family members was still persisting in the community. Regarding the correct practices the average score was only about 33% for the patients and 39% for the family members. The social acceptance of the cured patients by the community was still very poor in practice. This shows that some prejudices and misconceptions still exist in our community. These need to be tackled by vigorous health education and awareness programmes (Bajaj DR et al 2009).

India now accounts for the highest number of leprosy patients with about 133717 new cases detected in 2009 alone and registered prevalence of 87190 cases at the end of first quarter of 2010

(WHO 2010). The WHO has developed an enhanced strategy (plan period 2011-2015) for better patient care and early detection of leprosy to reduce the disability, stigma and discrimination towards leprosy patient (Kanodia SK et al 2012).

Conclusion

This study has revealed inconsistency and deficiencies in the knowledge, attitude and practice among the leprosy affected patients and their family members among the study population. A significant number of participants in this study had poor knowledge of the cause, mode of transmission, symptoms, referral pattern, cure and prognosis of leprosy. Continued health education and behavior change activities are still the only tool to increase awareness regarding leprosy to get rid of misconception about the medical causes and social issues related to leprosy at community level. This will help the affected persons realize the importance of correct knowledge, attitude and practice to make them socially adaptable, acceptable and independent.

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How to cite this article : Stephen T, Selvaraj I and Parmeswari PJ (2014). Assessment of Knowledge, Attitude and Practice about leprosy among patients and their families in a rural community in Tamil Nadu. *Indian J Lepr*. **86** : 7-14.