



QUALITATIVE APPROACH TO EXPLORE STIGMA AMONGST LEPROSY PATIENTS

Dr. Omair Aziz
Wani

Demonstrator Department Of Community Medicine Govt. Medical College
Srinagar

ABSTRACT

INTRODUCTION:- Leprosy is a chronic infectious disease caused by bacterial specie 'Mycobacterium Leprae' usually effecting nerve, skin, eyes and nasal mucosa. Despite a significant reduction in the prevalence of leprosy in India, the social stigma still exists which provides a major setback for eradication of leprosy.

AIM:- To determine the deeper reasons for stigma through Focus Group Discussion (FGD) amongst leprosy patients.

MATERIAL AND METHOD:- The study was undertaken at Dr. Bandorwala Leprosy Hospital, Kondhwa, Pune. Focus Group Discussion (FGD) was conducted amongst 20 leprosy patients to explore the deeper reasons for stigma.

RESULTS:- Negative societal behavior and a perception of being talked about negatively and looked down upon by the society causes reduction in self pride and self-esteem of the leprosy patients. Fear of possible discrimination especially after the development of disabilities plays an important role in concealment of the disease of leprosy, leading to stigma.

KEYWORDS : Stigma, Leprosy, Focus Group Discussion

INTRODUCTION

Leprosy is a chronic infectious disease caused by bacterial specie 'Mycobacterium Leprae' usually effecting nerve, skin, eyes and nasal mucosa. It is an age old disease, described in the literature of ancient civilizations. [1] Despite a significant reduction in the prevalence of leprosy in India, the social stigma still exists which provides a major setback for eradication of leprosy. Leprosy has long been seen as the epitome of stigmatization and has become a metaphor for degradation in colloquial english. [2] Stigma can be defined as an attribute that is deeply discrediting, and the stigmatized individual is one who is not accepted and is not accorded the respect and regards of his peers; one who is disqualified from full social acceptance. [3] Stigma has a pervading affect on a patient's life, affecting marriage, employment, interpersonal relationships, leisure activities and attendance at social and religious functions. In a culture where a person is valued by the ability to support their dependents, unemployment because of leprosy can be an enduring effect not only economically but psychosocially too. [4] The stigma related to Leprosy is often even more destructive than the health condition itself leading to shame, anxiety and a lack of self-confidence which can even result in suicide. [3] Patients may find it difficult to value themselves and have a positive self-image. The self-loathing associated with leprosy can be permanent and persisting even after the disease is cured. [5] Leprosy will never be eradicated if patients continue to delay initial presentation for fear of being shunned by society.

AIM-

To determine the deeper reasons for stigma through Focus Group Discussion (FGD) amongst leprosy patients.

MATERIAL AND METHODS

The study was undertaken at Dr. Bandorwala Leprosy Hospital, Kondhwa, Pune. The hospital provides preventive, curative, referral and rehabilitative services to leprosy patients under a single roof.

STUDY DESIGN:

Cross-sectional, nonrandom with a qualitative approach

STUDY PERIOD:

May 2017

STUDY SUBJECTS:

Leprosy patients of age 18 or more years attending Bandorwala Leprosy Hospital

METHODOLOGY

The study was approved by institutional ethics committee (ECR-518). Written permission from the concerned authority was obtained before the start of the study. The purpose of the study was explained to the respondents, after which written informed consent was obtained. Focus Group Discussion (FGD) was conducted amongst 20 leprosy patients to understand the reasons for development of stigma in leprosy. The session of FGD was conducted at Bandorwala's leprosy hospital in a separate room. Different domains i.e. concealment of the disease, social participation, self-esteem and discrimination were considered as themes for FGD to investigate the deeper reasons for stigma. Frequency of the answers for different domains was considered as evidence for the formulation of conclusion.

RESULTS

Focus Group Discussion (FGD) was conducted among 20 leprosy patients to explore reasons leading to stigma amongst leprosy patients.

Demographic profile revealed the mean age of the leprosy cases to be 57.85 years \pm 14.88 S.D. Out of 20 patients attending FGD session, 13 were males and 7 were females. A large proportion of leprosy cases i.e. 58% were illiterate. Around half (49%) of the leprosy cases were married and the remaining were widow/ widower (19%), divorced/ separated (18%) and unmarried (14%).

The most frequent reasons for the stigma described by the leprosy patients were:-

1) CONCEALMENT OF THE DISEASE:-

Majority of the cases (19 out of 20) believed that they had concealed leprosy from the society. All of the cases described that they were asked by their family members not to reveal the disease as the family members feared that it would be difficult for them to get married if the society comes to know about the leprosy patient in the family. One of the patient's grandmother asked the patient not to reveal the disease as it might stop people from visiting their house for the fear of getting infected by leprosy.

As described by a 60 year old male patient "Every leprosy patient tries to hide the disease from the society as a fear of possible discrimination by the society but it is difficult to hide the disease when the deformities develop. I even tried to hide the deformities initially by narrating to the people that the deformity of my finger is due to the result of an injury I received while fiddling with a bicycle chain".

In fear of stigmatization by the society which already exists, the cases try to conceal the disease.

2) SOCIAL PARTICIPATION:-

Leprosy may prevent a person from participating in the social events like marriage ceremonies, fairs and pooja or prayers held in the community. Fear of getting discriminated by the society was mainly perceived after the development of deformities and was described as a major reason causing hindrance in social participation.

One of the patient, a 58 year old male recalls that "After the development of ulcer on my leg, I stopped attending the social gatherings as I felt the bad odour coming out from ulcer may distract the people".

Restriction from social participation can also arise from the negative attitude of society towards leprosy patients during social gatherings. Majority of the patients (17 out of 20) were asked to stay in a separate room when they attended a social gathering as the people feared of getting infected from leprosy.

A 35 year old patient revealed that while performing ablution for congregational prayers, the priest of the religious place noticed deformity on his arm. The patient heard the priest saying that he must not be allowed to offer prayers in congregation as it may result in others getting infected with leprosy.

3) SELF-ESTEEM:-

Self-esteem can be severely dented by leprosy. Majority of the patients regard negative societal behavior as being a reason for low self-esteem.

One of the patients, a 25 year old female describes social isolation as being the cause for loss of self-esteem and had experienced more alienation from the illiterate people as compared to the literate people. Similar feeling was narrated by a 40 year old male patient who describes that mostly the illiterate people tend to stay away from him as compared to the literates.

A perception that the people discuss negative things related to leprosy on noticing a leprosy person and avoid contact with a leprosy person, was regarded by three patients as the cause for the loss of self-esteem.

4) DISCRIMINATION:-

Feeling of getting discriminated can be one of the reasons for development of stigma amongst leprosy patients.

A sense of inferiority creeps in the minds of leprosy patients as described by one of the patients that "My son, a graduate by education, may not get an appropriate match for marriage because of me as the people look down upon the family of leprosy patients, so we usually marry in leprosy family".

Stigma can also arise from the misconception and negative attitude of family members toward the leprosy patients. One of the patients recalls that her mother did not talk to her on knowing that she has been diagnosed with leprosy. Her mother regarded leprosy as a punishment of sins from God and asked the patient to perform sacrifice of goat as a repent for her sins.

Another patient a 60 year old male in his words said "people run away from me because they feel I am suffering from a disease which is like tuberculosis and fear that I may transmit the disease by coughing".

The discrimination could also be real in nature. Majority (18

out of 20) patients experienced of being avoided and discriminated by the society at one time or the other.

Ten patients revealed that they were served tea in a separate glass or were asked to get a glass of their own while visiting a tea stall. One of the patient recalls that "the manager of a hotel did not serve me tea because of the disease even on showing him the certificate of getting cured from leprosy. The manager although knowing that I am cured and cannot transmit the disease asked me to stay away from the hotel because the manager thought that he might loose the customers on seeing a leprosy patient drinking tea besides them".

A 40 year old female narrated that while catching an auto rickshaw for leprosy hospital, the driver of the auto rickshaw on hearing the name of leprosy hospital immediately looks for deformity in the patient, and if deformity is present the rickshaw driver refuses to carry the patient to the hospital probably for the fear of getting infected

The discrimination by the leprosy patients was even faced in the hospitals. Couple of patients revealed that while visiting other hospitals for treatment for the ailments other than leprosy, the health professionals of the hospitals did not treat them fairly on knowing that the patients suffer from leprosy. The patients were asked to get treatment of other ailments from the leprosy hospital.

CONCLUSIONS

Majority of the leprosy patients faced discrimination from the society and family members which indicates the misconceptions about leprosy in the community. Discrimination towards leprosy acts as an important factor in development of stigma as it leads to the sense of being inferior amongst leprosy patients. Influence of family members seems to have a big impact on the leprosy patients in concealing the disease of leprosy.

REFERENCES:

1. W.H.O. List of Tropical neglected diseases. Available from www.who.int/lep/en/. Accessed on 05/06/2016.
2. Harris K. Pride and prejudice-identity and stigma in leprosy work. *Lepr Rev* 2011; 82(2): 135-46. Available from <https://www.ncbi.nlm.nih.gov/pubmed/21888138>. Accessed on 15/06/2017.
3. Arole S, Premkumar R, Arole R, Maury M, Saunderson P. Social stigma; a comparative qualitative study of integrated and vertical care approaches to leprosy. *Lepr Rev* 2002; 73: 186-96. Available from <https://www.lepra.org.uk/platforms/lepra/files/lr/june02/0010.pdf>. Accessed on 15/08/17.
4. Adhikari B, Kaehler N, Raut S, Marahatta SB, Ggyanwali K, Chapman RS. Risk factors of stigma related to leprosy-A systematic review. *Journal of Manmohan Institute of Health Sciences* 2014; 1(2): 3-11. Available from <http://www.nepjol.info/index.php/JMMIHS/article/viewFile/9902/8077>. Accessed on 20/09/17.
5. Rafferty J. Curing the stigma of leprosy. *Leprosy Review* 2005; 76(2): 119-26. Available from <https://www.lepra.org.uk/platforms/lepra/files/lr/june05/150523.pdf>. Accessed on 5/05/17