Original Research Article

Conceptualization and Quantification of Perceived Stigma; A Study among Leprosy Affected Persons in A Block of Purulia District, West Bengal

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ABSTRACT

Background: Leprosy services have been integrated into the general health care system to reduce the differences between people affected by leprosy and those suffering from other health conditions. A large budget has been used in the effort to reduce stigma through information dissemination. This approach is unlikely to affect the perceived stigma. The main purpose of this study was to determine the level of perceived stigma and the risk factors contributing to it.

Methods: A cross-sectional study was conducted among 50 people affected by leprosy attending Joypur Rural Hospital (RH) of the Purulia district, West Bengal. Patients above the age of 14 were interviewed using a set of questionnaire form and Explanatory Model Interview Catalogue (EMIC).

Results: Among 50 leprosy affected persons, the median score of perceived stigma was 9 while it ranged from 0–31. The study revealed that higher age group (p = 0.016), illiteracy (p = 0.01), and women who were housewives (p = 0.034) were the significant (<0.05) predictors of perceived stigma among the leprosy patients.

Conclusion: The factors associated with higher stigma were age, illiteracy; occupation. There is an urgent need of stigma reduction strategies with more focus on health education and health awareness programs.

Key words: Perceived Stigma; Predictors; Conceptualization; Quantification.

INTRODUCTION

Leprosy is a chronic granulomatous disease caused by Mycobacterium leprae. Besides clinical sequel followed usually after infection, the consequences of stigma associated with leprosy outweigh the burden of physical afflictions. [1] Perceived stigma refers to the development of fear within an affected person where the fear may arise out of potential discrimination from family members, friends or society. As a consequence of stigma, a person over a long period of time may believe what others think and say about him, resulting to the loss of self-esteem and dignity which is referred to be a self-stigma or internalized stigma. [2]

Misconceptions about the disease have contributed to the development of negative attitudes to leprosy affected persons. Fear of infection, was the most important cause of stigma. In India, in addition to the fear of infection, false beliefs about leprosy, ignorance about the disease and lower socio-economic status were associated with stigma in leprosy. [3]

Stigma affects the psychosocial well-being of the affected person. A person may feel fear or shame which can lead to anxiety and depression. The resultant anxiety and depression may lead to decreased social participation and social exclusion. [4] Anticipation of stigma may cause affected person to conceal their condition. [5] The burden of keeping this secret, of being ever watchful and careful takes an emotional toll and adversely affects health seeking behavior. [4] Concealing the disease, avoiding the questions regarding the disease and at times even telling lie for the fear of disclosure was found to be a major concern for leprosy affected persons. [6] Stigma has been found to be associated with misconceptions about the disease, visible deformities and the development of ulcers. [5]

Many attempts have been made to reduce the stigma attached to leprosy. Leprosy services have been integrated into the general health care system to reduce the differences between people affected by leprosy and those suffering from other health conditions. A large budget has been used in the effort to reduce stigma through information dissemination. Although it has been shown that this approach is unlikely to affect the perceived stigma of the social disease.

Therefore, we hypothesized that there is association between the levels of perceived stigma in leprosy affected persons and the socio-demographic factors characterizing them. Most of the studies done till now are focused on the impact of the stigma, participation restriction and income generation. There has been no research so far in leprosy stigma reflecting the factors associated with it. Report shows that Joypur block in Purulia district has high PR (4.67/10000) and NCDR rate (38.65/100000). (Source: Joypur R.H.) Therefore, exploring the risk factors of stigma in leprosy affected persons attending Joypur R.H. can help to understand the leprosy stigma and therefore can direct the stigma reduction strategies. With this background a study was planned to ascertain the predictors of stigma among leprosy patients of leprosy affected persons attending Joypur R.H.

Objectives
1. To study the socio-demographic characteristics of the leprosy affected persons attending Joypur R.H.
2. To conceptualize the status of perceived stigma and quantify it among the study population.
3. To elicit the predictors of the above stigma.

MATERIALS AND METHODS
Study Design - Observational and Cross-sectional.

Sample Size- The study population comprised of all the 54 confirmed and registered PB and MB adult patients who were getting MDT from Govt .Health Centers under Joypur RH in the month of October 2014.

Participants- Total 50 leprosy affected persons were interviewed in the month of November 2014.The data was collected through an interview Questionnaire by face to face interview. It took about 20 minutes to administer the interview questionnaire on each subject.

Interview Questionnaire – Before the start of the study, ethical approval was obtained from the Institute Ethics Committee. Informed consent was taken from the study population. They were given the freedom of refusal to give response to all or any particular question(s) and even drop out at any stage of the study. Confidentiality and anonymity was ensured by not recording their names or any other information which would reveal their identity.

The schedule consisted of two parts prepared in the local language (Bengali),

made simple, easily understandable and unambiguous. The instrument was established by literature review.

The first part consisted of seven questions about demographic data (e.g., age of the respondents, sex, caste, religion, Marital Status, education, occupation).

Second part consisted of The EMIC scale developed to elicit illness related perceptions, beliefs and the practices. [7] Explanatory Model Interview Catalogue (EMIC) stigma scale, is one of the best known instruments to measure the perceived stigma in leprosy by The International Federation of Anti-Leprosy Association (ILEP) and the stigma research workshop held in Amsterdam in 2010. [8,9] The EMIC questionnaire has 15 items (0-3 response set) related to perception of stigma in leprosy and has been validated and shown to be reliable in a study in India. [10] The research team translated the English version into Bengali and back translation was made into English and it was ascertained that there was adequate similarity between the original English questionnaire and the translated English. Cronbach's α of the Bengali version was 0.79,(which indicate sufficient internal consistency) after eliminating the question" Have you been asked to stay away from work or social groups'? The response for which was "NO" by all the respondents. The content and face validity of the same was ensured by public health experts of All India Institute of Hygiene and Public Health, Kolkata.

Statistical analyses

It consists of EMIC attitudinal statements on "Yes", "Possibly", "Uncertain", and "No"on the basis of four point Likert scale. There were 14 statements on positive aspect, where a response of "Yes" was allotted a score of three (3), and response of "Possibly" was allotted two (2) , "Uncertain" one (1), and "No" zero (0).Question No 2 should be recoded on negative aspect where a response of "No"

was allotted three (3), "Uncertain" two (2), "Possibly" one (1) and "Yes" zero (0). All scores were added to get a sum score. The outcome score indicate the perceived stigma The higher the score, the higher the level of perceived stigma. Final data were entered in the master chart in statistical package for social science (SPSS); version 16 and analyzed with the help of SPSS itself and MS Excel.

- Descriptive statistics were used to describe the socio-demographic characteristics and conceptualize perceived stigma of the participants.
- Difference in total perceived stigma score using EMIC between different categorical variables were analyzed using Mann Whitney U test since these scores were not normally distributed.

RESULTS

Table 1. Background characteristics of the study population (*N*=50)

VARIABLE		NO (%)
Age (15-60) Median- 35 yrs	15-30	21(42)
	31-40	13(26)
	41-50	11(22)
	51-60	05(10)
Sex	Male	25(50)
	FEMALE	25(50)
Religion	Hindu	48(96)
	Muslim	02(04)
Caste/Tribe	SC	12(24)
	ST	03(06)
	OBC	04(08)
	OTHER	31(62)
Marital status	Ever married	09(18)
	Never married	41(82)
Education Level	Illiterate	33(66)
	Primary completed	15(30)
	Secondary completed	02(04)
Occupation	Cultivation	13(26)
	Daily Lab our	10(20)
	Student	05(10)
	Business	01(02)
	House wife	21(42)

Table shows Majority of subjects were Hindu (96%), Illiterate (66%), Never married (82%), mostly House wife by occupation (42%), commonly in age group of 15-30 year

The study included 50 respondents who agreed to participate. Median age of the respondents was 35 years. Table shows Majority of subjects were Hindu (96%),

Illiterate (66%), Never married (82%), most of the women were homemaker by occupation (42%), commonly in age group of 15-30 year (42%).

No	Items	Number (%)
1	Keep others from knowing if possible	43 (86)
2	Disclosed to the close person about this condition	20 (40)
3	Think less of yourself because of this problem	19 (38)
4	Shame or embarrassment due to Leprosy	06 (12)
5	Less respect from others because of this problem	11 (22)
6	Contact with you would have bad effects on others	04 (08)
7	Others have avoided you because of this problem	12 (24)
8	Others might refuse to visit your home	03 (06)
9	Others would think less of your family	16 (32)
10	Social problems to your children in community	03 (06)
11	Disease causes problems for your marriage	11 (22)
12	Causes marriage problems to your family	14 (28)
13	Decided on self to stay away from social group	01 (02)
14	Others presume you have other health problems	01 (02)
TOTAL STIGMA SCORE (0-31):		Median - 9

Table shows EMIC profile of anticipated stigma such as Keep others from knowing if possible (86%) and others presume you have other health problems (02%) amidst the subjects.

Total stigma score ranges from 0 to 31 with a Median of 9. Responses (YES) are variable in the profile of anticipated stigma such as Keep others from knowing if possible (86%), Disclosed to the close person about this condition(40%), Think less of yourself because of this problem(38%), Shame or embarrassment due to Leprosy(12%), Less respect from others because of this problem(22%), Contact with you would have bad effects on others(08%), Others have avoided you because of this problem(24%), Others might refuse to visit your home(06%), Others would think less of your family(32%) Social problems to your children in community (06%), Disease causes problems for your marriage (22%), Causes marriage problems to your family (28%), despite none of them asked to stay away from work or social group (02%) decided on self to stay away from social group, Others presume you have other health problems (02%),

Table 3. Socio-demographic characteristics in relation to the EMIC score: Mann Whitney U test (N = 50).

Characteristics	Group	Number (%)	Median (score)	Significance (2-tailed) *p*-value.
AGE(yrs)	36-60	21(42)	10	0.016
	15-35	29(58)	7	
SEX	FEMALE	25(50)	9	0.098
	MALE	25(50)	8	
CASTE	SC+ST+OBC	19(38)	9	0.313
	OTHER	31(62)	10	
TYPE	MB	43(86)	9	0.746
	PB	7(14)	10	
EDUCATION	ILLITERATE	33(66)	10	0.010
	LITERATE	17(34)	7	
OCCUPATION	HOUSE-WIFE	21(42)	19	0.034
	OTHERS	29(58)	7	

Mann Whitney U test shows significant association of age, education, and occupation in relation to the EMIC score.

Mann Whitney U test shows significant association of stigma with age (p=0.016), education (p=0.010), and occupation (p=0.034), in relation to the EMIC score. Age (>median) 36-60 yrs, education illiterate, and House wife by occupation had higher anticipated stigma median score.

DISCUSSION

In this study, the EMIC scale was used to measure the level of perceived stigma and its association with socio-

demographic conditions. These findings suggest that perceived stigma after disclosure was higher than the other aspects of EMIC which were more related to real life situations. This is consistent with study conducted in Northern India. [11]

In a study conducted in Nepal by Adhikari B et al(2014) the findings of EMIC profile of anticipated stigma (YES response) was highest for the statement "Keep others from knowing if possible'' (65.9%). In our study also this item has the highest percentage; 86% of the study participants agreed to the fact. [12]

In above study the statement "Disease causes problems for your marriage" and "Causes marriage problems to your family" had much lower YES response 8.9% and 19.3% as compared to our study where 22% and 28% subjects responded in the same direction respectively. The percentage of response for "Decided on self to stay away from social group" and "Others presume you have other health problems" were very low (2%) in our study unlike the result of the Nepal study in which those statements had a higher percentage of (12.6%) YES response in both the statements.

In this study higher perceived stigma score was found in patients of older age group , illiterate persons ,and who had occupation of house wife .This was also observed in a study done in India. [13] This can be explained by the fact that these are the people who remain indoors (older age group, house wife) and cannot comprehend the IEC massages (illiterate) for the general mass. As a result they are deprived of the true facts of leprosy like it is a curable disease, not a result of any curse and that there should be no stigma, myths and misconception regarding it. The impact of education on perceived stigma score could be to increase the overall knowledge on disease and an increased ability to resist the negative stereotypes attached to the disease.

Limitation
- All variables were self-reported which might lead to incorrect estimate of the associations observed.
- One main limitation of our study was the cross-sectional design with small sample size that did not allow us to conclude any causal association.
- There was only one patient with disability no analysis could be done for association between disability and stigma.

CONCLUSION

Self stigmatization grossly affects the quality of life of leprosy. People with leprosy may become ashamed, possibly because of local attitudes and deformity, may isolate themselves from society thus perpetuating the idea that leprosy is something shameful to be hidden away. The self –loathing associated with leprosy can be permanent; persisting even after the disease is cured leading to self disrespect and loss of self confidence.

The factors associated with higher stigma were higher age, illiteracy and occupation (Housewife). It is strongly felt that specially designed targeted interventions must be implemented in these areas. There is an urgent need of stigma reduction strategies focused on health education and health awareness programs. IEC Campaign Fortnight towards achieving "Leprosy free India" will be organized every year from 30th January, which is being observed as Anti Leprosy Day in the country.

Community participation and roping in influential personalities of the villages like religious leaders, school teachers, panchayat members, field level health workers for an organized, robust and intensive health education programme will go a long way in enhancing and enriching the knowledge of the villagers.

The concept of discussing issues of leprosy which is otherwise a taboo in the conservative set up of Indian society must be eliminated. Literacy plays a very important role in ameliorating the magnitude and impact of stigma. Therefore all steps must be taken to enhance and propagate school attendance for the young and a robust programme to educate the adults.

Even if patients are cured of their mycobacterial disease, the stigmatization can remain an insurmountable obstacle to the resumption of a normal life. Negative perceptions of leprosy still can be a barrier to the process of reintegration into their families, jobs and wider society.

Complete cure requires that the barrier be overcome and the cursed patients are brought in to the mainstream of the society.

ACKNOWLEDGEMENTS

Selected Acronyms

BMOH	Block Medical Officer of Health
CMOH	Chief Medical Officer of Health
EMIC	Explanatory Model Interview Catalogue
ILEP	The International Federation of Anti-Leprosy Association
MB	Pauci bacillary
MDT	Multi Drug Therapy
NCDR	New Case Detection Rate
PB	Multi bacillary
PR	Prevalence Rate
RH	Rural Hospital

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