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Community Attitudes towards Leprosy Affected Persons in Pokhara Municipality of Western Nepal

Adhikari B,[1] Shrestha K,[1] Kaehler N,[2] Raut S,[3] Chapman RS[4]

[1]Nepal Community Health and Development Centre, Kathmandu, Nepal, [2]Kanchanaburi Polyclinic, Kanchanaburi, Thailand, [3]Department of Microbiology, Manipal College of Medical Sciences, Pokhara, Nepal, [4]College of Public Health Sciences, Chulalongkorn University, Bangkok, Thailand.

ABSTRACT

Background: Stigma is a social process of interpretation of an attribute. Leprosy has been seen as the epitome of stigmatization. The psychosocial impact a person has to bear in a society after the diagnosis weighs heavier than the physical afflictions it causes, which does not get cured with the mere medical treatment. There are various factors which construct the perception of stigma in both leprosy affected persons and unaffected persons. The main purpose of this study was to determine the level of perceived stigma and the risk factors contributing to it among community people living in ward 15, Pokhara municipality.

Methods: Cross-sectional descriptive study among 281 community people above the age of 18 years was conducted. Two sets of questionnaire form with additional Explanatory Model Interview Catalogue (EMIC) for each individual were used.

Results: Among 281 community people, the median score of perceived stigma was 12 while it ranged from 0-30. Ethnic groups, Brahmins, Dalits and minorities had highest perceived stigma score of 15 and above compared to the rest ($p=0.001$), community people living at the distance more than 2 km had highest perceived stigma score of 15 compared to those living closer to the hospital ($p=0.019$) and nuclear family had highest perceived stigma score of 15 compared to the joint family ($p=0.014$). People who lacked information on leprosy had higher score of perceived stigma compared to those who had information on leprosy ($p=0.002$).Similarly, those who perceived leprosy to be difficult to treat ($p<0.001$) and a severe disease ($p<0.001$) had highest score of perceived stigma.

Conclusions: Stigma in leprosy was found highly associated with the lack of information about leprosy and their perception in treatment and disease severity. Stigma reduction strategies should focus on health education, targeting to alleviate their perception about the disease with their active participation.

Keywords: attitude;community; leprosy; stigma.

INTRODUCTION

Leprosy is more a social disease than a mere medical term as it bears the society's stereotype adhered to it since its recognition.[1] Despite the fact that leprosy is completely curable by medicine, the negative attitude towards leprosy still persists.[2]More than the disease itself, consequences of negative attitudes towards it have been found to be detrimental to a person affected by leprosy.[3]

Stigma is a dynamic process, as it continuously evolves by the interaction between labeled person and the rest.[4] In the event of leprosy, the disease is perceived by the health workers according to existing physical symptoms; the illness experienced and is shaped by the socio-cultural influences of the person; and the sickness is perceived by the society and is expressed as social stigma.[5]

Correspondence: Bipin Adhikari, Community Health and Development Centre, Balaju-Bypass, Kathmandu, Nepal. E-mail: biopion@gmail.com, Phone: 01-4382192.

In Nepal, misconceptions about leprosy are still prevalent.[1,2]The purpose of this study was to investigate the factors affecting the attitudes towards leprosy affected persons.

METHODS

The study was a cross-sectional descriptive in its design. The study population comprised of community people living close to Green Pastures Hospital and Rehabilitation Centre (GPH&RC) at ward 15 of Pokhara municipality, western region of Nepal. Two hundred and eighty one community people were interviewed; one from each house after systematic random sampling of households was done using the sample frame from the current voters list. Participants were chosen regardless of gender but age above 18 years and those unaffected by leprosy at present and at past. The study was conducted from February 2013 to April 2013 after the ethical permission was obtained from Nepal Health Research Council.

A questionnaire was developed to assess the socio-demographic characteristics (age, sex, ethnicity, marital status, location, type of family and leprosy affected persons in family/relatives/neighbors), socio-economic conditions (occupation, income, nature of work, job, education and religion), Knowledge about leprosy (information about leprosy, cause of leprosy, infectiousness, transmission, treatment, signs and symptoms about leprosy).

In addition, the Explanatory Model Interview Catalogue (EMIC) scale was used in each participant. The EMIC scale has been developed to elicit illness-related perceptions, beliefs and the practices.[6]The EMIC questionnaire has 15 items related to perception of stigma towards leprosy. Each question is scored as "Yes =2, Possibly = 1, No and Don't know = 0". The EMIC scale has been both validated and reliable as evident from study in India.[7] The EMIC scale has been available in different languages including Nepali and is the recommended instrument in terms of measuring leprosy related stigma. It has been classified as the instrument to measure the perceived stigma in leprosy as recommended by The International Federation of Anti-Leprosy Association (ILEP) and the stigma research workshop held in Amsterdam in 2010.[8,9]

Descriptive statistics such as frequency, percentage, mean, median and standard deviation were used to describe the socio-economic characters and knowledge level of the participants. Difference in total perceived stigma score using EMIC between different categorical variables were analyzed using Mann Whitney U test and Kruskal Wallis H test since these scores were not normally distributed.

RESULTS

The EMIC score was assessed for the measurement of perceived stigma in community participants. The total median score of EMIC scale was analyzed to compare between different groups. Each domain of EMIC scale has been calculated with the percentage answering 'yes' (Figure 1). More than half of the participants perceived that leprosy affected persons would conceal his/her disease. Similarly marriage problems were perceived by 48%, refusal to buy foods from affected persons were perceived by 47.3% and problem for family due to leprosy was perceived by 40.6% (Figure 1).

Table 1. Socio-demographic characteristics in relation to EMIC score (n = 281)

Characteristics	Number (%)	Median	P-value
Age in years			
≤ 30	83 (29.5)	10	0.964
31- 50	126 (44.8)	13	
≥ 51	72 (25.6)	12	
Mean = 40.56, Median = 39.00			
SD = 14.57, Range = 18 - 86			
Sex			
Male	136 (48.4)	12.5	0.636
Female	145 (51.6)	12	
Ethnicity			
Brahmin	44 (15.7)	15	0.001**
Chhetri	75 (26.7)	9	
Gurung	62 (22.1)	9	
Magar	48 (17.1)	13	
Dalits and Minorities	52 (18.5)	15.5	
Distance from Hospital			
< 500 meter	74 (26.3)	9.5	0.019**
500 to 1 Km	81 (28.8)	12	
1-2 Km	49 (17.4)	13	
> 2km	77 (27.4)	15	
Duration of stay in the area			
< 5 years	54 (19.2)	13.5	0.112
5 - 10 years	63 (22.4)	14	
11 - 20 years	42 (14.9)	11	
> 20 years	122 (43.4)	11	
Marital Status			
In relationship	244 (86.8)	12	0.887
Not in relationship	37 (13.2)	11	
Religion			
Hindu	233 (82.9)	12	0.308
Other	48 (17.1)	10	

**Significant by Kruskal Wallis H test
EMIC = Explanatory Model Interview Catalogue

Table 2. Socio-economic characteristics in relation to EMIC score (n = 281)

Characteristics	Number (%)	Median	P-value
Family Type			
Joint family	188 (66.9)	11	0.014*
Nuclear family	93 (33.1)	15	
Leprosy affected in family			
Yes	4 (1.4)	14.5	0.724
No	277 (98.6)	12	
Leprosy affected in relatives/neighbors			
Yes	15 (5.3)	9	0.772
No	266 (94.7)	12	
Level of Education			
Illiterate	47 (16.7)	15	0.125
Primary level (<5 years)	41 (14.6)	15	
Secondary and higher (>5years)	193 (68.7)	11	
Occupation			
Farmer and Laborer	60 (21.4)	10.5	0.608
Private business	93 (33.1)	13	
Housewife and unemployed	66 (23.5)	10	
Other	62 (22.1)	12	
Amount of Income			
≤4000 NRS	12 (4.3)	10.5	0.511
4001 - 8000 NRS	41 (14.6)	13	
8001 - 12000 NRS	64 (22.8)	14.5	
12001 - 16000 NRS	47 (16.7)	9	
≥16001 NRS	117 (41.6)	12	
Enough to sustain living			
Yes	277 (98.6)	12	0.687
No	4 (1.4)	9.5	

*Significant by Mann Whitney U test

EMIC = Explanatory Model Interview Catalogue

Table 3. Knowledge about Leprosy in relation to EMIC score (n = 281)

Characteristics	Number (%)	Median	P-value
Information on Leprosy			
Yes	140 (49.8)	10	0.002*
No	141 (50.2)	14	
Knowledge on Leprosy cause			
Yes	70 (24.9)	11	0.291
No	211 (75.1)	13	
Knowledge on transmission			
Yes	70 (24.9)	11.5	0.328
No	211 (75.1)	12	
Knowledge on sign and Symptoms			
Don't know	151 (53.7)	13	0.215
Single	91 (32.4)	11	
Multiple	39 (13.9)	12	
Leprosy is very infectious			
Yes	119 (42.3)	13	0.066
No	162 (57.7)	11	
Difficult to treat			
Yes	81 (28.8)	18	<0.001*
No	200 (71.2)	9.5	
Severe Disease			
Yes	102 (36.3)	16	<0.001*
No	179 (63.7)	10	

*Significant by Mann Whitney U test

EMIC = Explanatory Model Interview Catalogue

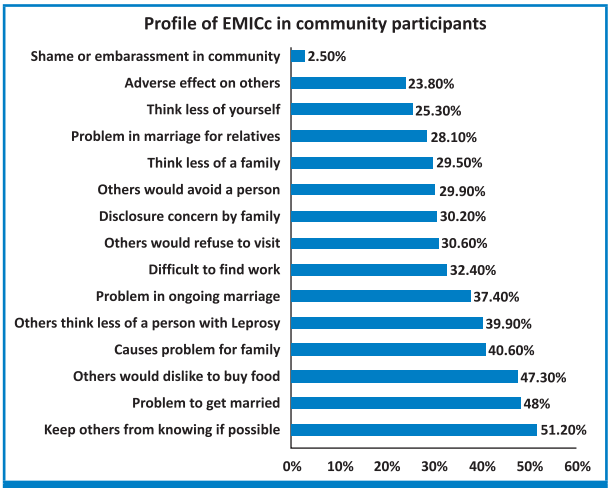

Figure 1. Percentage answering "Yes"

Among 281 community participants, proportional amount of participants were from the age group 31-50 years while male and female were equally distributed (Table 1). There was a significant difference in median perceived stigma score using EMIC scale in different ethnic groups (p=0.001). The ethnic groups Brahmin, Dalits and minorities had highest perceived stigma score of 15 and above, compared to the other ethnic groups (p=0.001) (Table 1).

Distance between the hospital and their residence was assessed in kilometers and it showed that there was a significantly higher perceived stigma in those who lived far from the hospital compared to those who lived closer (p=0.019). Similarly, the perceived stigma was higher in participants who belonged to nuclear family compared to the joint family (p=0.014) (Table 2).

Participants were asked if they ever had information on leprosy and basic knowledge about leprosy was assessed (Table 3). Participants who had information regarding leprosy had lower perceived stigma compared to those who did not (p=0.002). Similarly, participants who perceived leprosy as a severe disease (p<0.001) and difficult to treat (p<0.001) had higher perceived stigma compared to those who did not (Table 3).

DISCUSSION

Measurement of perceived stigma towards leprosy affected persons is a significant means of reflecting the attitudes and the stereotypes attached to leprosy in a society. In this study, the aspect on which community people showed major concern was on concealment of the disease after a person is diagnosed with leprosy. Consistent with a study done in Eastern Nepal, the concealment of the disease was applied as a strategy to preserve the social integrity by a leprosy affected person as the stereotypical views on leprosy were still found to be dominant.[4] Concealing the disease, avoiding the questions regarding the disease and at times even telling lie for the fear of disclosure was also a major concern for leprosy affected persons attending Green Pastures Hospital, Nepal.[10] Similarly concealment was a major finding in an Indonesian study where almost 40% of the community participants perceived that leprosy affected person would conceal the disease.[11]

Marital problems for leprosy affected persons were perceived by 48% which was consistent with an Indonesian study[11] where 48-50% of the community participants felt that leprosy affected persons would encounter marital problems. Similarly, the other prominent aspect of perceived stigma towards leprosy affected persons was shown in buying food from them. In our study, 47.3% of the participants perceived that others would dislike buying food from them which is even higher than a study in India,[12] where 21.8% of the community participants showed dislikes in buying food from them. However, measurement of this particular perception using EMIC in an Indonesian study,[11]was consistent with our study where 48-50% of the participants harbored this particular perception.

While different aspects of perceived stigma towards leprosy affected people were measured by EMIC, the total score of EMIC was used as a total perceived stigma score comparing with different socio-demographic features and their knowledge about leprosy. Regarding socio-demographic features of the participants, participants living closer to the Leprosy hospital had lesser perceived stigma compared to those living further. This might have been because of the greater acceptance level in people living closed to the hospital compared to living further. Both ethnic groups Brahmins and Dalits including minorities had higher perceived stigma compared to rest of the ethnic groups. Ethnicity and stigma association has been found in a study conducted in India[12] where socially classified lower caste groups had higher level of stigma, however, our study showed the higher perceived stigma in both higher caste group and the lower caste group. The higher perceived stigma in higher caste group 'Brahmin' might have been because of ruling nature of this caste, who might have looked critically at leprosy. Moreover, higher caste group tends to follow the religious rituals more strictly, which has been again found to be associated with the stigma.[1,2] In this study, higher perceived stigma was found in nuclear family compared to joint family. However, in a study conducted in India, leprosy affected persons from joint family were shown to have more stigma than nuclear family.[13] One reason for nuclear family to have higher perceived stigma towards leprosy affected persons in Nepalese culture could have been lack of familial harmony, sympathy and mutual sharing of problems which is socially abundant in joint family.

Among our participants, almost half of them had some information about leprosy and had lesser perceived stigma compared to those who lacked it. Overall knowledge on leprosy cause, transmission and clinical manifestations showed lower level of perceived stigma compared to those who lacked it. Lack of knowledge and prevalent beliefs about leprosy has been found to be associated with stigma in leprosy in many studies conducted in Nigeria,[14] China,[15] India[16] and Nepal.[1,17] In one systematic review related to risk factors of stigma in both leprosy affected and unaffected persons, the basis of stigmatization was found to be the visibility of disfigurements and disability largely augmented by the lack of education, ignorance about the disease and the stereotypes attached with the diseases.[18]

Similarly, higher perceived stigma was found in community people who had negative perceptions about leprosy. Those who felt leprosy as a severe, difficult to treat and highly infectious disease had higher perceived stigma. The negative perceptions regarding the leprosy were found to be highly associated with the stigma in a study conducted in eastern Nepal.[1]

In conclusion, the results of this study show that the negative attitude towards leprosy are prevalent even in urban settings where leprosy treatment center has been providing the treatment and rehabilitation to affected persons. Our study shows that community participants who live closer to the hospital had lesser stigma which implies that large number of population which is unaware of modern information about leprosy still harbor the negative stereotypes attached with the disease. This also shows the possibility to reduce the community stigma towards leprosy affected persons simply by providing them education about leprosy. While many perceived that leprosy affected persons would hide their disease, this has a dreaded implication, as hiding a disease because of the fear and potential discrimination can lead to development of disability and the deformity. This particular attitude of concealing the disease can only be avoided if the community is provided

with the education about the disease which can then lead an affected person to be socially acceptable and promotes the early treatment and prevents disability.

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