



Original Research Article

Stigma among Tuberculosis Patients under Directly Observed Treatment, Short Course at Urban Setting of Western Nepal

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Received: 29/03/2015

Revised: 21/04/2015

Accepted: 29/04/2015

ABSTRACT

Background: Tuberculosis (TB) stigmatization among the patients add perceived risk of transmission to its susceptible host and self discrimination attributed by stigma developed among the patients lead to social isolation that have a impact on TB control.

Objectives: To access Stigma among Tuberculosis Patients under Directly Observed Treatment, Short Course (DOTS) at Urban Setting of Western Nepal.

Methods: An institutional based descriptive cross-sectional study was done among 142 patients attending 12 Urban DOTS centre of headquarter of Western Development Region of Nepal. Probability Proportional to Size (PPS) sampling techniques was used to select the samples and was followed by Simple Random Sampling to select the subject were selected using a random technique. Piloted and Pretested structured questionnaire developed by the Department of Public Health, Pokhara University was used to collect regarding socio-demographic information, knowledge and self perceived stigma among TB patients. Microsoft Excel was used for data entry and cleaning and analysis was done through SPSS version 16.0. P-value less than 0.05 were taken as the cut-off values for test of statistical significance between the variables.

Results: Majority (56.5%) of the patients undergone DOTS still have stigma of TB and is statistically significant with marital status (P-value<0.05, Chi-square = 8.716), gender (P-value<0.05, Chi-square = 6.05), and age group of the patients (P-value<0.05, Chi-square=18.514).

Conclusion: Although the proportion of the stigma differs according to the other social stratifying factors like educational status, income level, knowledge of the TB but have no statistical significance.

Keywords: Stigma, Urban, DOTs, Patients, Tuberculosis.

INTRODUCTION

Stigma is typically a social construct, experienced or anticipated that is shaped by interpersonal attribute and norms of social institution.^[1,2] It can be both enacted and perceived. Enacted stigma concerns with experience of discriminations by other members of society resulting from social

inferiority while perceived or internalized stigma concerns with discrimination resulting from enacted stigma and sense of unworthy and guilty.^[3,4] Tuberculosis (TB) is a historically stigmatized disease and the stigma associated with it affects the institution, community and interpersonal factors.^[5,2] Stigma stands as decreasing

attribute which arises from social interaction and is related to the power dominance and difference. [6,3]

As TB is highly stigmatized disease which can be experienced and felt at different social setting like home, work place and community. [7] It has considerable impact on health that render patients to refuse disease and medical services through discouraging health seeking behavior which leads to distortion of health condition making difficult to treat that increases infectivity and communicability of the disease. [8,7]

Therefore understanding the stigmatization of TB has importance in reducing the impact on health of patients and medical services provided by the health institution. In Nepal prevalence of all TB holds 241 per 100000 people where as the incidence is 163 per 100,000 people. [9] National TB Program (NTP) mentioned stigma as a challenge for TB control program in the country. In order to combat with stigma and discrimination of the TB government of Nepal introduced Advocacy Communication and Social Mobilization (ACSM) intervention approach by conducting mass media activities, Behavioral Change Communication (BCC), and other TB awareness activates. [10]

MATERIALS AND METHODS

Study Design and Area:

An Institutional based Descriptive cross-sectional study was conducted from 15th September 2013-14th November 2013 in Pokhara Sub-metropolitan City, headquarter of Western Development Region of Nepal. The city (Latitude 28° 10' N - 28° 16' N Longitude 83° 58'30" E-80°02'30" E)lies 200 km West of Kathmandu, capital city of Nepal. [11] It has area of 55.33 square kilometers (km) with population density of 4,798.8 people per square km. [12]

There are 9 governmental and 3 private health institutes that provide Urban-DOTS services in the city.

Sample Selection:

All together there were 190 clients receiving Urban DOT (Directly Observed Treatment Short Course) service during the data collection period. Based on the prevalence of stigma of a similar study conducted at Nepal as 0.633 [13] and 95% confidence interval with margin of error 8%, the sample size got 140. By adjusting the non-response rate of 10%, the desired sample size got 154. To select the DOTS centers/ sub-centre for conducting the study, Probability Proportional to Size (PPS) was used as a sampling strategy. In order minimize the selection bias the samples were selected using simple random sampling technique using the lottery method based on the patients' TB registration number. During the data collection the 12 sampled patients were unable to provide the response. Therefore only 142 patients were interviewed for the study.

Inclusion Criteria:

- Cases above 15 years of age
- Using Urban DOTS services

Exclusion Criteria:

- Non-responses
- Too ill patients
- Hospitalized patients
- Registered patients of first day (24 hrs) because of his infectivity.

Measurements:

Data was collected from the patients during their visit for collecting TB drugs from respective Urban-DOTS centre. Data was collected by trained public health graduate using the structured questionnaire developed by Department of Public Health, Pokhara University. The questionnaire contains General characteristics, and stigma on TB.

Stigma about TB:

To access the level of stigma five items scales was used. Five-point Likert scale, with 1=strongly disagree, 2= Disagree, 3=Neutral and Non-Reponses for particular question, 4= Agree and 5=strongly agree were used to indicate the

degree of agreement by patients over every single question related to stigma. Scores for every statement were summed. All together there were 14 statements and total scores by a respondent could range from 14-70. And the median score value was used to categorized the patients in less stigmatized patients and highly stigmatized patients.

General Characteristics:

These are sex, age, gender, highest educational level current employment type, health seeking behavior.

Ethical Consideration:

Informed consent was taken from District Public Health Office (DPHO) Kaski, DOTS centers and patients.

Data Processing and Analysis:

The collected data were edited, coded and processed on the same day of data. Microsoft Excel was used for data entry and cleaning. In SPSS 16.0 (Statistical Package for Social Science) the data was imported to measure the descriptive statistics and to find the association between level of stigma and other variables Chi-square test was used. P-value less than 0.05 were taken as the cut-off values for test of statistical significance between the variables.

RESULTS

Table 1: Distribution of Stigma Score

Level of Stigma	Number of Respondent	Median Score	Inter-Quartile Range(Q ₁ Q ₃)
Low Stigma	63(44)	27	23-29
High Stigma	79(56)	37	34-42
Total	142(100)	32	28-37

Figures in parenthesis indicate the percentage

Table 1 illustrated that out of total score of 70 the median score obtained by patients was 32(28-37). The patients getting score more than 32 were regarded as highly stigmatized patients while the score less than median score is regarded as low stigmatized patients. Forty four percent patients were found to have low level of perceived stigma with median score of 27(23-29). Similarly

56% were found to have high level of stigma with the median score of 37 (34-42).

Table 2 disclosed that in the institutional based study of 142 patients, majority were man but higher proportion of females (67.8%) were found to be higher level of stigma and is supported by statistical significance of association between gender and level of stigma. (Chi-square square=6.05, P-value=0.017). Similarly stigma was also associated with age group of the patients, (Chi-square square=18.514, P-value=0.017). Majority of patients from age group 15-30 and ≥45 years were found to have higher level of stigma. Majority of the patients are married but only 44% of patients had higher level of stigma. Out of 67 patients other than married (non-married, separated, widow) 68.7% have higher level of stigma. The finding was supported by significance association between marital status and stigma level (Chi-square square=8.716, P-value=0.04).

The study showed that educational level, occupational status, income level of household, residence, types of TB and initial contact to types of intuition were not associated with stigma of TB.

Table 3 revealed that five different options of agreement for each statement are summarized to three options. Agree and strongly agree options are combined as At least Agreed and Disagree and strongly disagree are combined and made as single options as At least Disagreed while options with mid-point score is remain as usual. More than 63% patients at least agree that they feel as embarrassed of having TB and 66.2% hide the fact that they had TB with other. Forty five percent of the patients' response was neutral when question regarding TB effect on infertility of women was asked. Fourteen percent of the respondents regarded TB treatment as the burden to their daily life and 53.3% of the responses were in favor of TB as disease of poor.

Table 2: General Characteristic of Patients

Variables	Stigma		Chi-square value	P-value
	Low Stigma	High Stigma		
Gender			6.05	0.017*
Male	44(53.0)	39(47.0)		
Female	19(32.0)	40(68)		
Age in Years			18.514	<0.001***
15-30	24(33.3)	48(66.7)		
31-45	16(88.9)	2(11.1)		
≥46	23(44.2)	29(55.8)		
Caste/Ethnicity			0.069	0.86
Disadvantaged Caste	21(42.9)	28(57.1)		
Advantaged	42(45.2)	51(54.8)		
Religion			0.055	0.885
Hindu	45(45)	55(55)		
Non-Hindu	18(42.9)	24(27.1)		
No. of family Member			0.455	0.577
≤5	43(42.6)	58(57.4)		
>5	20(48.8)	21(51.2)		
Marital Status			8.716	0.04*
Married	42(56)	33(44.0)		
Others ⁺	21(31.3)	46(68.7)		
Education level			2.914	0.240
Illiterate	11(32.4)	23(67.6)		
Primary	25(51)	24(49)		
Secondary and above`	27(45.8)	32(54.2)		
Occupation			2.387	0.542
Unemployed	11(50.0)	11(50.0)		
Unskilled	11(34.4)	21(65.6)		
Skilled/Professional	20(51.3)	19(48.7)		
Own Business/Agriculture	21(42.9)	28(57.1)		
Income level of Household			0.967	0.617
≤1150	22(39.3)	34(60.7)		
11451-22850	11(47.8)	12(52.2)		
≥22851	30(47.6)	33(52.4)		
Residence			1.072	0.386**
Slum	59(45.7)	70(54.3)		
Non-Slum	4(30.8)	9(69.2)		
Type of TB			0.115	0.119**
Smear Positive Pulmonary TB	32(39)	50(61)		
Smear Negative Pulmonary TB	9(69.2)	4(30.8)		
Extra Pulmonary TB	22(46.8)	25(53.2)		
First Contact for health services			2.217	0.154
Government	25(53.2)	22(46.8)		
Non-Government	38(40.0)	57(60.0)		

Figures in parenthesis indicate the percentage
 Others⁺ = unmarried, widows, divorced
 * Statistically Significant at p<0.05
 ** *Exact P-value used

Table 3: Distribution of Stigma Score of TB Patients According to Different Items

Items	At least Agreed	Neutral	At least Disagreed
Feel embarrassed for having TB?	90(63.4)	0	52(32.6)
Hide TB diagnosis from the other people?	94(66.2)	0	48(33.8)
Affects relation with people other than family?	94(66.2)	3(2.1)	45(31.7)
Treatment cost as waste of money	97(68.3)	0	45(31.7)
Feel Isolated after diagnosed TB	87(61.3)	0	55(38.7)
Affects work performance	145(98.6)	0	2(1.4)
Affects conjugal life	91(64.0)	0	51(36)
Affects family responsibility?	89(62.6)	31(21.8)	21(15.6)
Problem of marriage despite cure?	139(97.9)	0	3(2.1)
Affects family relations	112(79.6)	0	29(20.4)
Cause female infertility	41(28.9)	64(45.1)	37(26.0)
Presumed to have other health problem	21(14.8)	53(37.5)	68(47.7)
TB treatment as burden	20(14.0)	54(38.0)	68(48.0)
Disease for poor?	76(53.5)	8(5.6)	58(40.9)

Figures in parenthesis indicate the percentage

DISCUSSION

This study highlights the stigma among TB patients in an urban setting of Nepal which is to be focused through National TB control program. The finding demonstrated the cause of stigma among the patients undergoing treatment. Factors affecting the level of stigma among the patients were gender, age and marital status of the patients.

In the study more than 63.4% of patients feel ashamed and 66.2% hide the disease from other people. The finding of the study was similar to the finding from the qualitative study conducted at Ghana. In order to get rid from discriminations and ill behavior from other people patients hide their disease. Patients expressed that they felt ashamed to interact openly with other member in the society. TB patients were devalued; disqualified and discarded from the regular activities.^[6] Similarly a study conducted among DOTS user in Dharan mentioned only 60% keep the disease knowing from other and around 58% feel embarrassed of having TB.^[13] In India patients were provide their wrong identity to the Tb service provider and keep the fact of having Tb from others than family.^[14] Due to fear of transmission patients even felt apathy and discrimination from family members and neighbors. It was found that in Bangladesh family members void to interact with patient, particularized the materials like bed, utensils for patients.^[15]

Patients perceived that bond between the members of society were found to be affected due to TB. Conjugal relationships are found to be affected by the TB. Separation from spouse, disruption of sexual life and closeness between spouses are some of the deviance of stigma of the disease. Sixty four percent patients perceive that the conjugal relationship get hindered after the diagnosis of TB. Similar to the finding of this study in Bangladesh TB have affected the congeal life. Faith over one another

diminished. Spouses were found to sleep separately, use of separate utensils and avoidance of sexual contact.^[15] This study revealed that more than one third patients' relation with family members got affected due to TB. In addition to it 66.2% patients revealed that after the TB diagnosis relation with other member of the society is affected. In an interventional study even after the implementation intervention 33.6% patients were unable to get back to socialize with other member of society where as among non-interventional patients 44.30% were unable to be socialized. Even the patient's right to express their opinion is void due to TB.^[3]

Due to various attributes like higher mobility, occupational exposure, males accounts higher proportion of TB. But in regards to stigma majority of female (68%) have higher level of stigma comparison to proportion of male (47%) with higher level of stigma. So gender factor plays its role in occurrence of TB and stigmatization of the disease. Women are restricted from mobility, increase in financial constraints and disclosure to the public about the TB from the fear of social isolation have discouraged women from seeking the health care services.^[16] Women perceived that people discriminate to the one with TB and due to fear of transmission people stay away from them.^[15] In contract to the finding of this study the proportion of male being stigmatized is higher than female but gender factor has no significant role in determining the level of stigma.^[17] In India women perceived that they hide the disease more to man because of fear of social isolation and lack of respect but quantitative finding showed higher proportion of male than female hide the disease. Parents restricted to marry their son with the girl who has had TB because of stigma associated with the inheritance of the disease to offspring that made a TB diagnosed married girl to return back to her natal house.^[18]

In this study majority of respondent agreed that TB affect the marital life. But study found higher level of stigma among respondent other than married and the significant value of statistical test of independence demonstrated there was a marital status was associated with the level of stigma. In contrast to the finding, another study conducted in Nepal reported that marital status was independent of the level stigma among patients. [13] In Rural Ethiopia 53% of marriage people have high level of stigma followed by 38% in single and 35% in Widow. [19]

This study showed the association between age group of the patients and level of stigma among them. Only 11.1% percent patients of age group 30-45 had high level of stigma while 55.8% and 66.5% of patients respectively form age group of 15-30 and more than 45 years have higher level of stigma. Different other studies revealed that level of stigma TB differs on the age group of the patients. [18,19]

Limitations of the study:

Stigma is a social-cultural determinant of health. So single quantitative techniques applied to access the level of stigma may not fully assess the stigma prevailing in the society. For better understanding of such socio-cultural context of TB mixed method can help in triangulation of the findings. The questionnaire was developed based on socio-cultural setting of the study area with extensive review of other literatures. The tool used was first hand so questions may arise on the reliability and validity of the tool.

CONCLUSION

The study demonstrated that majority (56%) of the patients in the urban setting of Nepal have high level of stigma. The study urges for the effective implementation of ACSM activities in order to combat with stigma, fear and discrimination associated TB through empowering patients, capacity

development of stakeholders, community awareness, behavioral change communication and political and social commitment against such social deviance.

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How to cite this article: Ritu K.C., Anup K.C., Sharma I et. al. Stigma among tuberculosis patients under directly observed treatment, short course at urban setting of western Nepal. *Int J Health Sci Res.* 2015; 5(5):357-363.
