RESEARCH ARTICLE

Stigma associated with tuberculosis – An Indian perspective

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ABSTRACT

Background: Social stigma has been identified as an important barrier that delays initiation and adherence to treatment thereby adding to the disease burden and prolong transmission in community. Stigma may limit social participation and lead to social exclusion which may result in an economic burden for the household and thus aggravate poverty. **Aims and Objectives:** The present study was carried out to estimate the level of perceived and enacted stigma experienced by tuberculosis (TB) patients and also their care providers. This study was planned with the following objectives: (i) To assess the prevalence of stigma among TB patients; and (ii) to assess the different factors associated with stigma. **Materials and Methods:** This was a prospective, observational, multi-centric study, undertaken on TB patients attending to directly observed treatment short (DOTS) course centers. Patients were interviewed about stigma associated with TB using questionnaire – Explanatory Model Interview Catalogue. Personal interview of the patients and the DOTS providers by a trained person to assess the stigma using pre-tested questionnaires after taking informed consent was arranged. **Results:** Around half (50.57%) of the patients perceived the social stigma. The present study has found that level of education and socioeconomic class of the patients are statistically significantly associated perception of stigma by patients but not for other socio-demographic characteristics such as age, gender, and marital status of the patients. **Conclusion:** Stigma associated with TB is significantly associated with patients with the lower level of education and with lower socio-economic status, which is certainly grave area of concerns as often these population are at higher risk for health disparities.

KEY WORDS: Tuberculosis; Stigma; Social Dimensions

INTRODUCTION

Tuberculosis (TB) is an infectious disease caused by *Mycobacterium tuberculosis* and transmitted through droplet nuclei from infected person.[1] TB is considered as the second leading cause of death from an infectious disease second only to human immunodeficiency virus (HIV). In 2013, 9 million people suffered from TB worldwide.[2] India is the highest TB burden country in the world, and also the largest number of cases, accounting for about 24% of the total global cases.[2,3] Considering the high burden of disease on the society, at the turn of the 21st century, TB was included in the Millennium Developmental Goal 6. The target to reduce TB incidence rate by 2015 has already been met. However, the targets to halve prevalence and mortality rates by 2015 are yet to be achieved.[2]

TB is a classic example of a disease with both social and medical dimensions.[3,4] Stigma is defined as a "powerful and tainting social label that radically changes the way individuals view themselves and are viewed by others."[5,6] In India, social stigma has been identified as an important

barrier that delays initiation and adherence to treatment thereby adding to the disease burden and prolong transmission in community.[7] Stigma may limit social participation and lead to social exclusion which may result in an economic burden for the household and thus aggravate poverty.[8] Non-disclosure to family leads to emotional trauma.[5] Patients who reveal their disease to the community may be looked down on or rejected by the community.[4] Stigma among providers is likely to affect health programs. Overall, stigma has a negative impact on the patient, provider, and community.

TB related stigma remains poorly understood in the developing world and the data on the assessment of stigma are scarce. The present study was carried out to estimate the level of perceived and enacted stigma experienced by TB patients and also their care providers. This study was planned with the following objectives: (i) To assess the prevalence of stigma among TB patients; and (ii) to assess the different factors associated with stigma.

MATERIALS AND METHODS

This was a prospective, observational, multi-centric study, undertaken on TB patients attending to directly observed treatment short (DOTS) Course centers of Gandhinagar and Department of TB and Chest Diseases, GMERS Medical College and Hospital, Gandhinagar, a tertiary care teaching hospital in West India. The research protocol was presented to the Institutional Ethics Committee (IEC) and approval was granted before commencement of the study (Ref. No. GMERS/MCG/IEC/27/2017, dated 09/03/2017). Patients were explained clearly about the nature and purpose of the study in the language they understood and written informed consent was obtained before enrolling the patient for the study. Permission from Medical Superintendent and the Head of the Department of TB and Chest Diseases was obtained before conducting the study.

Study Site

DOTS centers (around 10) randomly selected from Gandhinagar city and Department of TB and Chest Diseases, GMERS Medical College and Hospital, Gandhinagar.

Study Duration

Six months study duration was from March 2017 to August 2017.

Sample Size

Considering, the prevalence of TB as (5%) in West India, the sample size calculated was 73, using following formula:

$$n = \frac{Z^2 \, P(1-P)}{d^2}$$

Where,
Z = Z statistics for level of confidence (95%) = 1.96

P = Expected Prevalence = 0.05 (= 5%)
d = Precision = 0.05 (= 5%)

As this was a questionnaire-based study, considering non-compliance and dropout rate as 10%, total 87 patients will be enrolled.

Inclusion Criteria

The following criteria were included in the study:
- All patients with age 18 years and above and suffering from TB.
- Patients on anti-tubercular treatment for at least 1 month and attending to DOTS centers of Gandhinagar city and Department of TB and Chest Diseases, GMERS Medical College and Hospital, Gandhinagar (both indoor and outdoor) in the study duration.

Exclusion Criteria

The following criteria were excluded from the study:
- Freshly detected cases of TB.
- Patients who were mentally ill or unable to comprehend and respond with the questionnaire will be excluded.

Study Procedure

Gandhinagar district is divided into 30 different regions/sectors with population of about 206,167 according to provisional reports of Census India 2011. Each sector is having DOTS center. Ten DOTS centers were randomly selected from them using random number table as study site.

Patients were approached after they finished consultation with the physician at all the sites. All necessary information such as demographic data, history of illness, clinical data, and drug treatment were gathered by reviewing the hospital case file and by interview with patients. All the information was recorded in the structured case record form. The socio-demographic data included age, gender, social class, marital status, and education qualification. Clinical data included symptoms, duration of TB, comorbidities/complications, drugs prescribed, and non-pharmacological measures followed by patients.

Thereafter, patients were interviewed about stigma associated with TB using questionnaire. Personal interview of the patients and the DOTS providers by a trained person to assess the stigma using pretested questionnaires after taking informed consent was arranged.

Questionnaire to Measure Stigma in TB Patients

Explanatory model interview catalogue (EMIC)

EMIC was developed by Weiss *et al.*, which was adapted by International Federation of Anti-Leprosy Association (ILEP) specifically for leprosy.[7] EMIC was developed to measure

the patients' fear of discrimination and their awareness regarding negative attitudes on the basis of perceived or anticipated stigma.[7] EMIC also assesses the severity and the widespread nature of stigma. Considering the Indian geographical and cultural variation, EMIC questionnaire was further modified and six more questions were added to make total 21 questions. The responses for questions are coded on a numerical scale ranging from 0 to 3 as per following: (i) 0 = No; (ii) 1 = Uncertain; (iii) 2 = Possibly; and (iv) 3 = Yes. The scores of all the questions should be added up to get a sum score. The outcome score indicates the perceived stigma. Higher the score, higher is the level of perceived stigma. The total obtainable score was 63 and the least score was 0. For present study, a score of 31.5 or higher was considered as stigmatized. EMIC is available in multiple languages, including: English, Marathi, Bengali, Tamil. This EMIC questionnaire was specifically modified for TB and adapted.[7]

Social distance scale (SDS)

SDS was developed to measure the stigma from the perspective of the stigmatizer. The prototype of SDS questionnaire was developed by Emory S Bogardus from Brock University for mental illnesses, later modified and adapted for use in leprosy by ILEP. SDS questionnaire assesses provider's expression as to how close they are willing to be with a person affected.[7] The SDS questionnaire consists of six questions, each of them with four options with following numerical points: (i) 0 = "definitely willing;" (ii) 1 = "probably willing;" (iii) 2 = "probably unwilling;" and (iv) 3 = "definitely unwilling." The social distance score is calculated by summing up to create a total sum score. Higher mean score indicates tendency on the part of providers to keep more social distance from the person affected by a disease condition.

This questionnaire was translated in vernacular (Gujarati) language and back translated to ensure content validity. The questionnaire was designed for self-administration but structured interview was conducted to ensure reliability of data. In the interviews, the patients were asked to respond based on the past 7 days of health. To test feasibility of the instruments pilot study was carried out on 20 patients. It took approximately about 10 min to collect data from one patient (consent, history, and stigma scale).

Statistical Analysis

Microsoft Excel 2010 was used to analyze the data. Descriptive analysis included actual frequencies, percentage, calculation of means, and standard deviations of categorical variables. The statistical correlations between different determinants (patient related factors, drug related factors, and demographic parameters) with stigma were analyzed using Chi-square test. The *P*-value was considered statistically significant if it was <0.05.

RESULTS

Total 87 patients, who have fulfilled the selection criteria, were included in the present study. Among 87 patients, the majority of patients were belonged to 31–40 years (32, 36.78%) and 21–30 years (31, 35.63%) of age groups with mean age of 36.78 ± 16.89 years. The study included almost similar number of male (45, 51.72%) and female (42, 48.28%) patients. As per education status of the study population, almost half of the study population (43, 49.43%) have graduate and above education, followed by secondary education (18, 20.69%), illiterate (16, 18.39%), and primary education (10, 11.49%). A majority of the study population was married (64, 73.56%), followed by unmarried (19, 21.84%), divorced (3, 3.45%), and widow (1, 1.15%). Patients' socio-economic status was categorized using BG Prasad's socio-economic scale for 2017.[8] As per this categorization, most of the patients belonged to Class IV (27, 31.03%) and Class V (21, 24.14%) [Table 1].

Among 87 patients, a majority of patients (74, 85.06%) were suffering from pulmonary TB while 13 (14.94%) patients were suffering from extrapulmonary TB. According to treatment category, under Revised National TB Control Program,[3] 71 (81.61%) patients were enrolled under category 1 treatment while 16 (18.39%) patients were enrolled under category 2. Most of the patients (72, 82.76%) were taking treatment for TB for 2–6 months. Over 90% patients were utilizing government health facilities – DOTS center: 42 (48.28%) patients; and government hospitals: 38 (43.68%) – for treatment of TB. Very few patients (7, 8.05%) were utilizing private hospitals for the treatment of TB [Table 2].

As per the criteria and score defined for the present study, around half (44, 50.57%) of the patients perceived the social stigma [Figure 1]. In the present study, we have tried to find out correlation between socio-demographic characteristics [Table 3] and disease variables [Table 4] with perception of stigma by patients. It has been found that level of education (*P* < 0.00001) and socioeconomic class (*P* = 0.0021) of the patients are statistically significantly associated perception of stigma by patients. For other socio-demographic characteristics such as age (*P* = 0.2170), gender (*P* = 0.0707), and marital status (*P* = 0. 4597) of the patients, the present study not able to find out the significant association with perception of stigma. For different disease related variables, apart from type of TB (*P* = 0.1215), there is statistically significantly association has been found between other variables – treatment category (*P* = 0.0235); duration of treatment (*P* = 0.0344); and place of treatment (*P* = 0.0131) – perception of stigma by patients.

In the present study, we also measured the stigma from the perspective of the stigmatizer. Socio-demographic characteristics of DOT providers are summarized in Table 5. SDS responses of DOT providers are recorded in Table 6.

Table 1: Socio-demographic characteristics of study population (*n*=87)	
Variables	**Frequency (%)**
Age (years)	
11-20	4 (4.6)
21–30	31 (35.63)
31–40	32 (36.78)
41–50	10 (11.49)
51–60	9 (10.34)
>60	1 (1.15)
Gender	
Male	45 (51.72)
Female	42 (48.28)
Education	
Illiterate	16 (18.39)
Primary	10 (11.49)
Secondary	18 (20.69)
Graduate and above	43 (49.43)
Marital status	
Married	64 (73.56)
Unmarried	19 (21.84)
Divorced	3 (3.45)
Widow	1 (1.15)
Socioeconomic class*	
Class I	7 (8.05)
Class II	13 (14.94)
Class III	19 (21.84)
Class IV	27 (31.03)
Class V	21 (24.14)

*Prasad's social classification: Per capita income per month (in Rs.) (calculated from http://prasadscaleupdate.weebly.com/)[8]

Table 2: Disease variables of study population (*n*=87)	
Variables	**Frequency (%)**
Type of TB	
Pulmonary	74 (85.06)
Extrapulmonary	13 (14.94)
Treatment category	
Category 1	71 (81.61)
Category 2	16 (18.39)
Duration of treatment (Months)	
0–2	6 (6.9)
2–6	72 (82.76)
>6	9 (10.34)
Place of treatment	
DOTS center	42 (48.28)
Government hospitals	38 (43.68)
Private hospitals	7 (8.05)

Table 3: Socio-demographic characteristics and perception of stigma (*n*=87)				
Variables	**Perception of stigma**			
	Yes	**No**	**χ^2 value**	***P* value**
Age (years)				
11–20	1	3	5.7699	0.2170
21–30	12	19		
31–40	16	16		
41–50	7	3		
>50	7	3		
Gender				
Male	20	25	3.2664	0.0707
Female	23	19		
Education				
Illiterate	14	2	33.1019	< 0.00001
Primary	8	2		
Secondary	13	5		
Graduate and above	8	35		
Marital status				
Married	34	30	1.5545	0.4597
Unmarried	7	12		
Divorced/Widow	2	2		
Socio-economic class				
Class I	1	6	16.7675	0.0021
Class II	3	10		
Class III	6	13		
Class IV	18	9		
Class V	15	6		

Table 4: Disease variables and perception of stigma (*n*=87)				
Variables	**Perception of stigma**			
	Yes	**No**	**χ^2 value**	***P* value**
Type of TB				
Pulmonary	34	40	2.3984	0.1215
Extrapulmonary	9	4		
Treatment category				
Category 1	31	40	5.1300	0.0235
Category 2	12	4		
Duration of treatment (Months)				
0–2	3	3	6.7379	0.0344
2–6	31	41		
>6	8	1		
Place of treatment				
DOTS center	27	15	8.6739	0.0131
Government hospital	15	23		
Private hospital	1	6		

According to Table 6, for *"renting a room in your home to someone with TB;" "having someone with TB as a neighbor;"*

"having someone with TB as a caretaker of your children for a couple of hours;" and *"introducing someone with TB to a young*

woman you are friendly with," the commonest response of DOT providers was *"definitely willing."* While for *"having one of your children marry someone with TB;"* and *"recommending someone with TB for a job working for a friend of yours,"* DOT providers were *"probably willing"* to do so.

DISCUSSION

Approximately one-third of the world population is infected and TB is a leading cause of global morbidity and mortality.[9] Appropriate TB control very much relies on passive case finding, an effective alliance with patients and communities, adherence to a long course of treatment, and socio-cultural factors that influence illness behavior. Aspect of public health particularly important in this aspect with contexts of

Table 5: Socio-demographic characteristics of DOT providers (*n*=23)

Variables	Frequency (%)
Age (years)	
21–30	8 (34.78)
31–40	10 (43.48)
41–50	5
Gender	
Male	13 (56.52)
Female	10 (43.48)
Education	
Primary	10 (43.48)
Secondary	11 (47.83)
Graduate and above	2 (8.7)
Marital status	
Married	18 (78.26)
Unmarried/Divorced/Widow	5 (21.74)
Occupation	
Anganwadi worker	10 (43.48)
TB health visitor	5 (21.74)
Doctor	1 (4.35)
Lab technician	2 (8.7)
Health assistant	5 (21.74)

poverty, social stigma, and gender.[10,11] Stigma associated with TB is a major barrier to health care and quality of life in TB management.[12]

In the present study, total 87 patients, who have fulfilled the selection criteria, were included in the study. The majority of patients were belonged to younger age groups – 31–40 years (36.78%) and 21–30 years (35.63%). The study included almost similar number of males (51.72%) and females (48.28%) patients. Almost half of the study population (49.43%) have graduate and above education. Most of the patients belonged to Class IV (31.03%) and Class V (24.14%). Many patients (85.06%) were suffering from pulmonary TB and 81.61% of patients were enrolled under category 1 treatment. Most of the patients (82.76%) were taking treatment for TB for 2–6 months. Over 90% patients were utilizing government health facilities – DOTS center (48.28%); and government hospitals (43.68%) – for treatment of TB.

The present study has shown that around half (50.57%) of the patients perceived the social stigma. There are several studies which have captured the prevalence of perceived, internalized, and actually experienced stigma related to TB and compared the prevalence of TB stigma in different geographic areas. Many studies, like the present study, have used qualitative instruments to gauge the extent to which TB is seen as stigmatized in
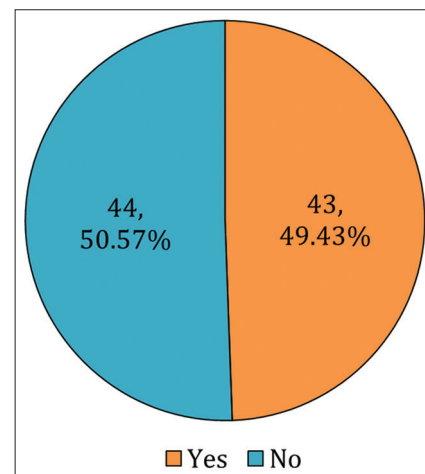

Figure 1: Perception of stigma by study population (*n* = 87)

Table 6: SDS responses of DOT providers (*n*=23)

Questions	Responses of DOT providers*			
	0	**1**	**2**	**3**
Renting a room in your home to someone with tuberculosis	13	3	1	6
Having someone with tuberculosis as a neighbor	10	7	1	5
Having someone with tuberculosis as a caretaker of your children for a couple of hours	8	5	3	7
Having one of your children marry someone with tuberculosis	5	8	4	6
Introducing someone with tuberculosis to a young woman you are friendly with	11	6	1	5
Recommending someone with tuberculosis for a job working for a friend of yours	4	12	2	5

*0=Definitely willing; 1=Probably willing; 2=Probably unwilling; 3=Definitely unwilling

a different community. There is considerable geographic variability which has been found in the perceived prevalence of TB stigma, with 27%–80%, in their communities.[13-15]

The present study has found that level of education and socio-economic class of the patients are statistically significantly associated perception of stigma by patients but not for other socio-demographic characteristics such as age, gender, and marital status of the patients. For different disease related variables, apart from type of TB, there is statistically significant association has been found between other variables – treatment category; duration of treatment; and place of treatment – perception of stigma by patients. It is important to understand the origins of/contributing factors for stigma associated with TB to reduce its impact on health. Using different types of methodology – surveys, personal interviews, standard questionnaires – many studies have explored the different causes of stigma associated with TB. There is, definitely, geographic and cultural variation may coexist in the understanding the causation of TB stigma, most studies have identified the perceived contagiousness of TB as a leading cause of stigmatization.[16-19]

Low level of education culminating into poor knowledge and understanding regarding TB may also contribute to stigma associated with TB.[20-22] The perceived risk of disease transmission can lead to stigmatization and isolation of patients with TB.[23] Other contributing factors which are responsible for of perceived stigma associated with TB include the malnutrition, poverty, being foreign-born, and low social class.[24-27] The less educated the patients, the more perceived stigma associated with TB was found in the present study. This finding has particular importance as it is implied for developing health literacy interventions to reduce stigma.

Patient with TB feel that they are at risk for a various social and economic consequences of stigma. The most common outcome of TB stigma is isolation of the particular patient from other members of the community. This can lead to substantial hampering of economic opportunities. Fear of TB stigma is such, it can lead to infected patients to hide their TB status from their own families also.[16,28] The socio-economic consequences of TB stigma may differ in men and women. Men are usually concerned with the impact of stigma on their economic aspects – losing a job loss and loss/reduced income.[29-31] As per women perspectives, apart from effect on financial status, women are also concerned that stigma will adversely affect their marriage prospects.[32,33]

Stigma is an adverse social process that originates due to labeling, stereotyping, separation, discrimination, and loss of status.[34] Stigma can significantly affect public health interventions as well as can produce social inequality.[35,36] Stigma and fear of discrimination can also significantly delay seeking for health services and leads to delay in diagnosis and management of TB which can further lead

to prolonged risk of transmission TB to contacts, poorer medication adherence, and drug resistance.[37,38] Prejudice and discrimination by health-care personnel or society may result in isolation and decreased self-esteem of the patients with TB, thereby significantly impeding that person's potential for empowerment.[19] Stigma and discrimination associated with TB can take different forms and are manifested at different levels of individual's life in different contexts. In spite of increase in knowledge regarding disease-related stigma and contributing factors, it still remains a difficult concept to measure and even difficult to eliminate it. The present study had some limitations. This study included only one particular population – patients with TB with treatment – and not community perspectives. There is probability of presence of stigma in other sub-groups, such as patients with TB but not on treatment. Patients' HIV status is also not included this study. We encourage further understanding of stigma among those persons affected by HIV/AIDS.

CONCLUSION

Stigma associated with TB is one of the hindering factors in eliminating TB from India. Stigma associated with TB is significantly associated with patients with the lower level of education and with lower socio-economic status, which is certainly grave area of concerns as often these population are at higher risk for health disparities. Therefore, stigma associated with TB may further worsen pre-existing class-based health disparities in countries like us. Measures should be taken to increase awareness among community and resolve myths related to it so that stigmatization can be minimized.

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