Prevalence of Stigma Among TB Patients and Its Associated Factors - A Community Based Cross-Sectional Study in Puducherry, India

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A B S T R A C T

Background: Tuberculosis (TB) is a disease that has both medical as well as social dimensions. Stigma and associated discrimination experienced by persons affected by TB is a barrier to the interventions towards TB elimination. A better understanding of stigma will improve the effectiveness of the interventions aimed to alleviate the effects of TB stigma. The objectives were to measure the prevalence of self, anticipated, experienced stigma and its associated factors and to explore the impact of tuberculosis related stigma among TB patients.

Methodology: A cross-sectional study was conducted in Puducherry district, Southern India among 420 adult drug sensitive non-HIV TB patients registered under NTEP. Data was collected by face-to-face interview using standardised questionnaire.

Results: The mean(±SD) age of the study participants was 44.5 (±15.03) years. Majority were males (267, 63.6%) and were married (330, 78.6%). The prevalence of stigma among TB patients was found to be 69.3%. Perceived stigma was noted in 47.1%, 33.6% had self- stigma and 26.0% had experienced stigma. On measuring the impact of stigma, 52.6% reported participation restriction. Illiteracy and lower-socio economic status were found to be significantly associated with TB stigma.

Conclusions: Stigma among TB patients was high. Tailored patient-centric interventions to address stigma and discrimination using culturally appropriate and locally available resources are necessary.

Key-words: Anticipated stigma, Experienced stigma, Perceived stigma, Tuberculosis patients

INTRODUCTION

WHO declared tuberculosis (TB) a global public health emergency in the year 1993.[1] 30 years later, TB continues to remain a global public health problem. Until the covid pandemic, tuberculosis was the leading cause of death from a single infectious agent, surpassing HIV/AIDS.[1,2] In 2021, the incidence of TB worldwide was 10.6 million.[2] India is the largest contributor (26%) to the total global TB burden with an incidence of 210 per 100,000 population.[2]

Tuberculosis has high social and medical dimensions. One of the social aspects of TB is the stigma associated with it which exacerbates the hardships of TB. This hinders the quality of life of TB patients and limits their access to TB services.[3,4] Stigma is characterised as a devaluation process in which, the stigmatised people lose their credibility, are viewed as a disgrace, are perceived to have less value or worth, or are even viewed as a danger.[5] The shame and expectation of discrimination that prevents people from talking about their experiences and feelings of unworthiness and guilt is referred to as perceived stigma. Self-stigma refers to the idea that people may come to endorse negative stereotypes and thus behave or think in accordance with these false portrayals and negative messages. The stigmatising behaviours and messages that are directly experienced by the person with TB are reflected in experienced stigma. Individuals who are stigmatised are frequently shunned by other members of society in various social settings such as the home, workplace, and community.[3,6,7] Hence, increased understanding of stigma is necessary for taking appropriate interventions to minimise the effects of TB stigma. To gain further insight into the dimensions of stigma related to TB, the present study was undertaken to measure the prevalence of self, anticipated and experienced stigma and its associated factors and also to explore the impact of Tuberculosis related stigma among TB patients in Puducherry.

METHODOLOGY

Study design and study setting: This cross-sectional study was conducted in Puducherry district with an area of 294 km[2], located on the southeast coast of India and is surrounded by the state of Tamil Nadu with which it shares most of its culture and language. As per Census of India 2011, Puducherry district has a total population of 9,46,600 with a TB notification rate of 226/lakh population.[8] There are 30 Primary health centers (PHCs) of which 13 are in urban, 17 are in rural area and 2 Community health centers (CHCs) are in rural areas. Field practice areas belonging to these centres were the study setting. We conducted the study for a period of one year from January 2021 to December 2021. We included TB patients diagnosed and registered under National Tuberculosis Elimination Program (NTEP) in all four quarters of 2021. The study was approved by the Institutional Ethics Committee, Indira Gandhi Medical College and Research Institute.

Inclusion and exclusion criteria: Drug sensitive TB patients aged 18 years or above, irrespective of gender, who are registered under NTEP, on anti-tubercular treatment for at least 1 month and are consenting were included in the study. TB patients with HIV or patients who are unable to comprehend and respond to the questionnaire were excluded.

Sample size determination and sampling technique: Using the formula for calculation of sample size for a cross-sectional study $n=Z^2 \, p(1-p)/d^2$, where Z is the standard normal variate, *p* value was taken from the study in Gujarat by Shah R B et al[9], which shows the prevalence of perceived social stigma among TB patients as 50.57%. Taking standard normal variate as 1.96 and precision as 5% the sample size was calculated to be 400 Assuming a non-response of 5%, the sample size was estimated to be 420. Out of the 755 adult drug sensitive patients diagnosed in 2021, the study participants were enrolled using consecutive sampling until the sample size was achieved.

Methods of Data collection: The purpose of the study was explained to the study participants and informed written consent was obtained. Patients were interviewed at the time and place convenient to them. The patients who gave consent were seated in a separate room and face-to-face interview was conducted using standardized questionnaires that included questions about the socio-demographic profile, comorbidity status, addictions, health seeking behaviour and scales to assess TB related stigma. The questionnaire was pre-tested and modified according to study setting. Face and content validation was done. For the purpose of measuring perceived stigma, Explanatory Model Interview Catalogue (EMIC) scale was used.[10] The scale had 4 options: yes (3), possibly (2), uncertain (1), no (0). The scores on the single questions were added up to get a sum score. The higher the score, higher the level of perceived stigma. For measuring self-stigma, Internalized Stigma of Mental Illness (ISMI) scale was used.[11] The scale had 4 options: strongly disagree (1), disagree (2), agree (3), strongly agree (4). Mean of all items were taken. Higher the mean score, higher the level of self-stigma. And to measure participation restriction, P-scale v.6.0 was used.[12] The scale has 18 questions with 5 options: not specified, yes, sometimes, no, irrelevant. If the response was yes or sometimes then they must answer the same question in likert scale with 4 options which includes: no problem (1), small problem (2), medium problem (3), large problem (5). Sum of all the scores were taken and a cut off of 12 was considered as no significant restriction. A score of 13-22, 23-32, 33-52, 53-90 indicated mild, moderate, severe and extreme restriction respectively. To measure experienced stigma questionnaire adapted from STOP TB was used.[5] Multiple responses were allowed, and the participant was asked if he had experienced stigma at each set-

ting like public places, workplace, family, community, hospitals during the course of their TB journey starting from recognising symptoms till they reach the phase of post treatment follow-up services. The interview was conducted in the local language and each interview lasted for about 10 minutes.

Statistical analysis and ethical considerations: The Statistical Package for Social Sciences (SPSS) version 21 (IBM Corp., Armonk, NY, USA), was used for data analysis. Normality was assessed before applying for tests of significance. Associations between categorical variables were done using the chi-square test. A *p*-value less than 0.05 was considered statistically significant. Independent variables which had a P value less than 0.25 in the univariate analysis were used in the model for multivariate logistic regression. And the outcome was reported as adjusted odds ratio (Adj OR) with 95% confidence interval (CI). Approval from the Institutional Ethics Committee (approval no: 333/IEC-32/IGMC&RI/PP-13/2021) and administrative approval from State NTEP OR Committee was obtained before the start of the study. Health education regarding stigma and ways of dealing it was given to all participants at the end of data collection. Confidentiality was maintained at all stages of the study.

RESULTS

The study involved a total of 420 patients. Out of which half were males (267, 63.6%). The mean(±SD) age of the study participants was 44.5 (±15.03) years. Half of the patients were aged more than 45years (213, 50.7%). Most of the patients were married (330, 78.6%). 214 (51.0%) belonged to lower/middle socio-economic status (SES) as per modified BG prasad scale.[13] Most of the study subjects were literates (319, 75.9%). Co-morbid conditions were present in 149 (35.5%) of them, of which 32.1% were diabetics. Current tobacco users in any form were 65 (15.5%), alcohol users were 35 (8.3%) and those using either of them were 89 (21.1%). 63.1% had pulmonary TB.

More than half the patients were in their continuation phase (CP) 363 (86.4%). Majority of them (313,74.5%) visited public health facility as their first point of care for their TB symptoms. Still, 3.6% and 2.9% visited retail pharmacy and traditional healers as their first point of care respectively as shown in table 1.

Table 2 shows that among the 420 study participants, stigma was noted among 69.3% of the study participants. When looked into the types of stigma faced by the study participants, 47.1% had perceived stigma, 33.6% had self-stigma, 26.0% had experienced stigma. Impact of stigma which was measured by participation restriction, was noted among 221 (52.6%) of the study participants. 24.8% had moderate participation restriction and 8.3% had severe participation restriction.

Table 1: Distribution of study participants based on Background characteristics (n=420)

Variable	Participants (%)
Age group (Years)	
18-44	207 (49.3)
45-60	154 (36.7)
>60	59 (14)
Gender	
Male	267 (63.6)
Female	153 (36.4)
Marital status	
Married	330 (78.6)
Unmarried	75 (17.9)
Divorced	6 (1.4)
Widow	9 (2.1)
Educational status	
Illiterate	101 (24)
Primary	134 (31.9)
Secondary	126 (30)
Graduate and above	59 (14)
Socio-Economic status	
Upper/ Upper middle	75 (17.9)
Middle	131 (31.2)
Lower middle/ lower	214 (51)
Co- morbidities	
Yes	149 (35.5)
No	271 (64.5)
Addictions	
Smoking	65 (15.5)
Alcohol	35 (8.3)
Either	89 (21.1)
Type of TB	
Extra Pulmonary	154 (36.7)
Pulmonary	266 (63.3)
Treatment phase	
Intensive phase	57 (13.6)
Continuous phase	363 (86.4)
First point of care health facility	
Public health facility	313 (74.5)
Private health facility	80 (19)
Retail pharmacy	15 (3.6)
Traditional healers	12 (2.9)

Table 2: Distribution of study participants as per TB stigma (n=420)

Stigma	Participants (%)
Any type of stigma	291 (69.3)
Perceived Stigma	198 (47.1)
Self-stigma	141 (33.6)
Ever experienced stigma	109 (26)
Impact of stigma (Participation restriction)	
No significant restriction	199 (47.4)
Mild restriction	82 (19.5)
Moderate restriction	104 (24.8)
Severe restriction	35 (8.3)

Fig 1. Among TB patients who experienced stigma at different settings (n=109) during their TB journey, stigma was experienced more during the initial phase of the TB treatment journey in family and stigma was faced more at workplace after they began treatment, and it continued till they received the post treatment follow-up services. The TB patients faced more stigma at home when compared to the other
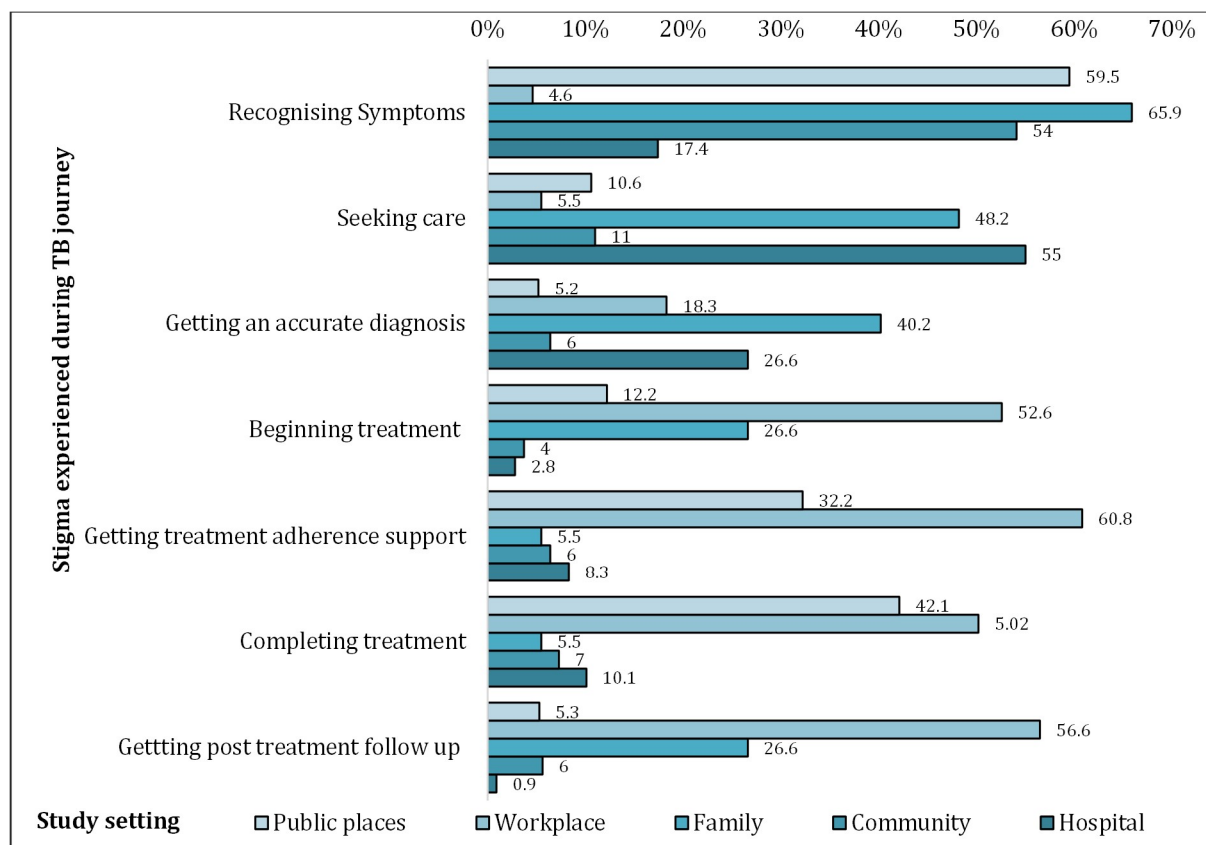
Figure 1: Stigma experienced by TB patients during the TB journey under different settings (n= 109)

Table 3: Association between background characteristics and TB stigma (N=420)

Background characteristics	Stigma		Univariate analysis		Multivariate analysis	
	Present (%)	Absent (%)	OR (95% CI)	P value*	Adj OR (95% CI)	P value
Age group (Years)						
18-44	147 (50.5)	60(46.5)	1.0	0.59	NA	NA
45-60	102(35.0)	52 (40.3)	1.0 (0.5-1.9)	0.98		
>60	42(14.4)	17 (13.1)	1.26 (0.6-2.4)	0.49		
Gender						
Male	185 (36.4)	82 (36.4)	1.0 (0.6-1.5)	0.99	NA	NA
Female	106 (63.6)	47 (63.6)	1.0			
Marital status						
Married	230 (79.0)	100 (77.5)	1.09 (0.6-1.8)	0.98	NA	NA
Others	61 (20.9)	29 (22.5)	1.0			
Educational status						
Illiterate	77 (26.5)	24 (18.6)	1.0		1.0	
High school	78 (26.8)	56 (43.4)	1.19 (0.5-2.4)	0.63	1.1 (0.5-2.4)	0.67
Higher secondary	93 (32.0)	33 (25.6)	0.51 (0.2-1.0)	0.05	0.5 (0.2-1.0)	0.59
Bachelor and above	43 (14.8)	16 (12.4)	1.05 (0.5-2.1)	0.89	1.0 (0.5-2.1)	0.89
Socio-Economic status						
Upper/Upper middle	54 (18.6)	21 (16.3)	1.0		1.0	
Middle	99 (34.0)	32 (24.8)	1.41 (0.7-2.5)	0.23	1.3 (0.7-2.3)	0.37
Lower middle/ Lower	138 (47.4)	76 (58.9)	1.70 (1.0-2.7)	0.32	1.7 (1.0-2.8)	0.02
Co- morbidities						
No	193 (66.3)	78 (60.5)	1.28 (0.8-1.9)	0.25	1.2 (0.7-1.9)	0.34
Yes	98 (33.7)	51 (39.5)	1.0		1.0	
Substance abuse						
Present	36 (12.4)	10 (7.8)	0.59 (0.2-1.2)	0.16	0.6 (0.2-1.3)	0.21
Absent	255 (87.6)	119 (92.2)	1.0		1.0	
Type of tuberculosis						
Extra Pulmonary	105 (36.1)	49 (38.0)	0.92 (0.6-1.4)	0.70	NA	NA
Pulmonary	186 (63.9)	80 (62.0)	1.0			
Health seeking behaviour						
Appropriate	273 (93.8)	120 (93.0)	1.38 (0.4-2.6)	0.76	NA	NA
In-appropriate	18 (6.2)	9 (7.0)	1.0			

*Chi-Square test, *p*<0.05 is statistically significant

settings especially when they are in the phase of recognising symptoms (65.9%) and seeking care (48.2%). The stigma was experienced more at workplace when the TB patient is in the phase of getting treatment adherence support (60.8%) and in getting post treatment follow up services (56.5%). Stigma is experienced more in public places during the phase of recognising symptoms (59.5%) and during treatment completion (42.1%). Stigma faced in the hospital while seeking care was 55.0%.

Table 3 shows the association between background characteristics and TB stigma. In univariate analysis only educational status of the TB patients was found to be significantly associated with TB related stigma (p=0.01). However, the variables which had a P value of less than 0.25 were put in the model for multivariate analysis. The variables included were educational status, socio-economic status, co-morbidities, substance abuse. In multivariate analysis illiteracy (p=0.01) and lower socioeconomic status (p=0.02) were found to be the significant independent predictor of TB stigma.

DISCUSSION

Majority of the study participants were in the age group of 18-44 years which was similar to study by Shah et al[9] and Duko et al.[14] Males were in majority (63.6%) which was similar to other studies.[9,15-19] Likewise, marital status, type of TB of the participants were similar to previous studies.[17-20]

The stigma associated with tuberculosis is a major barrier in accessing health care services and has an impact on the quality of life of TB patients.[3] Hence it is essential that we learn about stigma and its various dimensions in order to take appropriate action, however studies on measuring the different types of stigma were limited. In our study we found that more than two-thirds (69.3%) of the study participants reported stigma related to TB. But among the study participants only 26% have experienced stigma whereas 47% had perceived stigma. About 33.6% of them had self-stigmatising behaviours like alienation, stereotype endorsement and perceived discrimination. This shows that TB patients are much more likely to engage in self-stigmatizing behaviours because of the fear of being stigmatised rather than actually being stigmatized. The findings were similar to those studies conducted by Aryal et al[21] and Shivapujimath et al[15] where in the prevalence of stigma was 63.3% and 51.2% respectively. In both the studies EMIC scale[10] was used for data collection. Other studies by Shah et al[9], Rie et al[22], Mohammedhussein et al[23] showed the prevalance of perceived stigma as 50.57%, 63.3% and 57.1% respectively. Jaggarajamma et al[24] showed that more than one third of study population had perceived stigma and Duko et al[14] measured perceived stigma by using perceived TB stigma scale[25] and it was 42.4%.

The difference in the study findings might be attributed to the difference in the study design, data collection tool, sample size, difference in the eligibility criteria of the study participants, cultural and geographic variation of the study setting and the difference in the burden of the disease. In our study we included patients regardless of the type of TB as we wanted to include the prevalence of stigma among extra- pulmonary TB patients as well. Certain studies included only PTB citing that those patients had a high perceived stigma compared to patients with extra- pulmonary TB patients.[14,23] Studies have shown that TB and HIV are stigmatising diseases. Combining these illnesses could increase the patient's burden and conceal any stigma associated with TB.[14,23] We have excluded HIV co-infected TB patients from our study because we wanted to accurately estimate the stigma associated with TB alone.

Although age, gender, low socio-economic status, presence of comorbidities, type of TB was not observed to have significant statistical association with stigma, it was found that higher proportion of participants who had stigma were in the age group of 18-44 years (50.5%), females (63.6%), lower socio-economic status (47.4%), comorbidities (33.7%) and pulmonary TB (63.9%). Similar findings were observed in other studies[9,15,16] where factors like gender, occupation, family history, and marital status were found to be not significantly associated with stigmatization. This infers that stigma prevails irrespective of socio-demographic factors.

Study by Aryal et al[21] has shown that significant association exist between occupation, monthly family, treatment phase, category of the patient and stigma.

Though females had more stigma than males in our study, gender was not significantly associated with TB stigma, whereas in some studies[17,26] females faced higher stigma. Present study showed no significant association between addiction status and stigma but Duko et al[14] has showed that those using substance (alcohol, khat and cigarette) [AOR=1.78, (95% CI: 1.28, 3.17)] were more likely to have perceived TB stigma.

Illiteracy and lower socio-economic status were found to have significant association (p<0.05) with TB stigma in our study. Low level of education could lead to poor socio-economic status, poor awareness on risk factors and symptomatology of TB which might lead to increase in the risk of getting the disease. Moreover, previous studies have also reported significant association between education and stigma.[9,15,16]

The study highlighted that more than half of them had social restriction as the impact of stigma. We also highlight that stigma is experienced at workplace even after completing treatment, during the post treatment follow up phase as well. Similarly in a study by Kamble et al[16], 58.2% had perceived stigma at workplace. This reiterates the importance of in-

terventions concentrating on different settings especially workplace.

STRENGTHS AND LIMITATIONS

The biggest strength of the present study is that the stigma faced by the study participants was measured at different study settings during the entire course of TB journey. The study has used standard tools for data collection. The possibility of investigator bias was minimized because the study was conducted out by a single investigator. The in-depth exploration of stigma faced by the study participants was not done in our study. Potential confounders like knowledge regarding TB, stress and depression were not assessed in the study.

CONCLUSION

Self, perceived and experienced stigma is common among TB patients. Majority of the study participants had perceived stigma rather than actually being stigmatized. Stigma was commonly experienced by the TB patients during the entire course of the TB journey, both at workplace and family and it should be addressed by using a multi-stage approach with focus at each setting. All patients with TB should be screened for stigma at least once while receiving treatment, and those who qualify should have access to appropriate counselling and care. The interventions for TB stigma should be tailored, need-based and patient centric.

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