ORIGINAL ARTICLE

A Study Comparing Tuberculosis-related Stigma in Healthcare Providers and Receivers

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Abstract

Background: Global efforts to reduce tuberculosis (TB) are severely hampered by stigma. With a high number of TB infections, India struggles with the widespread stigma surrounding the illness, which makes it difficult to diagnose and treat patients promptly. To shed light on an important but often ignored component of TB management, we calculate the prevalence of TB-related stigma and variability in the manifestation in different groups.

Methods: After calculating the sample size, we stratified them into different groups: patients with TB, healthcare workers providing TB services, and family members living with the patients. A validated, predesigned questionnaire was employed to assess stigma across various domains. MS Excel was used to compile the data, and Epi Info 7 to analyze it.

Results: Health professionals made up the largest percentage of those who experienced stigma (11.78%), followed by family members (8.91%), and patients (6.05%). The association of stigma with different groups of study participants was statistically significant, implying that stigma exists variably in the other groups. The majority of the patients (3.50%) perceived stigma at their home, whereas the majority of the family members faced stigma in the community (5.41%). Healthcare workers face stigma majorly in the community (7.96%).

Conclusion: Stigma related to TB lays its foundation in varied perceptions by society. Societal norms determine acceptable and undesirable behaviors. Our study reveals major roadblocks on the way to TB eradication in the country and reveals a picture that can be extrapolated to most communities throughout. Aiming to reduce stigma will, in turn, improve treatment-related outcomes in TB and pave the way for smoother management and eradication.

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Introduction

Stigma, as defined by the World Health Organization, is a "mark of shame, humiliation, or disapproval causing an individual to be rejected, discriminated against, and excluded from engaging in various activities."[1] In the course of the history of tuberculosis (TB), it has posed a problem not only due to its serious health impacts but also through its social aspects. India leads in numbers out of the 8 countries responsible for the maximum burden of TB in the world.[2] Around 10 million people suffered from TB on a global scale in 2019, and about 1/3 of them went unreported.[3] India hosts 27% of cases of TB in the world.[4] About 73% of the people in the country harbor stigmatizing and discriminatory behavior toward TB patients.[5] This stigma stands as an obstacle to getting medical help and becomes a reason for significant suffering added to the illness. Stigma is not limited to patients but extends to their family members and also to the healthcare workers involved in TB caregiving. These range from subtle exclusions at school or workplace to people being thrown out of their houses and estranged from families. Often, both public and private health sector staff are accused of having discriminatory attitudes.[6] It is also noteworthy that education and awareness disseminated seek to target the medical aspects of the disease, and factors that lead to discrimination and stigmatization against patients often remain unaddressed.[5] Since stigma is associated with increasing the burden of the infectious pool and chain of transmission in the household, followed by the community, ultimately delaying seeking care and leading to a poorer prognosis, focus on this becomes imperative.[7,8] Sadly, India's TB eradication programs and strategies have never prioritized addressing social implications at the forefront. Keeping in mind that increased acceptability for the disease and utilization of healthcare services at the earliest will result in sooner and more widespread screening, testing, and diagnosis of TB, as well as improved treatment adherence and outcomes, we aim to bring the above to light. This study focuses on comparing stigma between the provider and receiver end of TB service and would add to the insufficient data on the social facet of the disease. Ending the stigma and discrimination associated with TB diminishes, and may even eliminate, the fearful nature of the disease, thus leading to a higher acceptability of healthcare services. This would reinforce the national TB strategy plan, with the goal of eliminating the disease by 2025.

Methods

This study was conducted in the district of Bhopal, Madhya Pradesh. The sample size was estimated based on the prevalence of TB stigma from the reference study, which reported a rate of 73%.[5]

$$\text{Sample size } (n_0) = z^2pq/e^2$$

Where p, prevalence, is 73%; q (100 – p) comes to 27; e is allowable error, which is taken to be 5%; and z is 1.96 (confidence interval of 95%).

The sample size as estimated by this comes out to be:

$$n_0 = 313.7$$

Therefore, the sample size (n_0) was determined to be 314. Stratified sampling was employed to divide the sample of 314 equally into three categories:

1. 105 patients.
2. 105 family members.
3. 104 healthcare workers.

We obtained the ethical clearance from the Institutional Ethical Committee (registration no. ECR/1055/Inst/MP/2018) under letter no. 30692/MC/IEC/2022 dated 04/08/2022. This study was conducted across 13 tuberculosis units (TU) located in the Bhopal district (Table 1). With the District TB Officer's approval, a list of

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TB patients seeking treatment at the respective TUs, along with their contact details, was obtained through the Nikshay portal. A total of 105 patients were selected evenly from the 13 TUs in the Bhopal district, utilizing a simple random sampling technique. Upon consent, the investigator visited the patients' homes and conducted interviews with the patients and 1 family member present, preferably the primary caregiver, with responses recorded in the questionnaire. Additionally, 104 healthcare workers involved in providing TB services were interviewed (Fig. 1).

Furthermore, each question or scenario was translated into the local language to maintain its original context and ensure understanding by the participants.

As for the study tool, a predesigned questionnaire was utilized, which was internally validated by pulmonologists and externally validated by the District Tuberculosis Officer (DTO). This questionnaire was developed with reference to the stigma assessment tool created by the Stop TB Partnership and hosted by UNOPS. Participants were questioned about their personal encounters with TB-related stigma, observations of stigma experienced by others, the role of stigma as a hindrance to accessing TB services, and suggestions for enhancing TB services, laws, and policies. The questionnaire encompassed various domains as outlined in (Fig. 2).[9]

Table 1: List of TUs in Bhopal district

S. no.	*TU in Bhopal district*	*DMC in Bhopal district*
1	DH Jaiprakash Hospital	2
2	Jawaharlal Nehru hospital	3
3	Civil Hospital Berasia	3
4	TB Hospital Bhopal	3
5	District TB Centre	3
6	Kailash Nath Katju hospital	2
7	AIIMS Bhopal	3
8	CHC Gandhi Nagar	2
9	Pulmonary Medicine Centre (Gas Rahat)	2
10	PHC Misrod	3
11	CHC Kolar	3
12	People's College of Medical Sciences and Research Centre	1
13	Civil Hospital Bairagarh	2

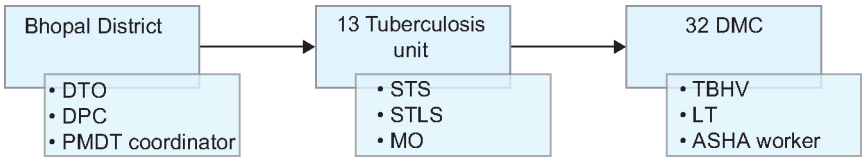

Fig. 1: National TB program healthcare workers organizational structure

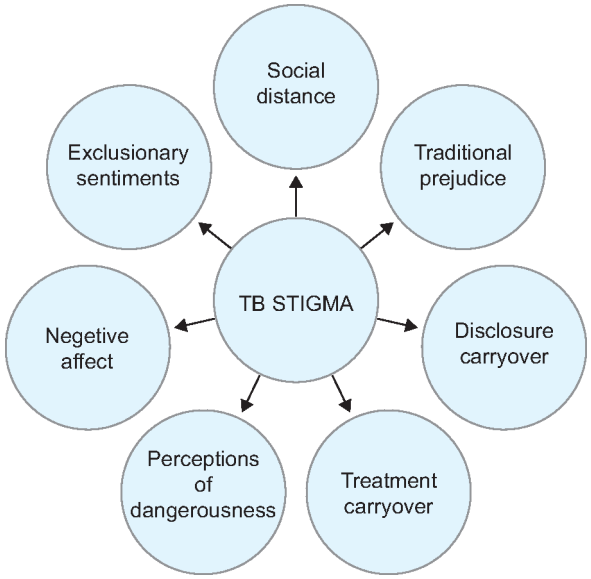

Fig. 2: Domains of TB stigma

Inclusion Criteria

- Tuberculosis patients of 18 years or older.
- Patients with proper communication and comprehension of the questionnaire's content.
- Patients who have provided consent to participate in the research and to share their perspectives on the issue honestly.
- Family members living with TB patients of 18 years or older, serving as caregivers, and willing to participate.
- Healthcare workers willing to participate and are employed under the National Tuberculosis Elimination Program (NTEP).

Exclusion Criteria

- Individuals not consenting to participate.
- Individuals under 18 years of age.

The data was collected and organized in Microsoft Excel, and subsequent analysis was conducted using CDC's Epi Info 7 software. Chi-square analysis was done to find any association between stigma and different participant groups.

Results

Table 2 demonstrates the association of stigma among different groups of the study. The maximum proportion of the population who faced stigma were health workers (11.78%), followed by family members (8.91%), and patients (6.05%). The association of stigma with different groups of study participants was statistically significant, with a *p*-value of 0.017, implying that stigma exists variably in the different groups.

Table 3 explains the prevalence of stigma observed among different groups, that is, whether they have seen others facing stigma related to TB. The majority of them were healthcare workers (12.73%), followed by family members (11.78%), and patients (7.96%). The association of secondary stigma with different groups was not statistically significant. This question was asked to see observed stigma in society, where all 3 groups responded invariably.

Table 4 shows the proportional distribution of study participants according to the places where they have faced stigma. The majority of the patients (3.50%) perceived stigma at their home, followed by at work (1.91%), and the least proportion faced it in the community (0.63%), whereas the majority of the family members faced stigma in the community (5.41%), followed by at home (1.91%), and at work (1.59%). Healthcare workers faced stigma majorly in the community (7.96), followed by

Table 2: Association of stigma with different groups of study participants ($n = 314$)

Group	*Have you ever faced stigmatizing behavior from others because of your TB status/a family member having TB/ having to work with TB patients?*		*Total*	*Pearson Chi-square*	*df*	*p-value*
	No n (%)	*Yes n (%)*				
Patients	86 (27.38)	19 (6.05)	105 (33.43)	8.149	2	0.017*
Family members	77 (24.52)	28 (8.91)	105 (33.43)			
Healthcare workers	67 (21.33)	37 (11.78)	104 (33.12)			
Total	230 (73.24)	84 (26.75)	314 (100)			

*p-value < 0.05 is statistically significant

Table 3: Association of stigma observed by patients, family members, and healthcare workers, with respect to different groups of study participants ($n = 314$)

		Have you seen any other person being stigmatized because of TB?		*Total*	*Pearson Chi-square*	*df*	*p-value*
		No n (%)	*Yes n (%)*				
Group	Patients	80 (25.47)	25 (7.96)	105 (33.43)	5.660	2	0.059
	Family members	68 (21.65)	37 (11.78)	105 (33.43)			
	Healthcare workers	64 (20.38)	40 (12.73)	104 (33.12)			
Total		212 (67.51)	102 (32.48)	314 (100)			

Table 4: Proportional distribution of study participants according to the places where they have faced stigma ($n = 314$)

Place where participants faced stigma	*Group*			*Total*
	Patients n (%)	*Family members n (%)*	*Healthcare workers n (%)*	
No stigma	86 (28.34)	77 (24.52)	67 (21.33)	230 (73.24)
Health facility	0 (0)	0 (0)	9 (2.86)*	9 (2.86)
Community	2 (0.63)	17 (5.41)	25 (7.96)	44 (14.01)
Home	11 (3.50)	6 (1.91)	3 (0.95)	20 (6.36)
Work	6 (1.91)	5 (1.59)	0 (0)*	11 (3.50)
Total	105 (33.43)	105 (33.43)	104 (33.12)	314 (100)

*Work and health facilities were evaluated as single entity for healthcare workers

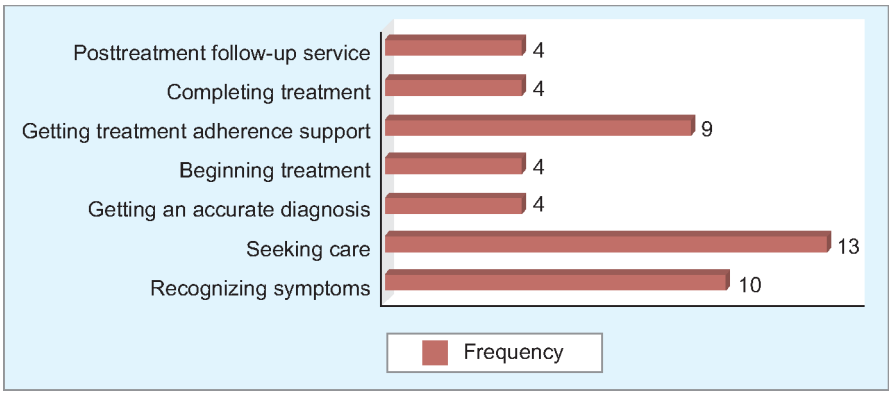

Fig. 3: Frequency distribution of patients and family members according to various aspects in which stigma acts as barrier ($n = 210$)

at home (0.95%), and health facility or work (2.86%).

Figure 3 conveys how stigma acts as a barrier during the course of TB. The leading aspect in the course of disease and utilization of TB services where stigma acts as a barrier to patients and family members, where seeking care was reported in 13 (6.2%), followed by recognizing symptoms in 10 (4.7%), and getting treatment adherence support in 9 (4.3%). Others are posttreatment follow-up service ($n = 4$), beginning treatment ($n = 4$), completing treatment ($n = 4$), and getting an accurate diagnosis ($n = 4$).

Discussion

Tuberculosis, despite being easy to diagnose and a treatable disease, claims at least 3 lives every minute.[10] However, this path of management and, ultimately, the eradication of TB have many obstacles to be overcome by the community as a whole. Among these, stigma and associated discrimination faced by those with or impacted by TB continue to be a significant barrier.

Keeping the above in mind, we chose this study to assess the biggest barrier faced during TB management: the stigma associated with it. In our study population, which included 105 patients and their family members, along with 104 healthcare workers, it was found that the maximum proportion of the study population that faced stigma were healthcare workers, that is, 11.78%. This data is strikingly similar to a study conducted by Muhandiki et al. in Tanzania,[11] which revealed that about 50% of the recruited healthcare workers perceived stigma. This was followed by family members and patients, 8.91 and 6.05%, respectively.

The study also revealed a significant association of stigma with different groups of study participants. Among the participants, 32.48% have reportedly observed others being subjected to stigma, with healthcare

workers forming the major chunk, which can be attributed to them being surrounded by patients and their families throughout, and also being surrounded by other patients and their kin in healthcare centers.

While assessing the places the participants have experienced this stigma, it was found that patients were subjected to most stigma at home, followed by workplace settings, and least in the community. This may be because of their confinement at home due to the illness and also because most conceal their illness status. The majority of the family members face stigma in the community, followed by home, and lastly, work. This may be attributed to them being more mobile and engaged in the community. Healthcare workers face the most stigma in the community, followed by home, and lastly, work, keeping in accordance with acceptance of the illness and its nature by their fellow workers. However, as they are the link of the important chain of transmission of any communicable disease to the community, the stigma is explained. The above has also been mentioned by Courtwright and Turner in their study assessing TB stigma, pathways, and intervention.[12]

While assessing the various aspects of how stigma acts as a barrier during the course of TB for patients and their family members, the leading was seeking care, followed by recognizing symptoms and getting treatment adherence support. Other aspects like getting a diagnosis, beginning and getting treatment, and post follow-up care were at the lower end. This can be explained by the active role of healthcare workers in the latter chunk, and hence better acceptance. The above findings are in accordance with the study conducted by Muhandiki et al. in Tanzania,[11] where the maximum percentage was at seeking care; however, it differs, with the percentage of the aspect of beginning of treatment being lower in our study.

Stigma is a social determinant of health and acts as a barrier to treating the disease in multiple ways. People may be reluctant to seek and complete medical care when diseases are stigmatized due to concern over the social and economic repercussions that may accompany a diagnosis. Due to stigma, a patient who exhibits TB symptoms may dismiss the idea of having the disease, which may prevent them from recognizing symptoms. Even if the patient is aware that their symptoms may be related to TB, they may still be reluctant to seek medical attention due to stigma. Patients who choose to seek care may choose to obtain unqualified views rather than receive an accurate diagnosis from a designated microscopy facility. People anticipate that receiving care at a nearby public institution will make their TB status known to others due to the visibility of TB testing and treatment facilities. Even when patients go to a clinic for therapy, social condemnation from family members, relatives, or the community lowers treatment compliance. Instead of receiving antitubercular therapy from a DOTS facility, patients who have been diagnosed with TB may choose to self-medicate or obtain prescriptions from quacks. Patients on antitubercular therapy may quit taking their medication as soon as they feel better because they ostensibly want to be free of the burden of having TB, which may lead to reduced treatment compliance and, eventually, treatment failure. Thus, at any stage of the disease course as described, stigma can act as a barrier to utilization of TB services. A study conducted in India estimated that about 200,000 patients in the national TB program undergo pretreatment loss to follow-up (PTLFU) each year.[6] This refers to patient dropout after diagnosis but before treatment registration, which is a serious gap in TB care in India and around the world. Proper adherence is critical to avoid the development of multidrug-resistant TB (MDR-TB).[13]

The study throws light on the necessity for the national TB response and various programs to include stigma-reduction interventions along with other measures. It should be kept in mind that these must be well-researched, though simple, and be developed through community engagement. Further research in this field needs to be encouraged along with continuous surveillance for the same.

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