

Perceived TB Stigma among General Population : A Cross Sectional Study

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Abstract

Introduction: Stigma and discrimination are recognised as the most commonly identified barriers to fight the TB epidemic. Reducing TB stigma is essential because it hinders care seeking, contact tracing, outbreak investigations, treatment initiation, adherence and quality of care. *Objective:* The objective of the study was to determine the stigma associated with tuberculosis and find out the association of TB stigma with selected demographical variables. *Methodology:* Descriptive design was used in the study and data collection was done in the urban and in the rural areas of Bangalore. The total sample size was 250 based on the review of literature. Convenient sampling was done to select the subjects. Data collection was done after getting the informed consent. Modified Tuberculosis-Related stigma scale was used. Data analysis was done by descriptive and inferential statistics. *Result:* Majority of the subjects 201 (80.4%) had moderate stigma, 31 (12.4%) had poor stigma and 18 (7.2%) had high stigma related to tuberculosis. In this more subjects had high stigma (58.4%) for the item "I am afraid of people who have TB" and lowest stigma for the item (8.8%) "People get TB because of multiple sex partners." The study findings also shows statistically significant association regarding tuberculosis stigma with gender (1.44), residence (3.41), family member having Tuberculosis (3.647) and friends or neighbours having Tuberculosis (2.41) at 0.05 level of significance. *Discussion:* In the present study, majority of population had moderate stigma (201) 80.4% similar to a study where 21 (34.43%) of the 61 DOTS patients were found to be stigmatised and 40 (65.57%) were not stigmatised. 10 (47.62%) females and 11 (27.5%) males were found to be stigmatised. 43 (70.49%) patients preferred to keep other people from knowing that they were suffering from tuberculosis. 27 (44.26%) patients decided to stay away from work/social groups and 26 (42.62%) felt that others gave them less respect. *Conclusion:* TB stigma is high and will likely affect care seeking behaviour; TB awareness campaigns should be a priority and emphasise the treatability and curability of TB.

Keywords: Stigma; Tuberculosis.

Introduction

In 2015, 10.4 million people were diagnosed with tuberculosis (TB) and 2.1 million people tested positive for HIV. Over two-thirds of new TB and HIV infections are in lower income and middle-income countries in sub-Saharan Africa and Asia. Together, TB and HIV cause over 2.5 million deaths each year, and immeasurable social calamities.¹ TB is often associated with factors that can themselves create stigma: HIV, poverty, drug and alcohol

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misuse, homelessness, disreputable behaviour or malnutrition.²

Stigma and discrimination are recognised as some of the most commonly identified barriers to fight the TB epidemic. Reducing TB stigma is therefore essential because it hinders care seeking, contact tracing, outbreak investigations, treatment initiation, adherence and quality of care. Moreover it degrades social capital, it deprives people with TB of their rights and the respect of others. Ultimately it can also contribute to catastrophic costs when people with TB are pushed out of their homes, communities and jobs-losing their security, support system and means of income. Stigma not only harms patients, but also erodes health care workers' commitment to high quality care. It is important to remember that we as a society are doing far worse to TB patients than the disease actually is.³

The TB community has always recognised the stigma that surrounds the disease but has done far less to confront it. In recent years, key factors in the TB community, such as the Stop TB Partnership, Treatment Action Group, TB PROOF, Global Coalition of Tuberculosis Activists and KNCV Tuberculosis Foundation, to name just a few, are creating meaningful change in the praxis of TB care with potential effects on stigma reduction. Terms that reinforce negative stereotyping of people with TB are being extricated from clinicians' and researchers' vocabularies. The hardline DOT approach is gradually ceding to patient-centred approaches that emphasise community engagement, patient counselling and structural aid in adherence promotion. Governments and industry are being held accountable for implementing new technologies to ensure equitable access to the fruits of scientific advancement. Global health ambassadors including TB survivors are raising awareness about TB on a societal level through messages that affirm the dignity of people with TB rather than amplify the fear of TB.⁴

Stigma is still a low-priority issue in international TB control efforts notwithstanding the numerous papers written on this topic. Stigma hinders, or even adversely influences the efforts to stimulate treatment compliance and reduce delays in diagnosis and treatment worldwide. Moreover, stigma impedes the application of preventive measures such as cough-hygiene and good ventilation at home resulting in increased transmission risk, severe morbidity and mortality and increased development of multi-drug resistance (MDR-TB), thus undermining successful TB control. Hence this study was done to assess the perceived stigma related to TB.

Objectives

1. To determine the stigma associated with tuberculosis.
2. To determine the association of the scores of stigma with selected demographic variables.

Research Methodology

Descriptive design was used in this study and it was done in the urban and rural areas of Bangalore. The total sample size calculated was 250 based on the review of literature⁵ at 95% confidence level, 5% precision and 80% power. Convenient sampling was done to select the subjects. The study included all the adults in the age group of 18–60 years living in urban and rural areas. And excluded all adults who were known to have psychiatric illness and tuberculosis.

The Tuberculosis-Related Stigma scale was modified, and the tool had 20 questions graded on a three-point Likert scale, ranging from disagree (0), Neutral (1), agree (2). The item scores from the questionnaire were summed and the scores ranged respectively from 20–40. Data collection was done after getting the informed consent. The subjects were met in their homes and interviewed. For each subject the time duration was 15 mts. Data analysis was done by descriptive and inferential statistics.

Results

Demographic data

Majority of the subjects, 60.8% were females, 34.8% were in the age group of 26–35 yrs, 30% were graduates, 25.6% were unemployed. Majority of the participants (85.2%) family members were not affected by tuberculosis and 78.2% of the subject's friends or neighbours had no history of tuberculosis.

Stigma of Tuberculosis

Majority of participants 201 (80.4%) had moderate stigma, 31 (12.4%) had poor stigma and 18 (7.2%) had high stigma related to tuberculosis.

Table 1: Distribution of subjects according to Tuberculosis-related stigma n=250

Level of Stigma	Frequency	Percentage (%)
Poor Stigma	31	12.4%
Moderate Stigma	201	80.4%
High Stigma	18	7.2%

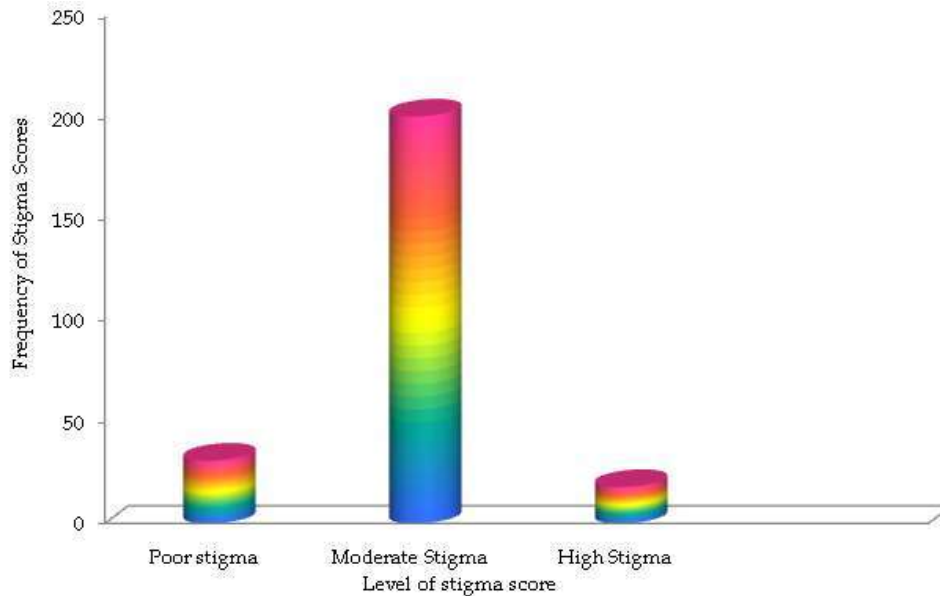


Fig. 1: Distribution of subjects according to Tuberculosis-related stigma

Table 2: Distribution of tool based on item wise Tuberculosis-related stigma.

Contents	Agree		Neutral		Disagree	
	No.	%	No.	%	No.	%
I prefer not to have any TB patient in the area I live	31	12.4	130	52.0	89	35.6
I believe TB is caused because of one’s own sins	75	30	84	3.6	91	36.4
I believe TB is caused by evil spirits	59	23.6	64	25.6	127	50.8
I think people with TB are disgusting	96	38.4	60	24.0	94	37.6
I don’t feel comfortable to be close to a person with TB	133	53.2	101	40.4	16	6.4
I don’t want people with TB to play with my children	73	29.2	96	38.4	81	32.4
I don’t want to talk and spend time with TB patients	24	9.6	118	47.2	108	43.2
I don’t wish to eat or drink anything with my friends who have TB	110	44.0	84	33.6	56	22.4
I don’t wish to eat or drink anything with my family members who have TB	110	44.0	70	28.0	70	28.0
I am afraid of people who have TB	146	58.4	40	16.0	90	36
People get TB due to multiple sex partners	22	8.8	93	37.2	113	45.2
People who have TB should not get married	128	51.2	96	38.1	26	10.4
TB is a familial inheritance	118	47.2	69	27.6	63	25.2
People with TB must restrict their freedom	99	39.6	76	30.4	75	30.0
A person with TB deserves to be punished	89	35	52	20.8	109	43.6
People who have TB should be isolated	74	29.6	66	26.4	110	44
People who have TB should not be allowed to work	64	25.6	48	19.2	138	55.2
I believe traditional rituals will cure TB	72	28.8	53	21.2	125	50.0
I think TB is caused if we don’t eat or drink properly	102	40.8	60	24.0	88	35.2
I think the vessels and other articles used by the TB patients should be washed many times in hot water	73	29.2	76	30.4	101	40.4

Data presented in the table 2 depict that in item wise stigma associated with tuberculosis. In this more subjects had high stigma (58.4%) for the item “I am afraid of people who have TB” and lowest stigma for the item (8.8%) “People get TB because of multiple sex partners.”

The study findings also shows statistically significant association regarding tuberculosis stigma with gender (1.44), residence (3.41), family member having Tuberculosis (3.647) and friends or neighbours having Tuberculosis (2.41) at 0.05 level of significance.

Discussion

In the present study, majority of population had moderate stigma (201) 80.4%. A similar type of study finding⁶ showed that out of 61 patients, 21 (34.43%) patients were found to be stigmatised and 40 (65.57%) were not stigmatised. 10 (47.62%) females and 11 (27.5%) males were found to be stigmatised. 43 (70.49%) patients preferred to keep other people from knowing that they were suffering from tuberculosis. 27 (44.26%) patients decided to stay away from work/social groups and 26 (42.62%) felt that others give them less respect. It is necessary to understand that self-stigma doesn't happen on its own. It happens because of the surrounding environment that is stigmatising and causes those with TB to start stigmatising themselves. Self-stigma occurs when an individual begins to internalise attitudes that can include shame, disgust, and guilt. These can result in withdrawing from normal social interactions, shunning personal relationships, even avoiding leaving the house, or adopting risky behavioural patterns. The negative psychosocial consequences can, in turn, include depression, anxiety and loneliness.⁷

Another study finding⁸ observed immense stigma at society level with 60% of the patients hiding their disease ($p < 0.05$) from friends and neighbours. Stigma was observed more among middle and upper middle class when compared to lower middle class and lower class ($p < 0.05$). Gender-wise further it was observed that stigma was more among females ($p < 0.05$) than in males. Stigma has long been recognised within the tuberculosis (TB) community as a barrier to ending the disease. It is a complex and challenging issue involving institutions, communities, and societal attitudes. The global TB and HIV epidemics are both worsened by stigma, incited by their association with poverty, social marginalisation, and the risk of transmission and death.

Conclusion

The study has demonstrated that despite good performance of Revised National TB Control Programme the stigma in tuberculosis still remains a problem. Maximum population have stigma

related to tuberculosis. We need to supplement the efforts in advocacy, communication and social mobilization for reducing the stigma problem among general population.

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