

# Social stigma among tuberculosis patients attending DOTS centers in Delhi

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## ABSTRACT

**Background:** Every year >9 million people suffer from tuberculosis (TB) and India accounts for >25% of global TB burden. Tuberculosis patients experience both psychological and social suffering. Amongst the problems met by tuberculosis patients, social stigma has been increasingly recognized. This study was done to assess social stigma and associated factors among the tuberculosis patients attending Directly Observed Treatment Short-course (DOTS) centers in South East Delhi. **Material and Methods:** It was a cross-sectional study carried out among tuberculosis patients availing treatment from DOTS centers of South East Delhi. Out of 48 DOTS centers in South East Delhi, 6 centers were selected on the basis of population proportion to size. A total of 270 TB patients were interviewed using a semi-structured, pretested questionnaire consisting of stigma-based questions. Fisher exact and Chi-square test applied. **Results:** The mean age of patients was 31.5 years (SD ± 11.5) with age ranging from 18 to 77 years. Males were higher (57.4%) compared to females (42.6%). 123 (45.5%) perceived stigma with family/friends and 92/158 (58.2%) perceived stigma at workplace. Young patients (<30 years), males faced more stigma at workplace and lower socioeconomic class faced higher stigma with family and friends ( $P < 0.05$ ). **Conclusion:** There is still higher stigmatization faced by patients with TB at family/friends and at workplace. Motivation by friends/family and support at workplace has been crucial in achieving successful treatment outcomes.

**Keywords:** Delhi, DOTS, stigma, tuberculosis patients, workplace stigma

## Introduction

Tuberculosis, one of the oldest diseases known to affect humans, is a major cause of death worldwide. This disease, which is caused by bacteria of *Mycobacterium tuberculosis* complex, usually affects the lung, although other organs are involved in one-third of cases. Transmission usually takes place through the air-borne

spread of droplet nuclei produced by patients with infectious pulmonary tuberculosis.<sup>[1]</sup> Globally, an estimated 10.0 million (range, 9.0–11.1 million) people fell ill with TB in 2018, a number that has been relatively stable in recent years with an estimated 1.2 million (range, 1.1–1.3 million) TB deaths among HIV-negative people.<sup>[2]</sup> India accounts for a quarter of the global TB burden with an estimated 27 lakh new cases in 2018 and 4.4 lakh deaths among HIV-negative people.<sup>[3]</sup>

TB is a social problem and could not be addressed by health professionals alone. Addressing TB needs intersectoral approach.<sup>[4]</sup> Social stigma is “an undesirable or discrediting attribute that an individual possesses, thus reducing that

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individual's status in the eyes of society."<sup>[5]</sup> Stigma and discrimination have an enormous impact on sufferers. While men have to deal with stigma at workplace and community level, women have to deal within the household and in the immediate neighborhood and society.<sup>[6]</sup> The obvious cause of discrimination is a fear of being infected, yet stigma and discrimination also occur for noninfectious diseases such as cancers<sup>[7]</sup> and mental health problems.<sup>[8]</sup> A lot of socioeconomic factors like poverty, nutrition, and diet, social stigma, poor accessibility to health services, lack of knowledge are responsible for late diagnosis and increased mortality among women due to TB. Amongst all the problems met by tuberculosis patients, social stigma has been increasingly recognized. The patient of TB experiences both psychological and social sufferings.

People have stigmatizing opinions and misconceptions about tuberculosis patients such as they are dirty, alcoholic, unemployed, hereditary-related, bad family, and occupation-related. These stigmatizing thoughts often lead to discrimination against people with TB in different ways like losing the current job or unable to get a new job, shunned by family and friends, cannot get married, and receiving poor treatment. People who face unaddressed stigma and discrimination develop poorer psychosocial health and are less likely to recover from disease due to lack of self-motivation towards treatment.<sup>[4]</sup>

Social stigma always remains an important and neglected aspect, which is leading to under-reporting of TB cases to the health system and taking treatment from quack/unqualified health care practitioners in India. Also, when people do not seek treatment because of stigma, they are more likely to transmit the disease to their family and friends. There was a paucity of studies focusing on this important aspect of tuberculosis in India. Thus, this study was done to assess social stigma and associated factors among the tuberculosis patients attending Directly Observed Treatment Short-course (DOTS) centers of the South East District of Delhi.

## Materials and Methods

### Study design and setting

The study was a cross-sectional, observational study conducted in DOTS Centers of the South East District of Delhi.

### Study duration

The study was carried out from April 2019 to August 2019.

### Study population

The study population included tuberculosis patients availing treatment from DOTS centers of South East Delhi.

### Inclusion criteria

1. Patients who were diagnosed with tuberculosis as per Revised National TB Control Program (RNTCP) and availing treatment from the DOTS centers

2. Patients of age more than 18 years.

### Exclusion criteria

The following patients were excluded.

1. Debilitated patients
2. Patients with other comorbid illness including HIV infection, diabetes, and other chronic diseases.

### Sample size

The sample size was calculated using the prevalence of social stigma among TB patients- 60% from the previous study<sup>[9]</sup> and relative precision of 10% using the formula:  $4pq/d^2$ , the sample size arrived was 267. The present study included a sample of 270.

### Sampling technique

There were total of 48 DOTS centers functioning in South East Delhi during the study period. Of these, six DOTS centers were selected on the basis of population proportion to size. Batla House, Garhi, Kotla, Nehru Nagar, Malviya Nagar, and Lajpat Nagar DOTS centers were selected in this study. 45 patients were interviewed at each of these six selected DOTS centers by consecutive sampling method.

### Data collection tool

Semi-structured, pretested questionnaire was used for data collection. The questionnaire consisted of questions related to the basic sociodemographic profile, treatment history, and social and perceived stigma among TB patients attending the DOTS center.

### Data analysis

The data was entered in Microsoft Excel spreadsheet and analyzed using Statistical Package for Social Sciences (SPSS IBM) version 22.0. Proportions and means were used for describing the data. Normality was assessed before applying for tests of significance. Chi-square test was applied and *P* value of < 0.05 was considered to be significant.

### Ethical considerations

Ethical clearance was obtained from the institutional ethics committee of North DMC Medical College, Delhi (No. IECDR-125/2019). The study participants were explained about the study and after obtaining informed written consent, data was collected. The confidentiality of the information provided was maintained.

## Results

In the present study total of 270 tuberculosis patients from six DOTS centers were studied, the mean age of patients was 31.5 years (SD  $\pm$  11.5) with age ranging from 18 to 77 years. The majority of the patients (56.7%) were in the age group of 18–37 years. Males were more (57.4%) as compared to females (42.6%), and more than half (58.9%) of patients

were married while only (1.1%) were divorcees. About three-fourth (73.3%) of the patients belonged to the nuclear family. The majority (82.9%) of patients were Hindus followed by Muslims (14.1%). Almost half (51.1%) of the patients belonged to the lower class of socioeconomic status. Mean (SD) of total family income per month (INR) was 12,860 ( $\pm$  14994) ranging from 1000 to 100,000 INR. Mean (SD) of per capita (INR) income was 270 ( $\pm$  2929) with a range of 100 to 20,000 Indian rupees [Table 1].

Among the 270 patients, about three fourth (73.3%) of them were in new while 71 (26.3) were previously treated patients. The majority (74.4%) of them had pulmonary TB while one fourth (25.6%) had extrapulmonary TB. About twothird (64.8%) of patients were in the intensive phase of treatment [Table 2].

Among 270 patients, nearly half (45.5%) of them had fear of disclosing the disease to their friends and family while about one third (31.5%) of patients had never disclosed their disease to friends. More than half (58.2%) of patients had feared to disclose their condition at the workplace [Table 3].

**Table 1: Distribution of patients according to sociodemographic profile (n=270)**

Variable	Category	Number (%)
Age group	18-37 years	153 (56.7)
	38-57 years	94 (34.8)
	58-77 years	23 (8.5)
Marital Status	Married	159 (58.9)
	Unmarried	108 (40.0)
	Divorced	3 (1.1)
Family Type	Nuclear	198 (73.3)
	Joint	72 (26.7)
Gender	Male	155 (57.4)
	Female	115 (42.6)
Religion	Hindu	224 (82.9)
	Islam	38 (14.1)
	Buddhist	5 (1.9)
	Sikh	2 (0.7)
	Jain	1 (0.4)
Socioeconomic class*	Upper	12 (4.4)
	Upper middle	39 (14.4)
	Lower middle	81 (30.0)
	Upper lower	122 (45.2)
	Lower	16 (5.9)

\*Revised Kuppuswamy scale 2019.<sup>[10]</sup>

**Table 2: Distribution of patients according to treatment details (n=270)**

Variable	Category	No. (%)
Type of patient	New	199 (73.7)
	Previously treated	71 (26.3)
Type of TB	Pulmonary TB	201 (74.4)
	Extra Pulmonary TB	69 (25.6)
Phase of treatment	Intensive phase	175 (64.8)
	Continuation phase	95 (35.2)

Out of 270 TB patients, nearly half (45.5%) of them perceived stigma with family/friends. Among 158 TB patients who were working, more than half (58.2%) perceived stigma at workplace. Further bivariate analysis showed that <30 years of age, males faced more stigma at workplace and lower socioeconomic class faced higher stigma with family and friends. These were statistically significant ( $P$ -value < 0.05) [Table 4].

## Discussion

In the present study, the basic sociodemographic profile was comparable with other studies as discussed below. The mean age of patients was 31.5 years (SD  $\pm$  11.5), which is comparable to other studies- Anand T *et al.*<sup>[11]</sup> in Delhi- 30.51 years (SD  $\pm$  11.3). The majority (56.7%) of patients in our study were in the age group of 18–37 years is similar to study by Duko B *et al.* in Ethiopia.<sup>[12]</sup> Males were more (57.4%) compared to females (42.6%) in our study. Similar results were found in a study conducted by Dhingra VK *et al.*<sup>[9]</sup> in Delhi, Rajeswari R *et al.*<sup>[13]</sup> in Tamil Nadu, and by Qiu L *et al.*<sup>[14]</sup> in China. Likewise, family type, marital status, categories of TB treatment, and phases of treatment were similar to previous studies.<sup>[9,13-16]</sup>

In the present study, nearly half (45.5%) perceived stigma with family/friends and more than half (58.2%) perceived stigma at workplace. In a study conducted in southern Thailand by Rie AV *et al.*<sup>[17]</sup> reported that 63.3% of the TB patients had experienced stigma. In the present study, almost half (45.5%) of patients had fear of disclosing the disease to their friends while about one third (31.5%) of patients had never disclosed their disease to friends. Similar findings were reported by Atre SR *et al.*<sup>[15]</sup> that 75% wanted to hide about their disease from others. Dhingra VK *et al.*<sup>[9]</sup> found that more than half (60.0%) of patients didn't want to disclose their disease to others. In another similar study conducted by Rajeswari R *et al.*<sup>[13]</sup> in Tamil Nadu, it was found that almost half (43.2%) of patients didn't want to disclose their disease and they gave dummy names and addresses to avoid being known and exposed to their acquaintances. In a qualitative study by Craig GM *et al.*<sup>[18]</sup> in the UK also found that most participants hid their disease condition and TB medications from relatives in order to avoid eviction and rejection by Somali community. More than half (58.2%) of the patients feared to disclose their condition at their workplace. In the other study, many men felt inhibited from disclosing the diagnosis to friends (43%) and nevertheless to their spouse (16%).

In our study, among those who disclosed, only (10.3%) of them had faced avoidance by their friends due to the disease while in the study by Aryal S *et al.*<sup>[16]</sup> almost half (43.3%) had faced avoidance by friends. The study participants expressed that if neighbors, colleagues, or others in the workplace know about the disease status they might avoid them. These concerns were also expressed by TB patients of a study by Lifeooghe R *et al.*<sup>[19]</sup> in which neighbors and friends attitude towards them was negative and tried to avoid mingling with them. Similarly, in a qualitative study done by Yellapa V *et al.*<sup>[20]</sup> among TB patients in south India

reported that most participants had a tendency to hide the disease status from relatives or neighbors.

In our study, males faced more stigma at workplace compared to females ( $P$ -value < 0.05). This was in contrast with the previous studies where females faced higher stigma. Dhingra VK *et al.*<sup>[9]</sup>,

Weiss MG *et al.*<sup>[21]</sup>, and Balasubramanian R *et al.*<sup>[22]</sup> reported that females were more stigmatized compared to males. This is because the majority of females in our study were homemakers and 33% were working females. Again unmarried/single males worried more than females and expressed issues related to prospects of marriage. This was similar to previous studies, Jaggarajamma *et al.*<sup>[23]</sup> reported that 63% expressed such concerns and 19.67% in the study by Padmanabhan N *et al.*<sup>[24]</sup> However, a study by Weiss MG *et al.*<sup>[21]</sup> reported that such concerns were higher in females. These differences could be due to local cultural practices and social situations related to marriage. Our findings were also supported by a systematic review done by Kane JC *et al.*<sup>[25]</sup>, which reported that TB-related stigma can impact employment, education, and the marriage prospects of TB patients.

At the workplace, there was a decrease in stigma with an increase in education status, family income, and socioeconomic status.

**Table 3: Distribution of patients according to disclosing the condition at workplace and with friends/family**

Variable	Category	No.(%)
Fear of disclosing disease to friends/family (n=270)	Yes	123 (45.6)
	No	147 (54.4)
Disclosed their disease to friends/family (n=270)	Yes	185 (68.5)
	No	85 (31.5)
Had fear to disclose at their workplace (n=158)	Yes	92 (58.2)
	No	66 (41.8)
Disclosed at their workplace (n=158)	Yes	100 (63.3)
	No	58 (36.7)

**Table 4: Association between perceived stigma and selected variables (n=270)**

Variables	Stigma perceived with friends/family (n=270)			P*	Stigma perceived at work place (n=158)			P*	
	Yes No. (%)	No No. (%)	Total No. (%)		Yes No. (%)	No No. (%)	Total No. (%)		
Age group	< 30 yrs.	69 (45.1)	84 (54.9)	153(100)	0.86	52 (66.7)	26 (33.3)	78 (100)	<b>0.034</b>
	> 30 yrs.	54 (46.2)	63 (53.8)	117 (100)		40 (50.0)	40 (50.0)	80 (100)	
Sex	Male	72 (46.4)	83 (53.6)	155 (100)	0.73	64 (53.3)	56 (46.7)	120 (100)	<b>0.027</b>
	Female	51 (44.3)	64 (55.7)	115 (100)		28 (73.7)	10 (26.3)	38 (100)	
Religion	Hindu	105 (46.8)	119 (53.1)	224 (100)	0.33	79 (59.4)	54 (40.6)	133 (100)	0.49
	Others	18 (39.1)	28 (60.9)	46 (100)		13 (52.0)	12 (48.0)	25 (100)	
Family type	Nuclear	88 (44.4)	110 (55.6)	198 (100)	0.54	63 (55.7)	50 (44.3)	113 (100)	0.31
	Joint	35 (48.6)	37 (51.4)	72 (100)		29 (64.4)	16 (35.6)	45 (100)	
Education	Illiterate	38 (44.7)	47 (55.3)	85 (100)	0.84	31 (59.6)	21 (40.4)	52 (100)	0.80
	Literate	85 (45.9)	100 (54.1)	185 (100)		61 (57.5)	45 (42.5)	106 (100)	
SES	Upper	29 (56.9)	22 (43.1)	51 (100)	0.01	21 (70.0)	9 (30.0)	30 (100)	<b>0.14</b>
	Middle	26 (32.1)	55 (67.9)	81 (100)		23 (47.9)	25 (52.1)	48 (100)	
	Lower	68 (49.3)	70 (50.7)	138 (100)		48 (60.0)	32 (40.0)	80 (100)	
Monthly Family income	≤ 5000	21 (42.9)	28 (57.1)	49 (100)	0.91	11 (42.3)	15 (57.7)	26 (100)	<b>0.19</b>
	5001-10000	56 (46.3)	65 (53.7)	121 (100)		43 (62.3)	26 (37.7)	69 (100)	
	> 1000	46 (46.0)	54 (54.0)	100 (100)		38 (60.3)	25 (39.7)	63 (100)	
Marital status	Married	75 (47.2)	84 (52.8)	159 (100)	0.52	53 (53.5)	46 (46.5)	99 (100)	<b>0.12</b>
	Single#	48 (43.2)	63 (56.8)	111 (100)		39 (66.1)	20 (33.9)	59 (100)	
Family members	< 6	83 (49.1)	86 (50.9)	169 (100)	<b>0.12</b>	58 (58.6)	41 (41.4)	99 (100)	0.90
	≥ 6	40 (39.6)	61 (60.4)	101 (100)		34 (57.6)	25 (42.4)	59 (100)	
Type of TB	Pulmonary	95 (47.3)	106 (52.7)	201 (100)	0.33	79 (61.2)	50 (38.8)	129 (100)	<b>0.10</b>
	Extra Pulmonary	28 (40.6)	41 (59.4)	69 (100)		13 (44.8)	16 (55.2)	29 (100)	
	Family H/O TB	Present	29 (43.9)	37 (56.1)		66 (100)	0.76	22 (56.4)	
Absent	94 (46.1)	110 (53.9)	204 (100)	70 (58.8)	49 (41.2)	119 (100)			

# unmarried, divorcee, separated, widowed/widower.\* Fisher exact test, Chi square test applied, P value<0.05 is significant

Lower socioeconomic class faced higher stigma with family and friends ( $P$ -value < 0.05). In another study conducted by Duko B *et al.*<sup>[12]</sup> in Ethiopia, similar results were found that perceived stigma decreases with an increase in education and job status. A systematic review on tuberculosis stigma also reported that ethnic status and socioeconomic status play an important role in stigmatization.<sup>[26]</sup> Avoidance by friends was experienced more in subjects belonging to low socioeconomic class. Similar results were found in a study conducted by Aryal S *et al.*<sup>[16]</sup> in which stigma was more in patients who were illiterate and with low family income ( $P$  < 0.05). Datiko DG *et al.*<sup>[27]</sup> in their study done in Ethiopia also revealed that higher education level and income level were associated with low TB-related stigma. Thus, literacy plays a crucial role in understanding the disease prospects, which is proven by study findings.

A patient-centered care approach was found to be an essential element in tackling tuberculosis. In order to provide patient-centered care, addressing stigma should start from the beginning of diagnosis, and the role of primary care physician is crucial.<sup>[2]</sup> Identification of stigma and addressing the stigma for better compliance in drug treatment, thereby improves the treatment outcome and also prevents further transmission of disease.

The strength of the present study is that stigma perceived with family/friends and at the workplace was studied, and its association with demographic profile was determined. Around forty-five percent of study participants perceived stigma with family/friends and participants belonging to a lower socioeconomic class faced higher stigma. Fifty-eight percent of study participants perceived stigma at workplace and younger patients (<30 years) and males were higher among them.

## Conclusion

In this study, perceived stigma found to be high with family/friends (45.5%) and at workplace (58.2%). More than half of TB patients feared disclosing their disease status at the workplace. TB patients faced avoidance by friends and family due to their disease. Young patients (<30 years), males faced higher stigma at workplace. At workplace, stigma was decreasing as education, income, and the socioeconomic class were increasing. Lower socioeconomic class faced more stigma with family and friends. It is clearly evident that there is still higher stigmatization faced by patients with TB at family/friends and at the workplace. Support to TB patients from family, friends, and at workplace may facilitate successful treatment outcomes. Active planning such as sensitization of family, community awareness about the disease, and emotional support by family/friends to TB patients are deemed necessary for reducing stigma against TB.

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## Conflicts of interest

There are no conflicts of interest.

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