

Perceived Discrimination among Tuberculosis Patients in an Urban Area of Kolkata City, India

Sitikantha Banerjee, Kajari Bandyopadhyay, Pranita Taraphdar¹, Aparajita Dasgupta²

Department of Community Medicine, All India Institute of Medical Sciences, Nagpur, Maharashtra, ¹Department of Community Medicine, NRS Medical College, ²Department of Preventive and Social Medicine, All India Institute of Hygiene and Public Health, Kolkata, West Bengal, India

Abstract

Context and Aims: Tuberculosis (TB) in India is a leading public health problem plagued by social determinants such as stigma and discrimination, which may affect treatment seeking, adherence, and possibly treatment outcome. This study was conducted to elicit the perceived discrimination, its determinants, as well as to determine whether perceived discrimination is predicting treatment outcome among TB patients registered in an Urban Health District, Kolkata City, India. **Settings and Design:** An institutionbased follow-up study was conducted where all the TB patients registered within the 1st 4 months of data collection were followed up for their current course of treatment. **Subjects and Methods:** Perceived discrimination was assessed at treatment initiation, after intensive period and after continuation phase using a predesigned and pretested questionnaire. **Statistical Analysis Used:** Multivariable logistic regression analyses were performed to identify the determinants of perceived discrimination as well as the treatment outcome. **Results:** Perceived discrimination by family members, neighbors, and colleagues was reported by 9.4%, 36.5%, and 34.2% participants, respectively, overall discrimination being 37.9%. Multivariable analysis revealed that discrimination was significantly more among patients with older age group, females, and from joint families. Perceived discriminated was found to be significantly predicting unfavorable treatment outcome even after adjustment with background and treatment-related variables. **Conclusions:** Sensitization programs should incorporate measures to address stigma and discrimination and more emphasis needs to be placed on women and elderly patients.

Keywords: Discrimination, treatment outcome, tuberculosis

INTRODUCTION

Discrimination is considered as the major social determinant in tuberculosis (TB) patients.^[1] Stigma is an attitude of disapproval toward a specific person by an individual or group, and discrimination is the behavior because of it.^[2] Discrimination occurs when people with stigmatizing attitudes deny others of their rights and life opportunities by marginalizing them.^[3,4] Affected individual lives in a state of poor mental and social health,^[2,5,6] hindering him from seeking treatment or from being adhered to the treatment regime,^[5,7] thereby possibly affecting treatment outcome.

India homes one fourth of the global burden (2.7 million out of 10 million new cases annually).^[8] The ongoing TB control programme (Revised National Tuberculosis Control Programme [RNTCP]) is in the process of constant innovation.^[9] In RNTCP treatment outcome is considered as the key prognostic indicator.^[9] In recent years, India is

progressing toward achieving global milestones and pacing towards 'End-TB' by 2030.^[10] In this regards, it was felt that one of the compelling strategies would be addressing social determinants,^[10,11] among which stigma and discrimination would be on the top of the list. Moreover, as discrimination is context specific, being inextricably linked to an individual's social positioning,^[12] understanding its socio-demographic determinants to plan specific intervention is also necessary to guide the programme managers to incorporate the measures for alleviating stigma and discrimination.

Address for correspondence: Dr. Kajari Bandyopadhyay,

Department of Community Medicine, All India Institute of Medical Sciences,
Plot No. 2, Sector-20, MIHAN, Nagpur - 441 108, Maharashtra, India.
E-mail: dr.kajari@gmail.com

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With this background, this study aimed to elicit the perceived discrimination among TB patients registered in an Urban Health District (UHD), Kolkata, its sociodemographic determinants and to find out whether perceived discrimination is predicting treatment outcome among the study participants

SUBJECTS AND METHODS

Study settings and design

An institution-based follow-up study was conducted in all the 10 DOTS centers under Bagbazar UHD, Kolkata, India. Kolkata city is divided into ten UHDS, which are the operational units for implementing RNTCP. DOTS centers are the facilities to provide directly observed short course DOTS treatment to TB patients.^[13] This follow-up study continued for a period of 2 years. The study participants were adult (≥ 18 years) “New” (Cat-1) and “Previously treated” (Cat-2) TB patients registered in the DOTS centers and started DOTS between May 2015 and August 2015. Multidrug Resistant (MDR), Extensively Drug-Resistant (XDR) TB patients and unwilling patients were excluded. A total of 140 patients were included in the study using complete enumeration. This cohort was followed up until the completion their current course of DOTS.

Data sources and measurements

Pretested structured schedule in local languages were used for collecting the data by face-to face interview. A pilot survey on 20 similar patients in a different UHD was conducted a-priori, to identify the discrimination-related items experienced most frequently by them. After discussing, the result of pilot study with institutional experts and after intensive literature search, it was decided to adapt the discrimination assessment scale used by Chowdhury MR *et al.* at Rajshahi Bangladesh.^[7] Perceived discrimination was elicited in the context of family, neighborhood, and workplace.^[7] Disclosure of disease status and perceived discrimination was measured using six close-ended questions representing the three domains family, neighbourhood, and workplace. Later on, it was converted to a single variable with binary response.

Data collection

Participants were recruited within 14 days of start of treatment at the DOTS centers or by home-visits for nonambulatory patients. 1st and 2nd follow-ups were carried out within 14 days of completion of IP and CP, respectively. Questions in relation to perceived discrimination were asked in all the three visits. If Failure/MDR is diagnosed before the completion of current treatment, follow-up was carried out within 14 days of start of next regimen. Definitions mentioned in RNTCP guideline^[9] were followed for treatment and outcome categories.

Statistical methods

Data were analyzed using the SPSS software, version 19.0 (Statistical Package for the Social Sciences Inc, Chicago, IL, USA). Proportion of patients who experienced discrimination in different context was expressed in number and percentage. A logistic regression model was generated

Table 1: Background information of the study population (n=140)

Parameters	Total, n (%)
Age (years)	
Mean (SD), range	34.04 (14.28), 18-80
Sex	
Male	71 (50.7)
Female	69 (49.3)
Marital status	
Never married	60 (42.9)
Currently married	65 (46.4)
Widowed	12 (8.6)
Separated	3 (2.1)
Religion	
Hindu	59 (42.1)
Muslim	81 (57.9)
Educational status	
Illiterate	31 (22.1)
Non-formal education	5 (3.6)
Below primary	24 (17.1)
Primary	37 (26.4)
Middle	20 (14.3)
Secondary and above	23 (16.4)
Occupation	
Unemployed	8 (5.7)
Homemaker	43 (30.7)
Student	23 (16.4)
Manual laborer	46 (32.9)
Businessman	9 (6.4)
Service (Government/private)	11 (7.9)
Type of family	
Nuclear	71 (50.7)
Joint	69 (49.3)
Socioeconomic status (Modified BG Prasad's classification 2015)	
Class-I	4 (2.9)
Class-II	39 (27.9)
Class-III	49 (35)
Class-IV	47 (33.6)
Class-V	1 (0.7)
Use of smoking tobacco	
Yes	44 (31.4)
HIV co-infection	
Yes	6 (4.3)

SD: Standard deviation

Table 2: Distribution of study participants according to disclosure and perceived discrimination

Context	Disclosure of disease status, n ^a (%)	Perceived discrimination, n ^b (%)
Family members (n=140)	138 (98.5)	13 (9.4)
Neighbors (n=140)	93 (66.4)	34 (36.5)
At place of work (among employed) (n=66)	41 (62.1)	14 (34.2)
Overall discrimination (n=140)		53 (37.9)

b is the percentage of a

considering sociodemographic factors as independent variables and perceived discrimination (yes/no) as outcome variable. Another regression model was built to find out the association of unfavorable treatment outcome with perceived discrimination in the presence of sociodemographic behavioral and treatment-related confounders. In both the model, variables already found significant in bivariate analysis were entered into a multivariable logistic regression model (binary logistic) by “Forced Entry” method.

Ethical issues

Ethical clearance for the dissertation was obtained from the Institute Ethics Committee of the concerned institution. Informed written consent was obtained from the study participants before starting data collection and confidentiality was maintained. At the end of each interview, participants and their relatives were taught about myths and facts about TB, the need of social support, and importance of compliance with treatment. Details of methodology have been described elsewhere.^[14]

RESULTS

All the participants ($n = 140$) who were included in the study could be followed up. Sociodemographic characteristics of the study participants are described in Table 1. Most of the male participants were manual laborer (53.4%) and female were homemakers (62.4%). Clinical profile revealed that more than two-third (96 [68.6%]) were New (Cat-I), and remaining were previously treated. Pulmonary TB patients exceeded extrapulmonary (85 [60.7%] vs. 55 [39.3%]).

Among the study participants, 98.5%, 66.4%, and 62.1% patients disclosed their disease status to family, neighbors, and at workplace, respectively. Perceived discrimination by family members, neighbors, and colleagues were reported by 9.4%, 36.5%, and 34.2% participants, respectively, overall discrimination being 37.9% [Table 2]. In bivariate analysis, discrimination was found to be significantly more among patients with >30 years age group, females, from joint families, illiterate, and divorced/separated compared to their corresponding categories. When adjusted with other variables, age (Adjusted Odds Ratio [AOR] confidence interval [CI] = 7.12 [2.13–16.5]), sex (AOR [CI] = 5.85 [2.1–16.53]), and family type (AOR [CI] = 3.2 [1.4–7.6]) remained significant predictors of perceived discrimination [Table 3].

Among participants, 29 (20.7%) had unfavorable treatment outcome. Category-wise distribution of treatment outcome is described in Table 4. In another multivariable analysis, perceived discrimination was found to be the predictor of unfavorable treatment outcome (AOR [95% CI] = 2.61 [1.04–7.84]) after adjusting with selected confounders. Unfavorable treatment outcome was also found to be significantly higher among males compared to female joint family compared to nuclear one and among Cat-II patients compared to Cat-I [Table 5].

Table 3: Predictors of discrimination among tuberculosis patients: multivariable logistic regression analysis ($n = 140$)

Factors	OR (CI)	AOR (CI)
Age (years)		
≤30	1	1
>30	2.9 (1.4-5.9)*	7.12 (2.13-16.5)*
Sex		
Male	1	1
Female	2.05 (1.03-4.13)*	5.85 (2.1-16.53)*
Type of family		
Nuclear	1	1
Joint	2.6 (1.3-5.4)*	3.2 (1.4-7.6)*
Marital status		
Unmarried	1	1
Currently married	1.95 (0.92-4.1)	0.88 (0.3-2.5)
Divorced/separated	5.5 (1.6-18.5)*	1.12 (0.21-5.89)
Educational status		
Literate	1	1
Illiterate	3.5 (1.5-7.9)*	3.02 (0.96-7.47)

* $P < 0.05$ was considered as statistically significant, Omnibus χ^2 statistic = ($\chi^2 = 62.45$, $P < 0.01$), Hosmer-Lemeshow statistic: $P = 0.19$, Nagelkerke $R^2 = 0.38$. CI: Confidence interval, OR: Odds ratio, AOR: Adjusted odds ratio

DISCUSSION

The findings of this study have sounded alarm bells with respect to the high burden (37.9%) of discrimination among TB patients. Discrimination was found to be ranging from 30.7% to 85.9% in different studies conducted in India and other South-East Asian countries.^[6,7,15] Neglect by family members, neighbors, and work place was found to be 15.4%, 45.9%, and 61.9% in a similar study, the figures being worse to that of our study (9.4%, 36.5%, and 34.2%, respectively).^[7]

The results of the present study indicated that discrimination was significantly more among women, patients aged >30 years, belonging to joint family, divorced/separated, and illiterate compared to their counterparts. In a systematic review, Courtwright and Turner found that it was experienced more strongly by women and people with lower education levels, which is also in line with this study.^[12] A number of studies also demonstrated the association of discrimination with older age^[6,7,16] and marital status^[16] and low educational qualification.^[6,16] and female sex.^[7] Some studies reported TB-related discrimination to be significantly higher among patients with pulmonary TB compared to extrapulmonary substance users and those with HIV coinfection.^[4,17] In this study, no such association was observed.

Courtwright Turner^[12] also observed that discrimination contributes to delays in TB diagnosis and negatively impacts treatment compliance and deteriorating quality of life, all of which can adversely affect the treatment outcome.^[14,18] In this study also, perceived discrimination was found to be a major threat to treatment success. Stigma/discrimination was found to be linked with poor treatment compliance in some previous

Table 4: Distribution of study population according to treatment outcome among different types and categories of Tuberculosis patients (n=140)

Outcome	n (%)				
	New (n=96)	Previously treated (n=44)	Pulmonary (n=85)	Extra-pulmonary (n=55)	Total (n=140)
Favorable outcome					
Cured	32 (33.3)	19 (43.2)	50 (58.8)	NA	50 (37.5)
Treatment completed	52 (54.2)	8 (18.2)	11 (12.9)	50 (90.9)	61 (43.6)
Unfavorable outcome					
Defaulted	2 (2.1)	Nil	2 (2.4)	Nil	2 (2.1)
Failure converted to MDR	2 (2.1)	9 (20.5)	10 (11.8)	1 (1.8)	11 (7.9)
Failure-not converted to MDR	7 (7.3)	5 (11.4)	10 (11.8)	2 (3.6)	12 (8.6)
Died	1 (1.0)	3 (6.8)	2 (2.4)	2 (3.6)	4 (2.9)
Total favorable outcome	84 (87.5)	27 (61.4)	61 (71.8)	50 (90.9)	111 (79.3)
Total unfavorable outcome	12 (12.5)	17 (38.6)	24 (28.2)	5 (9.1)	29 (20.7)

MDR: Multidrug resistant

Table 5: Association of unfavorable treatment outcome with perceived discrimination: bivariate and multivariable analysis (n=140)

Characteristics	Total number of patients	Unfavorable outcome (%)	OR (95% CI)	AOR (95% CI)
Sex				
Female	69	9 (13)	1	1
Male	71	20 (28.2)	2.6 (1.1-6.2)*	3.07 (1.11-8.52)*
Educational status				
Literate	109	18 (16.5)	1	1
Illiterate	31	11 (35.5)	2.78 (1.14-6.78)*	1.19 (0.36-3.9)
Type of family				
Nuclear	71	9 (12.7)	1	1
Joint	69	20 (29.0)	2.8 (1.2-6.7)*	4.71 (1.66-13.39)*
Smoking tobacco use				
Never smoker	96	15 (15.6)	1	1
Eversmoker	44	14 (31.8)	2.5 (1.2-5.8)*	1.5 (0.3-6.9)
Type of disease				
Extrapulmonary	55	5 (9.1)	1	1
Pulmonary	85	24 (28.2)	3.9 (1.4-11)*	1.9 (0.52-6.9)
Category of disease				
Category - I	96	12 (12.5)	1	1
Category - II	44	17 (38.6)	3.6 (1.5-8.5)*	3.39 (1.23-9.34)*
Perceived discrimination				
No	87	13	1	1
Yes	53	16	2.26 (1.09-5.65)	2.61 (1.04-7.84)*

[#]Engaged in gainful occupation (Business, Service, and Manual laborer, etc.), [§]Modified BG Prasad's classification 2016,^[22] Nagelkerke $R^2=0.29$, *Statistical significance at 95% CI ($P<0.05$ was considered as statistically significant). CI: Confidence interval, OR: Odds ratio, AOR: Adjusted odds ratio

studies,^[12,19] which could not be elicited here, as defaulter rate was very low.^[2] The main strength of the study was its longitudinal design and assessment of perceived discrimination at different time points. It is evident from existing literature that preferred approach to assess stigma/discrimination among TB patients is a prospective study,^[5] as patients can face discriminating attitude at any time point during the treatment. Research conducted in this field till date is predominately cross-sectional.^[2,4,6,7]

The result of this study should be interpreted with limited generalizability. Some other potential confounders of unfavorable treatment outcome, such as quality of life, mental health status of patients, etc.^[14,20,21] were not taken into account in this study. These factors could be considered in future studies to enrich the current findings. Qualitative exploration on other possible domains of discrimination could bring more insight into this important public health problem.

CONCLUSION

Discrimination persists among people due to misconceptions and lack of awareness. Collaborative efforts by government, nongovernment, social, cultural, and religious institutions are essential in strengthening the efforts against the social stigma and discrimination. Community awareness should be increased by media campaigning. Women faced significantly more discrimination than males, which emphasizes the need to develop special support groups in the community for women TB patients. Attempts should also be made to minimize workplace discrimination in various organizations through interpersonal communication and legislative measures.

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Conflict of Interest

There are no conflicts of interest.

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