

## Research Article

# Cultural disgrace among tuberculosis patients in Sagar district of Madhya Pradesh in India

Talha Saad<sup>1\*</sup>, Abhay Shashin Tirkey<sup>2</sup>, Wahid Khan<sup>3</sup>

<sup>1</sup>Department of Tuberculosis and Chest Diseases, Bundelkhand Government Medical College, Sagar, Madhya Pradesh, India

<sup>2</sup>Department of General Medicine, Bundelkhand Government Medical College, Sagar, Madhya Pradesh, India

<sup>3</sup>Dept of Internal Medicine, Royal Court Affairs Hospital, Muscat, Oman

**Received:** 18 December 2015

**Accepted:** 06 January 2016

### \*Correspondence:

Dr. Talha Saad,

E-mail: [dr.talhasaad@gmail.com](mailto:dr.talhasaad@gmail.com)

**Copyright:** © the author(s), publisher and licensee Medip Academy. This is an open-access article distributed under the terms of the Creative Commons Attribution Non-Commercial License, which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original work is properly cited.

## ABSTRACT

**Background:** The overall objective of the research study was to gather new empirical evidence and develop further theoretical understanding of the mechanisms of stigma associated with TB and delay in seeking its treatment.

**Methods:** This prospective study was carried out in the outpatient of Pulmonary Medicine at Bundelkhand Government Medical College, Sagar. The sample consisted of 300 tuberculosis patients. Between patients who consider TB a stigmatizing disease and patients who did not consider TB a stigmatizing disease distribution of patient delay was compared.

**Results:** Of the total of 300 patients 79 (26.3%) considered TB a socially stigmatizing disease. Among them 43 (54.4%) were females and 36 (45.6%) males. Among patients in the age group 18-24 years, nine (50%) considered TB a socially stigmatizing disease compared to seven (12.3%) among patients in the age group 65-75 years. The average time interval from the appearance of first symptoms of tuberculosis until the first visit to a health care facility for those who consider TB a stigmatizing disease was 6.41 weeks and for those who did not consider it a stigmatizing disease the average time interval was 4.99 weeks.

**Conclusions:** Most TB patients failed to recognize their symptoms as due to TB, because of the stigma attached to the disease in society. The way people treat those with TB, especially close contacts is also a source of worry to the patients. This may lead to delay in reporting to the hospital and consequently increase mortality from the disease. It may also make it difficult for the patients to comply with the long duration of TB treatment. Study results revealed high stigma-generating attitudes towards tuberculosis.

**Keywords:** Community norms, Tuberculosis, Health-seeking behaviour, Tuberculosis stigma

## INTRODUCTION

Tuberculosis (TB) is one of India's most important public health problems. India accounts for nearly one fifth of the global TB burden. Every day in India more than 20,000 people develop the disease, and more than 1000 die from TB.<sup>1</sup> TB is a classical example of a disease with both medical and social dimensions, characterized by its close relation to poor socio-economic conditions.<sup>2</sup> Understanding the origins of TB stigma is integral to reducing its impact on health. Using surveys, focus

groups, and unstructured and focused interviews, a number of studies have explored the causes of TB stigma.<sup>6-8</sup> Although there is geographic and cultural variation in the explanations for why TB is stigmatized, most authors identify the perceived risk of transmission from TB-infected individuals to susceptible community members as a leading cause of stigmatization.<sup>9-12</sup> Tuberculosis is also stigmatized because it is closely associated with HIV, poverty, low social class, malnutrition, or disreputable behaviour.<sup>13</sup> The stigma attached to TB adds to the burden of disease for both men

and women, and even more so if they are of marriageable age.

While men have to deal with the stigma at their work place and at the community level, women are faced with ostracism within the household and in the immediate neighbourhood.

We know that TB-related stigma exists, we know little about the forms it takes, why it exists or what can be done about it. The purpose of this study is to deepen our understanding of TB-related stigma. Few previous studies have set out to explore the causes or mechanisms of TB-related stigma and those that have tended to identify correlations of TB-related stigma and inferred causality, with insufficient evidence for a causal association. This can lead to inappropriate stigma-reduction interventions being developed which at best do not work and at worst may even increase stigma. For example, both TB-related stigma and a misconception regarding TB may prevail in a community, but this does not necessarily mean that the misconception is the cause of TB-related stigma. If it were then in a community all those with TB would experience stigma in exactly the same way, all the time. This clearly is not the case and indeed research on various stigmatized conditions has shown a wide variation in people's experiences of stigma according to gender, marital status and individual circumstances.<sup>1-4</sup>

## METHODS

A prospective study was conducted in the period 2011-2012. Adults ( $\geq 18$  years) with diagnosed TB were enrolled from the patients attending the outpatient department of Pulmonary Medicine at tertiary care hospital in central India. The study was approved by the Ethics Committee of the Medical College.

All these patients were subjected to personal detailed interview according to a pre-designed semi-structured questionnaire after taking informed consent of the patients. The questionnaire contained various questions formed to elicit requisite information about the knowledge of tuberculosis action taken by the patients, their experience at work place and their family response. Before conducting the study, the Performa was pre-tested and evaluated for proper conduct of the study. The investigators had taken special interest and supervision during these interviews. The interviews were conducted in the intensive phase of treatment. The information was elicited from TB patients regarding 'problems faced in their homes, attitudes of neighbours, friends and co-workers.

Interview included questions regarding data on socioeconomic and awareness of TB and the nature of their disclosure of their disease to family members, relatives, neighbours, friends and employers. The information was also elicited regarding behavioural

changes with family members neighbours, friends and other fellow employees.

A case of sputum smear positive pulmonary tuberculosis involves a patient with at least two initial positive sputum smears, or one sputum smear positive plus radio-graphic abnormalities consistent with active pulmonary tuberculosis as determined by a clinician; or one sputum specimen positive plus culture specimen positive for *Mycobacterium tuberculosis*. A sputum smear negative pulmonary tuberculosis case was defined as a patient diagnosed with pulmonary tuberculosis by a clinician, who did not meet the above criteria for smear-positive disease.

Social-stigma (social consequences of a person with tuberculosis) refers to consequences of patients' discrimination by society and other people's antagonistic practices or attitudes.

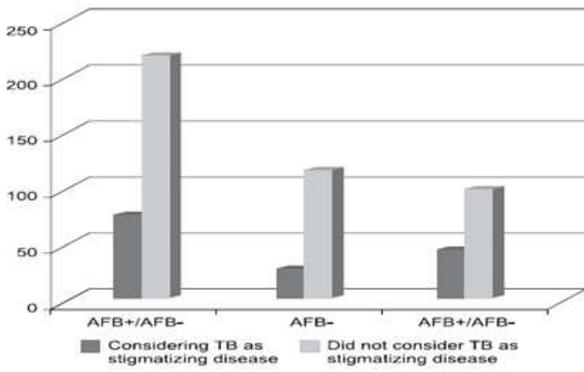
Patient delay, defined as the period (in weeks) from onset of the first symptom(s) possibly related to pulmonary TB to the date when the patient first contacted qualified primary health care services as a result of the symptoms, was the focus of interest. Patients were asked to recall the duration of their symptoms and when they first visited a doctor. Delay was calculated as the time between these two points.

The chi-square test was applied to analyse the categorical variables. Statistical significance was considered when  $p < 0.05$ . The standard deviation (SD) and 95% confidence intervals (CI) were calculated. The correlation among individual perception of TB such as social stigmatization of the disease and patient delay was calculated with the display of the relevant probabilities that were obtained based on a Sig. 2-tailed test.

## RESULTS

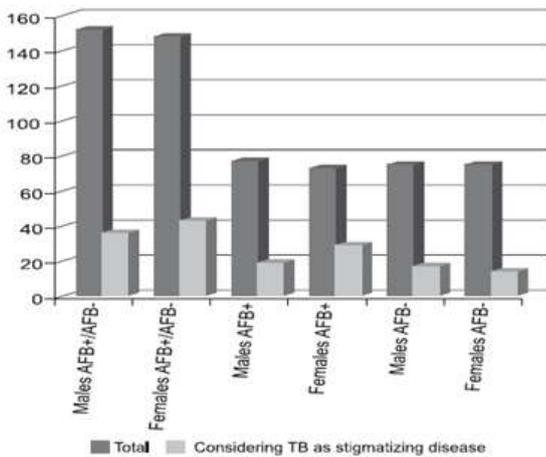
A total of 300 tuberculosis patients were included in the study. Among them 150 (50%) had sputum smear positive for pulmonary tuberculosis and in 150 (50%) it was negative. The participants included 152 (50.7%) males and 148 (49.3%) females. The largest number of participants, 57 (19%) was between 65 and 75 years of age, followed by persons in the age group 55-64 years, 52 (17.3%) and  $>75$  years, 51 (17.0%).

Of the total of 300 AFB-positive /AFB-negative patients 79 (26.3%) considered TB a socially stigmatizing disease (95% CI=0.21-0.32,  $p < 0.05$ ). Among 150 AFB-negative patients 31 (20.7%) (95% CI=0.14-0.28,  $p < 0.05$ ) declared that TB is socially stigmatizing disease. Among 150 AFB positive patients 48 (32%) declared that TB is socially stigmatizing disease (95% CI=0.25-0.40,  $p < 0.05$ ) (Figure 1).



**Figure 1: The perception of tuberculosis as a stigmatizing disease according acid-fast bacillus status.**

Among 152 males and 148 females 36 (23.7%) and 43 (29.1%), respectively, considered TB a socially stigmatizing disease (95% CI=0.17-0.31, and 95% CI=0.22-0.37, respectively). Of 75 AFB-negative males and 75 AFB- females 17 (22.6%) and 14 (18.7%), respectively, considered TB a socially stigmatizing disease (95% CI=0.14- 0.34 and 95% CI=0.11-0.29). Of 75 AFB-negative females 14 (18.7%) considered TB a socially stigmatizing disease (95% CI=0.11-0.29). Of 77 AFB-positive males and 73 AFB-positive females, 19 (24.7%) and 29 (39.7%) respectively, considered TB a socially stigmatizing disease (95%CI=0.15-0.36 and 5% CI=0.28-0.52, respectively). Of 73 AFB-positive females, 29 (39.7%) considered TB a socially stigmatizing disease (95% CI=0.28-0.52) (Figure 2).

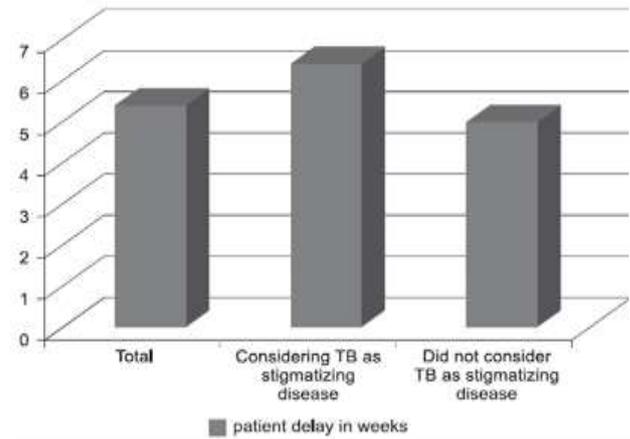


**Figure 2: Distribution of males and females among the patients who consider tuberculosis a stigmatizing disease.**

Of the total of 79 patients, who considered TB as a stigmatizing disease, 48 (60.8%) were AFB positive and 31 (39.2%) AFB-negative. The percentage of patients (AFB-positive/ AFB-negative), who stated that TB is socially stigmatizing disease was higher in younger age groups (18-24 years of age), nine (50%), than in the age group above 75 years, 8 (15.7%); in the age groups 65-75

and 55-64 years there were 7(12.3%) and 14 (26.9%), respectively.

The average time interval from the appearance of the first symptoms of tuberculosis until the first visit health care facility was 5.4 weeks (5.3 weeks by AFB-negative and 5.4 weeks by AFB positive patients). Patients who considered TB a socially stigmatizing disease had a longer delay in seeking care for TB symptoms (6.41 weeks by AFB-positive/AFB negative patients, 6.77 weeks by AFB-negative patients, 6.17 weeks by AFB-positive patients) than the average delay in seeking care for TB symptoms for total number patients and average delay in seeking care for TB symptoms for those who did not consider TB a socially stigmatizing disease (4.99 weeks by AFB-positive/AFB negative patients, 4.97 weeks by AFB-negative patients, 5.02 weeks by AFB-positive patients) (Figure 3).



**Figure 3: The perception of tuberculosis as a stigmatizing disease and status of patient delay.**

**DISCUSSION**

This study investigated the prevalence of perceived TB related stigma and its impact on health seeking behaviors. The results revealed high stigma-generating attitudes towards tuberculosis. In the study the percentage of the patients considering TB as a stigmatizing disease, 26.3%, is far higher than the percentage reported in Croatia (less than 10%)<sup>15</sup>, and it is below that found in Pakistan (48.2%)<sup>16</sup>. Considerable geographic variability exists in the perceived prevalence of TB stigma, with 27% to 80% of individuals at risk reporting that TB is stigmatized in their communities<sup>18-20</sup>. Based on review of the published literature gender was considered as a potential factor associated with TB stigma<sup>21</sup>. In our study the perception of TB as a stigmatizing disease differed by gender and it was greater in females than in males. Numerous studies have shown that females are somewhat more likely to perceive TB as a stigmatizing disease<sup>6,22</sup>. Qualitative studies have reported that TB stigma more adversely affects females than males, primarily because of their sensitivity to social interaction<sup>23</sup>. TB stigma is felt more

strongly in certain subpopulations, including people with lower education levels and higher age.<sup>1,25</sup>

Most of the patients said that they have impaired self-esteem, felt shamed or embarrassed, and have felt less respect from others in the society. One of the patient said he is even treated badly even by his own wife since he couldn't earn money because of the disease. Some of them even told that they are treated very badly at their home by their own family members which have affected much on their self-esteem. Greater number of patients thought disease might cause adverse effect on others even after treatment because the germs may live on their breath forever and got transmitted. Even though other persons didn't verbalize that they don't want to sit nearer to the TB patients but they show through their behavior that they don't want TB patients near them. This was revealed by one of the TB patients.

Few have felt that the other people don't want to come to their home. When asked about what may be the reason they told that most of them have TB patients in their home itself at one of the time. The study showed that if neighbors, colleagues or others in the community know about the disease they might avoid the family. The study conducted by Lifeooghe R revealed that the TB patients perceive their neighbors and friends attitudes towards them as rather negative.<sup>16</sup> TB patients felt they are feared and that contact with them is avoided. This negative attitude persists during the first months of treatment, as neighbors and friends do not seem to be aware that TB is no longer contagious after a few weeks of treatment.<sup>16</sup>

Tuberculosis-related stigma is perceived to increase time intervals from onset of symptoms to seeking care.<sup>26</sup> In population with a relatively short median patient delay in seeking care for TB symptoms the impact of TB stigma translates into a minimal change in delay time. The impact of stigma would likely be greater in population where median delay times in seeking care for TB symptoms are much longer.<sup>27</sup>

In our study the median time interval from onset of symptoms to seeking care was 5.4 weeks. Patients who considered TB as a socially stigmatizing disease had a longer patient delay in seeking care for TB symptoms than those that did not. The association between patients' perception of TB as a socially stigmatizing disease and length of patients delay in seeking care for TB symptoms was statistically significant. The study conducted in Cameroon found that perceived TB stigma was a significant predictor of delays in seeking care for TB symptoms of more than four weeks.<sup>28</sup> Similar results were shown in a study conducted in Afghanistan where a high level of social stigma was an independent explanatory factor for increased risk of patient delay in seeking care for TB symptoms.<sup>29</sup> A multi-country study by the World Health Organization in the eastern Mediterranean region reported that increased stigma was associated with decreased patient delay in seeking care

for TB symptoms in Somalia.<sup>30</sup> Although a great deal of research in public health is based on a trend to increase focus on social determinants of health, including TB-related stigma, there are few studies about this problem conducted in India. More studies in Indian states can be expected in the future.

### **Limitation**

The study was undertaken to examine site-specific socio-cultural and gender-related features of TB at designated treatment sites. Although sample sizes were moderate, they were adequate for gender comparisons within site. Clinical samples were selected to represent the patient population of the well-functioning Medical college hospital at the study site, but it was not intended to represent a profile of TB for the entire country or even the community. Because the studies were based on single Medical College hospital outpatient, the question of how to generalize findings must be considered carefully.

### **CONCLUSIONS**

Owing to the large psychosocial impact of this debilitating disease, the focus should not just be on early detection and symptomatic and microbiological cure but should also be on providing psychosocial support to the patients and their families. Although the importance of research and clinical trials of TB is unquestionable, health education of the masses by community health programs to dispel the myths and stigma surrounding the disease and its treatment cannot be over emphasised in India's progress towards controlling TB – “the captain of all men of death”.

*Funding: No funding sources*

*Conflict of interest: None declared*

*Ethical approval: The study was approved by the Institutional Ethics Committee*

### **REFERENCES**

1. RNTCP status report. Central TB Division, Director General of Health Services, Ministry of Health & Famil Welfare, New Delhi. 2001.
2. Jaggarajamma K, Ramchandran R, Charles N, Chandrasekaran V, Muniuandi M, Ganapathy S. Psycho- social dysfunction: Perceived and enacted stigma among tuberculosis patients registered under RNTCP. *Indian J Tuberc.* 2008;55:179-87.
3. Macq J, Solis A, Martinez G, Martiny P, Dujardin B. An exploration of the social stigma of tuberculosis in five “municipios” of Nicaragua to reflect on local interventions. *Health Policy.* 2005;74:205-17.
4. Joseph HA, Waldman K, Rawls C, Wilce M, Shrestha- Kuwahara R. TB perspectives among a sample of Mexicans in the United States: results from an ethnographic study. *J Immigr Minor Health* 2008;10:177-85.

5. Jaramillo E. Tuberculosis and stigma: predictors against people with tuberculosis. *Health Psychology.* 1999;4:71-9.
6. Dodor EA, Neal K, Kelly S. An exploration of the causes of tuberculosis stigma in an urban district in Ghana. *Int J Tuberc Lung Dis.* 2008;12:1048-54.
7. Gelaw M, Genebo T, Dejene A, Lemma E, Eyo G. Attitude and social consequences of tuberculosis in Addis Ababa, Ethiopia. *East Afr Med J.* 2001;78:382-8.
8. Baral SC, Karki DK, Newell JN. Causes of stigma and discrimination associated with tuberculosis in Nepal: a qualitative study. *BMC Public Health.* 2007;7:211.
9. Sharma N, Malhotra R, Taneja DK, Saha R, Ingle GK. Awareness and perception about tuberculosis in the general population of Delhi. *Asia Pac J Public Health.* 2007;19:10-5.
10. De-Graft Aikins, A. Reframing applied disease stigma research: a multilevel analysis of diabetes stigma in Ghana", *Journal of Community & Applied Social Psychology.* 2006;16,(6):426-41.
11. Khan M, Walley J, Witter S, Shah S, Javeed S. Tuberculosis patient adherence to direct observation: results of a social study in Pakistan. *Health Policy and Planning.* 2005.
12. Liefoghe R, Michiels N, Habib S, Moran MB, De Muynck A. Perception and social consequences of tuberculosis: a focus group study of tuberculosis patients in Sialkot. 1995.
13. Weiss MG, Auer C, Somma DB, Abouihia A. Pakistan. *Social Science & Medicine. Gender and tuberculosis: cross-site analysis and implications of a multi-country study in Bangladesh, India, Malawi and Colombia, WHO.* 3. 2006;41,(12):1685-92.
14. Jurcev-Savicević A. Attitudes towards tuberculosis and sources of tuberculosis-related information: study on patients in outpatient settings in Split, Croatia. *Acts Clin Croat.* 2011;50:37-43.
15. Christodoulou M. The stigma of tuberculosis. *Lancet Infect Dis.* 2011;11:663-4.
16. Joseph HA, Waldman K, Rawls C, Wilce M, Shrestha- Kuwahara R. TB perspectives among a sample of Mexicans in the United States: results from an ethnographic study. *J Immigr Minor Health.* 2008;10:177-85.
17. Qureshi SA, Morkve O, Mustafa T. Patient and health system delays: health-care seeking behaviour among pulmonary tuberculosis patients in Pakistan. *J Pak Med Assoc.* 2008;58:318-21.
18. Mushtaq MU, Shahid U, Abdullah HM, Saeed A, Omer F, Shad MA, et al. Urban-rural inequities in knowledge, attitudes and practices regarding tuberculosis in two districts of Pakistan's Punjab province. *Int J Equity Health.* 2011;10:8
19. Sabawoon W, Sato H, Kobavashi Y. Delay in treatment of pulmonary tuberculosis: a report from Afghanistan. *Environ Health Prev Med.* 2012;17:53-61.
20. Ali SS, Rabbani F, Siddiqui UN, Zaidi AH, Sophie A, Virani SJ, et al. Tuberculosis: do we know enough? A study of patients and their families in an out-patient hospital setting in Karachi, Pakistan. *Int J Tuberc Lung Dis.* 2003;7:1052-8.
21. Karim F, Johansson E, Diwan VK, Kulane A. Community perceptions of tuberculosis. A qualitative exploration from a gender perspective. *Public Health.* 2011;125:84-9.
22. Long NH, Johansson E, Diwan VK, Winkvist A. Fear and social isolation as consequences of tuberculosis in Vietnam: a gender analysis. *Health Policy.* 2001;58:69-81.
23. Ottmani S, Obermeyer Z, Bencheikh N, Mahjour J. Knowledge, attitudes and beliefs about tuberculosis in urban Morocco. *East Mediterr Health J.* 2008;14:298-304.
24. World Health Organisation. *Global tuberculosis report.* Geneva: World Health Organisation. 2012.
25. Kipp AM, Pungrassami P, Nilmanat K, Sengupta S, Strauss RP, Chongsuvivatwong V, et al. Sociodemographic and AIDS related factors associated with tuberculosis stigma in southern Thailand: a quantitative, cross-sectional study of stigma among patients with TB and healthy community members. *BMC Public Health.* 2011;11:675.
26. Eastwood SV, Hill PC. A gender-focused qualitative study of barriers to accessing tuberculosis treatment in The Gambia, West Africa. *Int J Tuberc Lung Dis.* 2004;8:70-5.
27. Pungrassami P, Kipp AM, Stewart PW, Chongsuvivatwong V, Strauss RP, Van Rie A. Tuberculosis and AIDS stigma among patients who delay seeking care for TB symptoms. *Int J Tuberc Dis.* 2010;14:181-7.
28. Somma D, Thomas BE, Karim F, Kemp J, Arias N, Auer C, et al. Gender and socio-cultural determinants of TB-related stigma in Bangladesh, India, Malawi and Colombia. *Int J Tuberc Lung Dis.* 2008;12:856-66.
29. Cambanis A, Ramsay A, Yassin MA, Cuevas Duration and associated factors of patient delay during tuberculosis screening in rural Cameroon. *Trop Med Int Health.* 2007;12:1309-14.
30. Noyes J, Popay J. Directly observed therapy and tuberculosis: how can a systematic review of qualitative research contribute to improving services? A qualitative meta-synthesis. *J Adv Nurs.* 2007;57:227-43.

**Cite this article as:** Saad T, Tirkey AS, Khan W. Cultural disgrace among tuberculosis patients in Sagar district of Madhya Pradesh in India. *Int J Res Med Sci* 2016;4:562-6.