

## TUBERCULOSIS AND STIGMA IN INDIA: EVIDENCE FROM A NATIONALLY REPRESENTATIVE SURVEY

Barman P<sup>1</sup>

<sup>1</sup> Assistant Professor in Economic, Faculty of Commerce and Management, St. Xavier's University, Kolkata, India

### ABSTRACT

**Introduction:** Infectious nature of pulmonary tuberculosis (TB) is one of the major reasons behind the prevailing stigma and negative attitude towards the disease. These factors stand in the way of seeking an early diagnosis or continuing treatment following a positive diagnosis. This study aims at exploring the shares of adult men and women conforming to TB related stigma in India, a high TB burden nation, and the causal factors behind the same.

**Methodology:** The study uses unit level data on adult men and women from the nationally representative survey NFHS-3 (2005-06). Simple tools for descriptive statistics and logistic regression analysis have been employed.

**Results:** Factors affecting TB related stigma among Indian men are age, religion, economic class, education level, family structure and marital status. In case of women age plays no role. However, place of residence, social group and employment status emerge as significant factors impacting stigma among Indian women. Further, stigma levels vary across Indian states for both genders.

**Conclusion:** Socio-economic and demographic factors that have a role to play in shaping people's attitude towards disease and related health seeking behaviour need to be acknowledged and incorporated in policies targeted towards elimination of TB.

**Key words:** Tuberculosis, Stigma, Negative attitude, Socio-economic factors

### INTRODUCTION

Tuberculosis (TB) continues to plague the world as one of the top ten causes of death globally and the leading infectious cause of mortality. The 30 High Burden Countries including India, identified by WHO, account for around 86 per cent of the annual global TB incidence. India alone contributes towards 17 per cent of the global gap between estimated incidence of TB and notification. Further, the COVID-19 pandemic in

2020 threatens to stall the progress in arresting the global TB disease burden<sup>1</sup>. In 2018, India had 2.69 million new cases and 4.4 lakh deaths due to TB<sup>2</sup>. Although the Revised National Tuberculosis Control Programme (renamed recently as National Tuberculosis Elimination Programme) is running in India for two decades now, the burden of TB continues to be appalling. India's contribution to the 'missing millions' suggests that a large number of chestsymptomatics either go completely undiagnosed or are not notified to the national programme even if diagnosed. Stigma potentially has a significant role to play in determining the care seeking discourse of TB suspects and poses a major challenge to TB control<sup>3</sup>. Negative attitudes that societies and communities attach to this disease often act as deterrents to timely care seeking by patients due to fear of social isolation as well as compel a patient to abandon treatment midway.

### Correspondence:

Ms. Paramita Barman  
Assistant Professor in Economics  
Faculty of Commerce and Management  
St. Xavier's University  
Action Area IIIB, Plot IIIB/1  
New Town, Kolkata 7000160, India  
Email: paramitabarman11@gmail.com

Most authors have identified the contagiousness of pulmonary TB as a leading cause of stigma. Even among people with relatively good knowledge of TB transmissibility, the perceived risk of transmission can lead to social isolation of individuals with TB. Among other factors fuelling stigma are the perceived associations of TB with malnutrition, poverty, low socioeconomic class, HIV and TB co-infection, etc. Several authors have also tried to capture the prevalence of perceived, internalized and actually experienced TB related stigma and compare its extent in different geographic regions. Concern about suffering the consequences of stigma prevent at-risk individuals from undergoing TB screening and seeking medical assistance after surfacing of symptoms. Even after start of treatment, fear of revelation of positive TB status may result in treatment drop-outs<sup>4</sup>. Studies exploring the attitude, behaviour and understanding of TB by communities in a district in the western region of Ghana, Africa, finds through in-depth interviews with respondents that primarily fear of infection gave rise to negative attitudes towards TB leading to imposition of socio-physical distance and participatory restrictions on patients. Stigma in fact led individuals with obvious symptoms of TB to attribute it to other non-stigmatising conditions or conceal diagnosis from others as well as default on treatment. The study indicated that TB related stigma, ingrained in most societies was a major setback to the success of the national programs to combat TB, in particular with regards to case finding and adherence to treatment.<sup>5,6</sup> Qualitative studies in India find that the manifestations of TB stigma were through social isolation, gossip, uncertain prospects of marriage, verbal abuse, etc. Concealment of TB status was the response to fear of job loss, marital problems and discrimination.<sup>7,8</sup> Often it is through health professionals themselves that TB patients are exposed to stigma.<sup>9</sup> Research has highlighted the inadequacy of an entirely disease-specific focus on TB control without simultaneously understanding the broader family, community and social context in which the illness occurs.<sup>10</sup> Since qualitative studies on TB stigma are quite a few, the present study would contribute to existing literature by exploring the proportions of Indian adults (male and female) who conform to TB

related stigma and trying to look into its potential drivers.

## METHODOLOGY

The study uses unit level data on adult men and women from the nationally representative *National Family Health Survey 3* (2005-06). It covers adult men in the 15-54 years age group and adult women in the age group 15-49 years.

Simple tools for descriptive statistics and multivariate logistic regression analysis have been employed in the study. Logistic regression analysis is used to study how the likelihood of an event occurring varies in the presence of confounding factors. It presents an appropriate method of regression analysis when the discrete dependent variable Y is dichotomous in nature, taking only two values 0 (failure) and 1 (success) and involves estimation of the log odds of success. Mathematically, logistic regression estimates a multiple linear regression function of the following form:

$$\log [P(Y=1)/1-P(Y=1)] = \beta_0 + \beta_1X_{i1} + \beta_2X_{i2} + \beta_3X_{i3} + \dots + \beta_nX_{in} \text{ for } i=1,2,3,\dots, n$$

Data has been analysed with the help of the Stata 14 software.

Question regarding TB related stigma were asked to only those respondents who conformed to ever having heard of TB. 8 per cent of male and 12 per cent of female respondents who said that they had never heard of TB have been eliminated from the final dataset for analysis in the study. The specific stigma related question asked was whether the respondent would keep it a secret if any member of his or her family had TB. To locate the causal factors, 'Stigma' (0=No Stigma, 1=Stigma) was framed as the binary dependent variable. The explanatory variables considered were residence, religion, reservation, age, level of education, income class, marital status, occupational status and family structure. Except age, all other predictors are categorical. Statistical significance has been considered at  $p < 0.05$ .

## RESULTS

In India, 18.60 per cent males wanted to keep TB infection in the family a secret. The corresponding share for females was 19.37 per cent as indicated in Table 1.

TB related stigma	Men	Women
No	50,932 (81.40)*	77,854 (80.63)
Yes	11,638 (18.60)	18,702 (19.37)
Total	62,570 (100)	96,556 (100)

Source : Author's calculation from NFHS 3 data

Figure 1 depicts the percentage shares of men with TB stigma across Indian states. It is revealed that the states of Tamil Nadu, Andhra Pradesh, Meghalaya, Rajasthan, Goa and Karnataka have higher than all-India share of adult men with TB related stigma. States like Bihar, Uttar Pradesh, Madhya Pradesh, Gujarat and Kerala have lower levels of stigma among men compared to the national level. Some of the lowest percentages of stigma are found in West Bengal, Maharashtra, Manipur, Orissa and Assam.

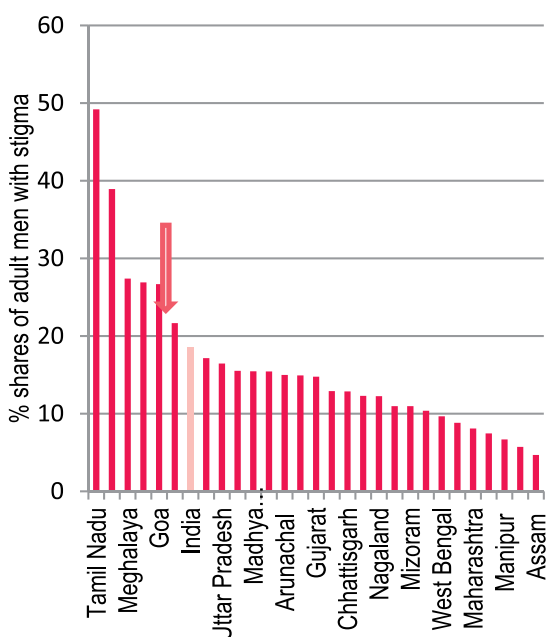


Figure 1: States with higher and lower shares of males with TB stigma compared to all India level

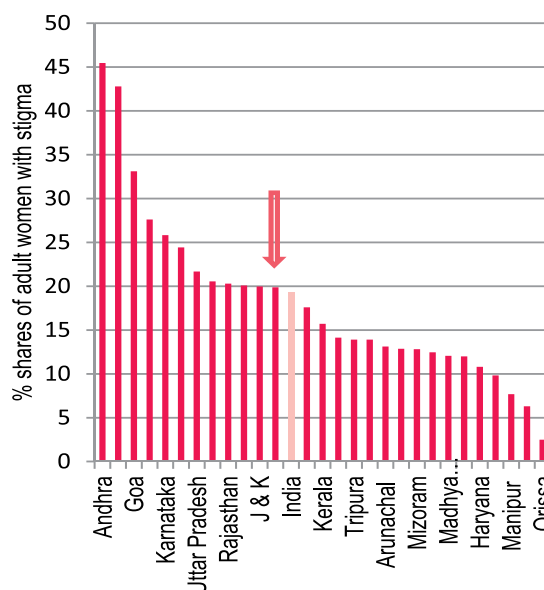


Figure 2: States with higher and lower shares of females with TB stigma compared to all India level

Figure 2 depicts the percentage shares of women with TB stigma across Indian states. Some of the major states like Andhra Pradesh, Tamil Nadu, Karnataka, Gujarat, Uttar Pradesh, Rajasthan, Punjab and Bihar have higher than the all-India percentage of adult women nurturing TB related stigma. In Maharashtra, Kerala, states in the Northeast, Jharkhand and Madhya Pradesh, stigma burden is lower than the national level. Some of the lowest stigma percentages among women hail from West Bengal, Manipur, Assam and Orissa.

Table 2 reports the results of logistic regression analysis to determine the causal factors behind TB related stigma among adult men and women in India. In case of males, the likelihood of TB stigma increases with age (OR 1.15,  $p=0.038$ ). It falls with non-Hindu religion (OR 0.85,  $p=0.000$ ), rich income class (OR 0.88,  $p=0.000$ ), both primary (OR 0.93,  $P=0.049$ ) and 'secondary and higher' (OR 0.70,  $p=0.000$ ) education levels, non-nuclear family background (OR 0.91,  $p=0.000$ ) and married males (OR 0.81,  $p=0.000$ ). Females from rural areas (OR 0.95,  $p=0.007$ ) and reserved category (OR 0.88,  $p=0.000$ ) are less likely to suffer from TB related stigma. It also falls with secondary and higher levels of education (OR 0.82,  $p=0.000$ ) and married women (OR 0.91,  $p=0.000$ ). The likelihood is higher among women both from the middle (OR 1.10,  $p=0.000$ ) and rich (OR 1.05,  $p=0.028$ ) income classes and those who are employed (OR 1.03,  $p=0.046$ ).

Table 2: (Annex 4). Logistic regression results for stigma among adult men and women in India						
Explanatory Variables	Men			Women		
	OR	P value	95% CI	OR	P value	95% CI
	Residence Urban ( <i>Ref</i> )					
Rural	1.00	0.909	0.95 – 1.05	0.95	0.007***	0.91 – 0.98
Religion Hindu ( <i>Ref</i> )						
Non-Hindu	0.85	0.000***	0.81 – 0.90	1.02	0.348	0.98 – 1.06
Reservation Unreserved ( <i>Ref</i> )						
Reserved	0.97	0.244	0.93 – 1.02	0.88	0.000***	0.85 – 0.91
Wealth index Poor ( <i>Ref</i> )						
Middle income	1.05	0.128	0.99 – 1.12	1.10	0.000***	1.04 – 1.16
Rich	0.88	0.000***	0.82 – 0.93	1.05	0.028**	0.99 – 1.10
Education level No education/Preschool ( <i>Ref</i> )						
Primary	0.93	0.049**	0.86 – 1.00	0.97	0.296	0.92 – 1.02
Secondary & Higher	0.70	0.000***	0.65 – 0.74	0.82	0.000***	0.79 – 0.86
Age	1.15	0.038**	0.96 – 1.27	0.99	0.214	0.92 – 1.05
Household structure Nuclear ( <i>Ref</i> )						
Non-nuclear	0.91	0.000***	0.87 – 0.95	0.98	0.288	0.95 – 1.01
Marital status Single ( <i>Ref</i> )						
Married	0.81	0.000***	0.77 – 0.84	0.91	0.000***	0.88 – 0.95
Employment status Unemployed ( <i>Ref</i> )						
Employed	0.98	0.653	0.93 – 1.05	1.03	0.046**	1.00 – 1.07
<b>Total Sample</b>	62,570			96,556		
<b>LR Chi2 (11)</b>	420.75			168.34		
<b>Pseudo R2</b>	0.007			0.002		
<b>p&gt;chi2</b>	0.000			0.000		
<b>Log likelihood</b>	-29846.389			-47376.047		

Source: Analysis of NFHS 3 unit level data; \*\*\*significant at 1 per cent \*\*significant at 5 per cent

## DISCUSSION

The above results hint at a difference in the TB related stigma scenario between adult men and women with respect to quite a few Indian states as well as the national level. At an all-India level, share of women nurturing TB stigma is marginally more compared to men. The state of Meghalaya appears to be a high stigma burdened state in case of men (in comparison to the all India share) but has lower stigma among women. Major states like Gujarat, Himachal, Uttar Pradesh, Punjab and Bihar where stigma from TB among women are on the higher side, are found to have lower

stigma among men. An exploration of the possible causal factors behind TB stigma reveals that being married and having secondary and higher level of education significantly decrease the chances of stigma for both sexes. Similar results on the impact of education on TB related stigma have been arrived at by a study conducted in Lagos, Nigeria<sup>11</sup>. Residence and ethnicity are strong determinants of stigma in case of women but not men. Economic class impacts the genders differently with respect to stigma. Men from the rich income class are significantly less likely while women from the same class are more likely to carry TB stigma. The middle income class also increases the chances of stigma

among women while it has no impact in case of men. Studies conducted on TB patients in Addis Ababa, Ethiopia and Lagos, Nigeria, reveal that lower economic status is significantly associated with stigma<sup>11,12</sup>. Primary education and non-nuclear family structure are found to reduce stigma among men while having no influence on stigma among women. Men of higher age are more likely to nurture stigma from TB. Employed women have significantly higher chances of having TB stigma while in case of men employment status seems to have no role to play.

Stigma, which is moulded and disseminated by institutional and community norms and interpersonal attitudes, is a social determinant of health. Being a communicable disease, TB remains shrouded in severe social stigma in some communities which is even more aggravated by incomplete and often incorrect information particularly in relation to the path of spread of infection. Fear of isolation from friends and family may compel individual with symptoms to conceal their health condition and avoid diagnosis. Stigma is also believed to be one of the prime reasons for treatment non-compliance among patients. Defaulting on treatment can have serious consequences for community health including the emergence of more resistant strains of the bacterium.

As studies reveal, the association of negative attitudes like embarrassment, isolation, self-identification as a disease transmitter, etc. with TB discourage timely health-seeking and treatment adherence<sup>6</sup>. Hence providing correct information relating to TB and removing baseless fears can improve the stigma situation and motivate patients to seek health care on time. This is extremely crucial for arresting the spread of infection and effective TB control by the national program. Unidirectional focus on medical treatment of reported cases leaves out many who completely slip out of the program due to lack of a diagnosis, often demotivated by reasons including TB related knowledge deficiency and/or stigma issues. Further, on diagnosis becoming public, most of them suffered shunning and hostile behaviour from friends and family, to which they reacted by isolating themselves, becoming secretive about their illness and even abandoning treatment midway<sup>10</sup>. Since

incomplete TB treatment has serious implications for community health, a modification in the outlook and behaviour of community is needed. Paramedical health service providers could play an effective role by counselling patients and their family members on their visits to health facilities about the curable nature of TB and length of treatment necessary to render it non-infectious, thereby providing social support.

---

## CONCLUSION

---

Due to excessive focus on achieving 'detection and cure rate' targets, the national program dedicated to the control of TB in India often tends to lose sight of the deeper socio-economic issues that shape and mould people's perception of TB including the severe stigma that leads to under-diagnosis, under-reporting and treatment default. Although steps have been taken by the Ministry of Health to improve knowledge and awareness about the disease among the general public, more conscious efforts need to be directed to the spread of correct information about TB taking particular care to reach out to the socio-economically vulnerable strata like the poor, illiterates and socially backward communities who also happen to be the most susceptible groups for contracting the TB disease. Gender sensitive interventions incorporating inter-state variations in TB related stigma burden are also crucial for the program's success in meeting international targets.

---

## ACKNOWLEDGEMENT

---

The author wish to acknowledge National Family Health survey 3 for giving permission to use the national data.

---

## CONFLICT OF INTEREST

---

None

---

## REFERENCES

---

1. WHO. Global Tuberculosis Report 2020 available at [https://www.who.int/tb/publications/global\\_report/en/](https://www.who.int/tb/publications/global_report/en/)

2. GOI. Annual Tuberculosis Report 2020 available at [www.tbcindia.gov.in](http://www.tbcindia.gov.in)
3. Yin et al. Status of TB related stigma and associated factors: a cross sectional study in central China. *Tropical Medicine and International Health*. 2018;23(2):199-205 DOI: 10.1111/tmi.13017
4. Courtwright, A and Turner, A. N. Tuberculosis and Stigmatization: Pathways and Interventions. *Public Health Reports*. 2010;125(Suppl 4):34-42 DOI: 10.1177/00333549101250S407
5. Dodor, E. A., Neal, K. and Kelly, S. An Exploration of the Causes of Tuberculosis Stigma in an Urban District in Ghana. *The International Journal of Tuberculosis and Lung Disease*. 2008;12(9):1048-1054
6. Dodor, E. A. and Kelly, S. We are Afraid of Them: Attitudes and Behaviours of Community Members towards Tuberculosis in Ghana and Implications for TB Control Efforts. *Psychology, Health & Medicine*. 2009;14(2):170-179
7. Mukherji, R. and Turan, J. M. Exploring Manifestations of TB-Related Stigma Experienced by Women in Kolkata, India. *Annals of Global Health*. 2018;84(4):727-735 <http://doi.org/10.29024/aogh.2383>
8. Atre et al. Gender and community views of stigma and tuberculosis in rural Maharashtra, India. *Global Public Health*. 2011;6(1):56-71 DOI: 10.1080/17441690903334240
9. Dodor, E.A. Health Professionals Expose TB Patients to Stigmatization in Society: Insights from Communities in an Urban District in Ghana. *Ghana Medical Journal*, 2008;42(4):144-148
10. Kelly, P. Isolation and Stigma: The Experience of Patients with Active Tuberculosis. *Journal of Community Health Nursing*. 1999;16(4):233-241 [https://doi.org/10.1207/S15327655JCHN1604\\_3](https://doi.org/10.1207/S15327655JCHN1604_3)
11. Abiyoe, I. A., Omotayo, M. O. and Alakija, W. Socio-demographic determinants of stigma among patients with pulmonary tuberculosis in Lagos, Nigeria. *African Health Sciences*. 2011;11(S1):S100-S104 DOI: 10.4314/ahs.v11i3.70078
12. Adilo, T. K. Determinants of TB Stigma, and its Effects on Health Care Seeking Behaviour and Treatment Adherence among TB Patients in Addis Ababa, Ethiopia: A Cross Sectional Study Design. *EC Microbiology*. 2017;12(1):37-51 DOI: 10.31080/ecmi.2017.12.00379