

# A Systematic Review of Stigma Among Tuberculosis Patient and Its Effect

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**Abstract---***The cause of success in the process of treating tuberculosis patients is the emergence of stigma. Stigma has been argued as a barrier to tuberculosis therapy, because, with the stigma, the patient will become more closed, withdrawn and difficult to monitor treatment. The purpose of this systematic review is to determine the stigma among tuberculosis patients and its effect. This study used systematic review with literature search using online reference databases: ProQuest, ScienceDirect and Scopus. The keywords used in this research were tuberculosis OR TB AND social OR public stigma. A full literature search and study selection process was in accordance with the PRISMA guidelines. Studies will be a part of this research if they explain about stigma among tuberculosis patients. The review of 15 articles that met the criteria showed that many tuberculosis patients receive negative stigma in their life. The level of stigma is mostly high. In general, the majority of the community indicated that they would treat TB patients differently for the rest of their lives, do not want those with TB to play with their children, do not want to eat or drink with friends who have TB, and are uncomfortable about being close to those with TB. The stigma among tuberculosis patients is of high rate, so stigma reduction should prioritize the involvement of clients living with the stigmatized condition or behavior and health workers living with stigmatized conditions and should address both individual and structural level stigma.*

**Keywords---** Tuberculosis; Stigma; Effect of Stigma

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## I. INTRODUCTION

Stigma is a major social determinant of health that drives morbidity, mortality, and health disparities, and has been described by the World Health Organization as a ‘hidden’ burden of disease [1]. Stigma is characterized by cognitive, emotional, and behavioral components and can be reflected both in the attitudes, often conceptualized as perceived, anticipated, or internalized stigmas, and experiences, including enacted or experienced stigmas affecting a particular trait, among individuals. Perceived stigma refers to a person’s understanding of how others may act toward, and think or feel about, an individual with a certain trait or identity. Anticipated stigma refers to expectations of stigma experiences happening in the future. Internalized stigma refers to the individual level process of awareness, acceptance, and application of stigma (to oneself). Finally, experienced or enacted stigma refers to discriminatory acts or behaviors [2].

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. The burden of disease varies enormously among countries, from fewer than five

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to more than 500 new cases per 100,000 population per year, with the global average being around 130. Geographically, most TB cases in 2018 were in the WHO regions of South-East Asia (44%), Africa (24%) and the Western Pacific (18%), with smaller percentages in the Eastern Mediterranean (8%), the Americas (3%) and Europe (3%). Eight countries accounted for two-thirds of the global total: India (27%), China (9%), Indonesia (8%), the Philippines (6%), Pakistan (6%), Nigeria (4%), Bangladesh (4%) and South Africa (3%). These and 22 other countries in WHO's list of 30 high TB burden countries accounted for 87% of the world's cases [1]. According to research conducted by Orovwigbo [3] in Enugu, Nigeria, more than half or as many as 65.1% of pulmonary TB patients have low self-esteem; this is partly the perception in the social environment about pulmonary TB disease as an infectious disease stigma. According to Flanagan [4] in his study conducted in Brazil, as many as 20% of pulmonary TB patients have low self-esteem because of the stigmatization of negative emotions, social rejection and self-isolation.

Stigma is a negative perception that individuals have that they cannot be socially acceptable [5]. According to Rusch, et al. [6], stigma is divided into two, namely community stigma (public stigma) and self-stigma. Community stigma, or also called social stigma, consists of stereotypes, prejudices and discrimination that lead to negative evaluations to distinguish individuals based on something, whereas self-stigma has the same components as community stigma. Self-stigma is a negative perception that is owned by individuals that it cannot be socially accepted, which can cause a decrease in self-esteem, so individuals tend to withdraw from the environment and interact less with the social environment [7].

This paper presents a scoping review of the literature on the health consequences of stigma and effect of stigma. The main purpose of this research is to explore the social or public stigma on tuberculosis patients and its effect. In so doing, this review highlights the community stigma of patients with pulmonary tuberculosis and the effects of the stigma given by the community to tuberculosis patients.

## II. METHODS

- Searching strategy for studies

This systematic review includes original articles that discuss about social or public stigma on tuberculosis patient and the effect of the stigma to the patient. A systematic literature search was carried out in a number of major databases such as ProQuest, ScienceDirect and Scopus. A full literature search and study selection process was in accordance with the PRISMA guidelines. Articles will be a part of this study if they are talking about social or public stigma on tuberculosis patients and the effect of the stigma to the patient.

- Study selection

The search results by using a keyword obtained 320 articles and, after we limited with the year (2016-2020), we obtained 121 articles. Fifteen articles met the inclusion criteria. Each study contains stigma on tuberculosis patients. Studies that use another theme are excluded from this research. All studies were selected by the criteria of: (1) document type was an original article; (2) sourced from journals; (3) article in English; (4) article available in full text.

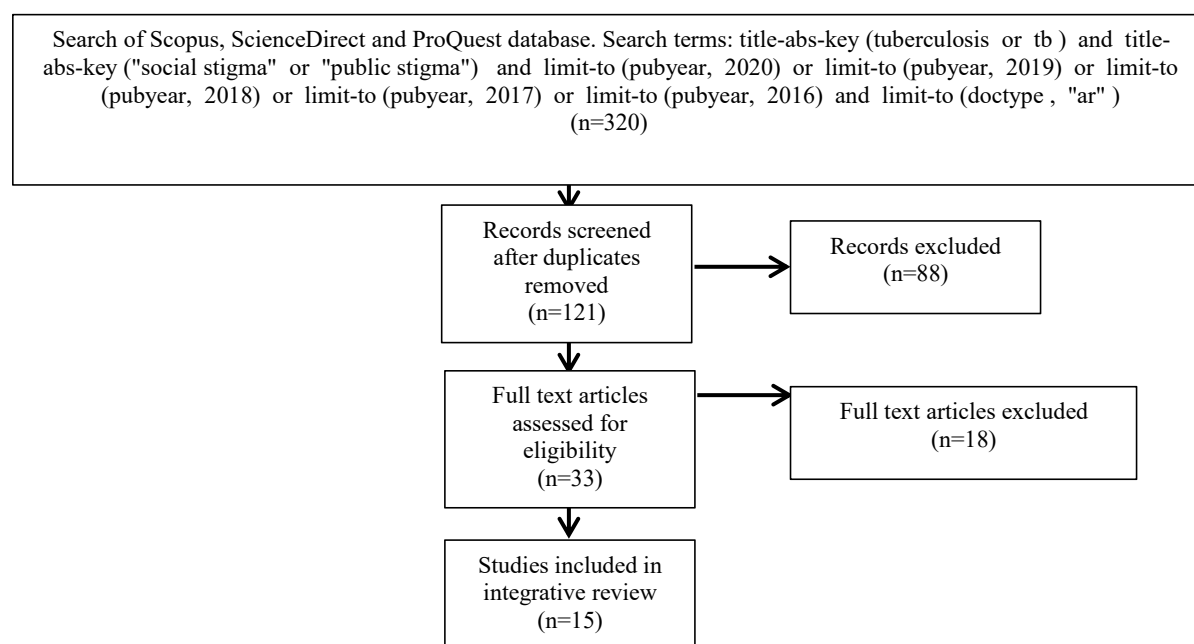


Figure 1 – flow diagram of search results for tuberculosis social stigma and its effect with the PRISMA guidelines.

Inclusion criteria in the literature are studies about social or public stigma on tuberculosis patients and the effect of the stigma to the patient with a limitation of the years used for the past five years (2016-2020). The outcomes produced are social or public stigma on tuberculosis patients and the effect of the stigma to the patient. Ethical issues in preparing the manuscript of systematic review are as follows: 1) avoiding plagiarism; 2) avoiding duplicate in publication; 3) transparency in searching, screening, processing and evaluating articles.

### III. RESULTS

- General features and type of study

From 15 articles, data collection was carried out in India as many as five articles, China four articles, Iraq one article, England one article, Bangladesh one article, South Africa one article, Tanzania one article, and Lesotto one article. The number of participants in each article is more than 150 participants for quantitative and more than 10 for qualitative. All articles are talking about social or public stigma on tuberculosis patients and the effect of the stigma to the patient. Most articles use randomized sampling to obtain the participants.

Table 1. General characteristics of selected studies (n=15)

Category	N	%
Year of publishing		
2016	1	6.67
2017	7	46.66
2018	3	20
2019	4	26.67
Topic of study		
Social stigma	8	53.33
Effect of stigma	7	46.67
Type of social stigma		
Social isolation	3	37.50

Category	N	%
Verbal abuse	2	25
Different social treatment	3	37.50
Effect of stigma		
Low treatment adherence	3	42.86
Psychological impact (depressive, stress, and fear)	4	57.14
Type of study		
Cross-sectional	8	53.33
Qualitative	4	26.67
Descriptive	2	13.33
Mixed Method	1	6.67

- Tuberculosis Stigma

The 15 articles discuss about social or public stigma on tuberculosis patients and the effect of the stigma to the patient. In general, the majority of the community indicated that they would treat TB patients differently for the rest of their lives, do not want those with TB to play with their children, do not want to eat or drink with friends who have TB, and are uncomfortable about being close to those with TB.

Our results indicated that TB stigma mainly manifested through social isolation and avoidance due to fear of contagion, gossip and verbal abuse, failed marriage prospects, and neglect from family. It can be inferred in patients' love narratives too. The mechanism at the heart of the theory is TB's disruptiveness to the gendered roles of wife (or daughter-in-law) and mother. It is this disruptiveness that gives legitimacy to the rejection of marriage to a woman with TB.

- The Effect of Stigma on Tuberculosis Patients

The main components of stigma were fear, self-isolation, ostracization, loss of status in the community, and discrimination by providers. Participants described the cultural context in which stigma operated as characterized by a general lack of health knowledge, cultural beliefs about TB, and engendered beliefs about disease in general. Both genders described some similar effects of stigma, including relationship difficulties and specifically challenges forming new relationships, but many effects of stigma were distinct by gender: women described challenges including assumptions about promiscuity and infidelity, as well as rejection by partners, while men described survival challenges. Stigma acted as a barrier to care through a cyclical pattern of stigma and fear, leading to health-seeking delays, with resulting continued transmission and poor health outcomes that further reinforced stigma. The impact of stigma and depressive symptoms on medication adherence was significant.

## IV. DISCUSSION

- Tuberculosis Stigma

Table 1 shows that, in this study, TB sufferers who experienced stigma in the form of social isolation totaled 37.5%. This shows that people discriminate against tuberculosis patients by giving labels to stay away from them. Some tuberculosis patients often report discrimination from the community. This is because people feel afraid of contracting the disease. Patients assess whether others will avoid themselves or maybe some patients will avoid by rarely socializing in the community. Although there are variations in the socio-cultural and socio-demographic factors in each country that contribute to determining the stigma, the main cause is a concern about the transmission of tuberculosis, in addition to which the lack of knowledge about the route of tuberculosis transmission can also cause stigma [8].

Patients who experienced verbal abuse in this study amounted to 25%. This can be interpreted that, until now, there are still many social communities who use inappropriate terms for tuberculosis sufferers. Related research

conducted by Cremers et al. (2015) found that tuberculosis sufferers who experience stigma are treated differently by relatives / neighbors / friends after disclosure of suffering from tuberculosis, such as facing ridicule, derogatory comments, discrimination, social exclusion, and social isolation. Social exclusion is often triggered by the opinion that tuberculosis is highly contagious which then manifests in separate eating and drinking, avoiding sexual intercourse, and exclusion from school or workplace activities [9].

Another stigma given by the community in this study of TB sufferers is the existence of different treatments for TB sufferers, amounting to 37.5%. This other treatment is felt to be very different between TB sufferers and non-TB sufferers. People with TB are often treated with irreverence, receive harsh words and are even excluded from the social community. Even related to marriage, there are also people who refuse to marry women who suffer from tuberculosis. Based on the research by Hatherall et al., it is this disruption that gives legitimacy to the rejection of marriage to a woman with TB. Whether or not this mechanism results in a negative impact of TB on marriage prospects depends on a range of contextual factors, providing opportunities for interventions and policies [10].

In general, the majority of the community indicated that they would treat TB patients differently for the rest of their lives, do not want those with TB to play with their children, do not want to eat or drink with friends who have TB, and are uncomfortable about being close to those with TB. Most studies on stigma, including those on HIV and TB stigma, are rooted in the work of Erving Goffman. He defined stigma as a discrediting social label that changes an individual's self-image and disqualifies him or her from full social acceptance [11].

- The Effect of Stigma on Tuberculosis Patients

Table 1 shows that, in this study, the psychological effect of community stigma on TB sufferers was 57.14%. Many factors can affect this condition. Negative views of society to TB sufferers can cause stress for patients. Pulmonary TB can also cause psychosocial problems; psychosocial effects include psychological problems related to illnesses, such as feeling bored and lacking motivation, extending to serious mental disorders such as major depression. Other psychosocial problems are stigma in the community, feeling fear of the incurable disease, feeling ostracized, and not confident, as well as economic problems [12]. These things certainly make pulmonary TB patients experience stress due to pressure from both inside and outside [13]. Unresolved stress will stimulate the hypothalamus to secrete corticotropin releasing factor (CRF), which causes the pituitary gland to secrete adrenocorticotropin releasing hormone (ACTH), which stimulates the adrenal cortex to secrete cortisol. Increased excessive cortisol secretion in patients with pulmonary TB can cause complications, decrease the immune system, and result in excessive metabolism [14].

Stigma can cause non-compliance with treatment in TB patients by 42.86% in this study. In the aspect of treatment (curative), the success of TB treatment is influenced by several factors, including medical and non-medical factors. Medical factors include first complaint before treatment, comorbidities, side effects and drug retention, while non-medical factors include age, type of work, communication of educational information, attitudes of health workers, affordability of treatment, Drugs Supervisors (PMO) and regularity of taking medication [15]. A literature review on research that examined TB treatment adherence found four main factors that were interrelated and influenced TB treatment adherence. These four factors include structural factors (including poverty and gender discrimination), social context, health service factors, and personal factors [16]. Factors related to non-compliance with TB / HIV treatment were socioeconomic conditions and personal behavior. Non-compliance with TB treatment was due to patients feeling better and, thus, stopped treatment before the allotted time. Not infrequently, this is triggered by a lack of financial support for the continuity of the treatment. However, aspects of social support are considered

important for medication adherence [17].

Stigma acted as a barrier to care through a cyclical pattern of stigma and fear, leading to health-seeking delays, with resulting continued transmission and poor health outcomes that further reinforced stigma. The impact of stigma and depressive symptoms on medication adherence was significant. Many experts believe that it will be difficult to find the estimated 4 million missing TB cases without addressing TB stigma.1, 4. Experts also believe that the full potential of new drugs and regimens for multidrug-resistant TB (MDR-TB), pediatrics TB and latent tuberculous infection (LTBI) cannot be realized without addressing TB stigma [18].

## V. CONCLUSION

The stigma among tuberculosis patient is of a high rate, so stigma reduction should prioritize the involvement of clients living with the stigmatized condition or behavior and health workers living with stigmatized conditions and should address both individual and structural level stigma.

## CONFLICT OF INTEREST

No conflicts of interest have been declared.

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## VI. APPENDIX

Table 2. Summaries of selected study

Writer (year) And country	Research Title	Method	Research result
[8] India	Study of social stigma among tuberculosis patients from northern India	Design: Descriptive Sample: 150 tuberculosis patient Instrument: semi-structured, pre-tested questionnaire	Out of total of 65.3% subjects who experienced stigma. 42% had fear of disclosing illness to his or her friends. Almost 31% did not disclose their illness to friends. In 20% of the cases, their friends

		Analysis: -	avoided them after knowing about their illness. About 64% had fear of disclosing illness at place of work. Almost 34% of study subjects did not disclose their illness at workplace.
[9] Iraq	Social stigma circumstances toward tuberculosis in Hilla city / Iraq: Community insight	Design: Descriptive Sample: 200 of both genders of the clients who visit the primary healthcare centers in Hilla city Instrument: semi-structured questionnaire Analysis: -	The results of the present study have indicated that the overall assessment reveals that the majority (61.5%) were positive social stigma toward patients with TB. The study concluded that there is a significant association between the social stigma and the sample demographic characteristic regarding age, educational level and occupation
[12] China	Perceived Stigma and Depression in Initially Diagnosed Pulmonary Tuberculosis Patients	Design: Cross-sectional Sample: A total of 84 subjects, obtained through convenience sampling Instrument: a structured questionnaire with a demographic component, the Tuberculosis-related Stigma Scale (TSS), and the Beck Depression Inventory II (BDI-II) Analysis: analyses of variance (ANOVAs)	Of the participants, the community perspectives toward TB stigma subscale mean score was 27.05 (SD = 8.73). In general, the majority of the community indicated that they would treat TB patients differently for the rest of their lives, do not want those with TB to play with their children, do not want to eat or drink with friends who have TB, and are uncomfortable about being close to those with TB.
[19] India	Exploring Manifestations of TB-Related Stigma Experienced by Women in Kolkata, India	Design: Qualitative Sample: 20 female TB patients who were either currently on treatment or had undergone treatment at a TB clinic in Kolkata Instrument: In-depth interview Analysis: NVivo qualitative software using a thematic approach	Our results indicated that TB stigma mainly manifested through social isolation and avoidance due to fear of contagion, gossip and verbal abuse, failed marriage prospects, and neglect from family. Consequences of stigma described by the women included non-disclosure, feelings of guilt, and mental health issues including suicidal ideation. Positive coping strategies used by women to cope with the experiences of stigma included positive reframing, prayer, talking to other patients, focusing on school work, and relaxation activities. Negative coping activities included self-imposed social isolation and anger. In some cases, non-disclosure due to stigma had an impact on TB transmission and control behaviors.
[20] England	A disease called stigma: the experience of stigma among African men with TB diagnosis in London	Design: Qualitative Sample: 10 men who lived in London Instrument: In-depth semi-structured interviews Analysis: thematic analysis, using the interactive framework approach	Men were unable to recognize TB symptoms and subsequently made late clinical presentation when they were also diagnosed with HIV. A few were diagnosed when in immigration detention centers. The experience of late diagnosis informed their understanding of the word stigma. The link between HIV and TB compounded experiences of stigma, which led to depression and compromised HIV confidentiality
[21] India	A cross-sectional study to assess the stigma associated with tuberculosis among tuberculosis patients in Udupi district, Karnataka	Design: A cross-sectional study Sample: 209 sputum-positive and sputum-negative tuberculosis patients. Instrument: pretested proforma from Explanatory Model Interview Catalogue developed by World Health Organization Analysis: Chi-square test	The study revealed that, out of 209 respondents, 51.2% of the respondents experienced some form of stigma. Majority of the patients have received only primary education and 71.3% of the respondents were males. Most of the patients were under category 1 of Directly Observed Treatment Short course. Age, education, and smear status of the patient were found to be associated with stigmatization ( $p < 0.05$ ), whereas factors like gender, income, occupation, family history, and marital status were found to be not significantly associated with stigmatization.
[10] Bangladesh, Nepal, and Pakistan	“Who Will Marry a Diseased Girl?” Marriage, Gender, and Tuberculosis Stigma in Asia	Design: Qualitative Sample: 73 interviews and eight focus groups conducted in five sites across three countries (Bangladesh, Nepal, and Pakistan) Instrument: interview guides Analysis: NVivo 7	The mechanism at the heart of the theory is TB’s disruptiveness to the gendered roles of wife (or daughter-in-law) and mother. It is this disruptiveness that gives legitimacy to the rejection of marriage to a woman with TB. Whether or not this mechanism results in a negative impact of TB on marriage prospects depends on a range of contextual factors, providing opportunities for interventions and policies.
[22] South Africa	Stigma as a barrier to the use of occupational health units for	Design: Cross-sectional Sample: 221 Male 583 Female Instrument: the witnessing of	Study results demonstrate that there is a definite negative association between witnessing TB stigma in the workplace and willingness among



	tuberculosis services in South Africa	stigmatizing attitudes or behavior on the part of HCWs directed toward colleagues Analysis: WLSMV estimate command	HCWs to use the OHU for TB services, especially for screening. This suggests that the perception of stigma is an important barrier to healthcare uptake.
[23] China	Survey on Tuberculosis Patients in Rural Areas in China: Tracing the Role of Stigma in Psychological Distress	Design: Cross-sectional Sample: A total of 342 eligible and accessible TB patients being treated at home were included in the survey Instrument: interviewer-led questionnaires Analysis: multiple logistic regression	This study revealed that 65.2% (223/342) of the participants were categorized as having psychological distress. Both the stigma questionnaire and the K10 were proven to be reliable and valid in measurement. Further analysis found that experienced stigma and illness severity were significant variables to psychological distress in the model of logistic regression. The model was assessed well in predicting distress by use of experienced stigma and illness severity in the form of ROC and AUC. Rural TB patients had a high prevalence of psychological distress. Experience of stigma played a significant role in psychological distress.
[14] Tanzania	'It makes the patient's spirit weaker': tuberculosis stigma and gender interaction in Dar es Salaam, Tanzania	Design: Qualitative Sample: 48 TB patients and their household members Instrument: Focus group discussion Analysis: thematic content analysis	The main components of stigma were fear, self-isolation, ostracization, loss of status in the community, and discrimination by providers. Participants described the cultural context in which stigma operated as characterized by a general lack of health knowledge, cultural beliefs about TB, and engendered beliefs about disease in general. Both genders described some similar effects of stigma, including relationship difficulties and specifically challenges forming new relationships, but many effects of stigma were distinct by gender: women described challenges including assumptions about promiscuity and infidelity, as well as rejection by partners, while men described survival challenges. Stigma acted as a barrier to care through a cyclical pattern of stigma and fear, leading to health-seeking delays, with resulting continued transmission and poor health outcomes that further reinforced stigma.
[24] China	Nonadherence to Antituberculosis Medications: The Impact of Stigma and Depressive Symptoms	Design: Cross-sectional Sample: 1,342 TB patients were recruited from TB dispensaries Instrument: structured questionnaires that addressed medication adherence, TB-related stigma, and depressive symptoms. Analysis: multinomial logistic regression analysis	The percentage of TB patients with high, medium, and low medication adherence was 32.12%, 34.58%, and 33.31%, respectively. The impact of stigma and depressive symptoms on medication adherence was significant. TB patients with medium (odds ratios [OR]: 1.54, 95% confidence interval [CI]: 1.08–2.21) or high (OR: 5.32, 95% CI: 3.34–8.46) stigma or patients with mild (OR:1.92,95%CI:1.34–2.75) or severe (OR:3.67,95%CI:2.04–6.61) depressive symptoms showed a higher likelihood of having low adherence than those with low stigma or without depressive symptoms. TB-related stigma and depressive symptoms were common among TB patients in China, as was nonadherence, and independently associated with their adherence behavior.
[13] China	Depressive Symptoms Mediate the Associations of Stigma with Medication Adherence and Quality of Life in Tuberculosis Patients in China	Design: Cross-sectional Sample: 1,342 TB patients Instrument: structured questionnaire that measured TB-related stigma, depressive symptoms, medication adherence, and QOL Analysis: multinomial logistic regression analysis	Mediation analyses showed that depressive symptoms partially mediated the association between TB-related stigma and medication adherence (standardized indirect effect = -0.16, 95%bias-corrected confidence interval [CI] [-0.19, -0.13], p<0.01). Moreover, depressive symptoms fully mediated the association between TB-related stigma and QOL (standardized indirect effect = -0.17, 95% bias-corrected CI [-0.21, -0.14], p < 0.01). The results suggest that depressive symptoms played a key role in the relationships among TB-related stigma, medication adherence, and QOL in patients with TB. Therefore, the alleviation of depressive symptoms could be an important strategy for improving medication adherence and QOL in patients with TB

[25] Lesotho	Depressive symptoms and hazardous/harmful alcohol use are prevalent and correlate with stigma among TB-HIV patients in Lesotho	Design: A mixed-methods cluster-randomized trial Sample: 371 TB patients Instrument: In-person interviews Analysis: Odds ratio	Among 371 participants, 29.8% reported moderate/severe depressive symptoms, and 24.7% reported hazardous/harmful alcohol use; 7% reported both. Depressive symptoms were significantly associated with less education, more difficulty understanding written medical information, non-disclosure of TB, greater TB stigma, and the SOC study arm. Hazardous/harmful alcohol use was significantly associated with male sex, as well as greater TB and external HIV stigma.
[26] India	Tuberculosis related stigma and its effect on the delay for sputum examination under the Revised National Tuberculosis Control Program in India	Design: Cross-sectional Sample: 135 persons of 15–60 years Instrument: pretested structured questionnaire Analysis: Chi-square and logistic regression analysis	Among the 'lower stigma' group (score 4–24), 'delay' (14–25 days) is found among 46.2% respondents and 'much delay' (26–120 days) among 53.8%. Among the 'higher stigma' (score 25–36) group, 'delay' is found among 20.5% respondents and 'much delay' among 79.5%. Persons with lower stigma are 0.17 times likely to delay than persons with higher stigma [adjusted odds ratio (AOR): 0.17 (0.044–0.668), $p = 0.011$ ]. Important influencers of stigma are caste [AOR: 5.90 (1.66–20.90), $p = 0.006$ ], number of family members [AOR: 3.46 (1.08–11.06), $p = 0.009$ ] and residence in urban or rural [AOR: 3.97 (1.03–15.27), $p = 0.045$ ].
[16] India	Tuberculosis-related stigma attached to the adherence of Directly Observed Treatment Short Course (DOTS) in West Bengal, India	Design: Cross-sectional Sample: 145 DOTS defaulters from three randomly selected districts in West Bengal Instrument: a pretested questionnaire Analysis: Chi-square and multivariate logistic regression models	Mean stigma score for the state was 23.0. Total 51 (40.69%) persons were within the low stigma group and 94 persons (59.31%) were within high stigma score group. District-wise mean score was 19.8, 22.8 and 24.5, respectively, for Birbhum, Jalpaiguri and North 24 Parganas. In North 24 Parganas, the high stigma score group accounted for 85.5% compared to 35.9% in Birbhum. Among the low stigma group, late default was 52.1% compared to 66.7% in high stigma group ( $p = 0.054$ ). People with lower stigma level were 8.59 times more likely to have late default than the people with higher stigma level ( $p = 0.001$ ).