



PERCEIVED TUBERCULOSIS STIGMA IN INDIA: A NARRATIVE REVIEW

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ABSTRACT Tuberculosis (TB) remains one of India's most pressing public health concerns, and despite measurable gains under the National Tuberculosis Elimination Programme (NTEP), stigma continues to undermine progress at every level of care. This narrative review draws on evidence published between January 2015 and March 2026 to examine how self-stigma develops among people living with TB, how communities in India perceive and respond to the disease, how stigma disrupts treatment adherence, and what kinds of interventions have been tried to address it. A structured literature search was conducted across PubMed/MEDLINE, EMBASE, Web of Science, and Google Scholar. Search terms combined 'tuberculosis' and 'TB' with 'perceived stigma,' 'self-stigma,' 'social stigma,' and 'India.' Peer-reviewed original research, review articles, and programme evaluations that met predefined criteria were included, supplemented by relevant government policy documents and World Health Organization (WHO) reports. TB stigma is common across India and falls disproportionately on women, who experience it at substantially higher rates than men. TB stigma in India is structurally embedded, multidimensional, and causally linked to adverse health outcomes. Without integrating validated stigma measurement tools into national programme monitoring and expanding gender-responsive community interventions, elimination targets will remain elusive.

KEYWORDS : Tuberculosis; perceived stigma; community stigma; treatment adherence; NTEP

INTRODUCTION

India bears a disproportionate share of the global tuberculosis burden, accounting for close to one-quarter of all new TB cases worldwide each year. The country has demonstrated serious political commitment to ending this epidemic, formalised through the National Tuberculosis Elimination Programme (NTEP) and the National Strategic Plan for TB Elimination 2017–2025, both of which set targets more ambitious than those outlined by the World Health Organization (WHO) [1]. Substantial headway has been made on the technical front over the past decade: molecular diagnostic capacity has grown, standardised drug regimens are more widely available, and the Nikshay digital platform has modernised patient tracking and programme surveillance [2]. Yet these advances have not translated fully into population-level impact, largely because social and behavioural factors continue to keep many people with TB outside the reach of care.

Of these dimensions, perceived stigma draws particular interest because it shapes behaviour even in the absence of any real discrimination. Research has shown that to be stigmatized fears lead people to avoid clinics when symptoms first appear, decline to disclose their condition to those closest to them, and disengage from treatment when continuing it risks exposure [2-5]. The WHO End TB Strategy has acknowledged this reality explicitly, recognising stigma as a social determinant of TB outcomes that cannot be resolved through biomedical tools alone [6].

However, no recent review has brought together, within the Indian context, what is known about patient experiences of self-stigma, how communities perceive people with TB, how stigma shapes treatment adherence, and whether current interventions are working. This narrative review attempts to fill that gap, synthesising evidence from 2015 to 2026 across

these four interconnected areas.

METHODOLOGY

This review was conducted in accordance with the Scale for the Assessment of Narrative Review Articles (SANRA), which provides a structured framework for appraising methodological transparency in narrative syntheses [7]. The literature search was carried out across PubMed/MEDLINE, EMBASE, Web of Science, and Google Scholar using the following Boolean string: ('tuberculosis' OR 'TB') AND ('perceived stigma' OR 'self-stigma' OR 'social stigma' OR 'TB stigma' OR 'community stigma') AND 'India.' The search covered publications from January 2015 to March 2026.

To be included, a study had to meet four criteria: it must have been conducted in India or have contained a substantial India-specific component; stigma had to feature as a primary or secondary outcome; the paper had to be published in English in a peer-reviewed journal; and it had to be based on original data collection or a systematic synthesis of existing evidence. Editorials, conference abstracts, and studies that did not formally measure stigma were excluded. Policy documents from the Ministry of Health and Family Welfare [1,8], WHO Global TB Reports [6,9], and NTEP programme data were reviewed for contextual grounding. After deduplication and screening, approximately 38 studies and reports met criteria and were thematically analysed.

Review

Patient-Level Self-Stigma Among Persons with Tuberculosis in India

In line with this context, various studies have been upright to emphasize the problem on how stigma curtails the TB elimination [Table 1].

Table 1: Summary of studies on patient-level self-stigma among persons with TB in India

Title	Study design	Author(s) (year)	Journal	Key findings
Stigma associated with tuberculosis in patients, family members and health-care staff in central India	Cross-sectional study	Mustansir et al (2024) [5]	Indian J Tuberc	Stigma present in 26.75% of participants; enacted and perceived stigma most common among patients. Female patients ~13× more likely to experience stigma (OR 13.25) and those with limited TB knowledge ~3× (OR 3.0).

<i>TB stigma in India: a narrative review of types of stigmas, gender differences and potential interventions</i>	Narrative review	Carwile et al (2025) [4]	PLOS Glob Public Health	Concealment driven by fear of dismissal, lost marriage prospects and social exclusion; rural patients conceal with more difficulty, while urban/higher-income patients report actual discrimination roughly twice as often. Self-stigma is inseparable from gender and social position.
<i>Psycho-socio-economic issues challenging multidrug-resistant tuberculosis patients: a qualitative study</i>	Qualitative study	Thomas et al (2016)[10]	PLoS One	PWTB frequently conceal the diagnosis from employers and wider family, fearing job loss, damaged marriage prospects and severed social ties.
<i>Exploring manifestations of TB-related stigma experienced by women in Kolkata, India</i>	Qualitative study	Mukerji & Turan (2016) [11]	Ann Glob Health	Documents broken engagements, spousal abandonment and social withdrawal; a diagnosis can fundamentally reshape a woman's social world and daily existence.
<i>Depression and stigma among tuberculosis patients in a tertiary care hospital in India</i>	Cross-sectional study	Lytton et al (2025) [12]	Indian J Tuberc	Depression elevated among PWTB; stigma and psychological distress reinforce one another in both directions.
<i>Dual burden of TB and mental ill-health: anxiety and depression among TB patients in Gujarat</i>	Cross-sectional study	Chauhan et al (2024) [13]	J Family Med Prim Care	Anxiety and depression markedly elevated among TB patients, compounding the experience of stigma.
<i>Mental health impacts of multidrug-resistant tuberculosis in patients and household contacts</i>	Mixed-methods study	Murugan et al (2024) [14]	Cureus	MDR-TB patients carry a heavier stigma burden, tied to the social belief that drug resistance reflects a personal failure of responsibility or discipline.

Community and Social Stigma Toward Persons with Tuberculosis

In India, community-level stigma toward people with TB tends

to be organised around fear of contagion that significantly exceeds what the epidemiological situation warrants. [Table2]

Table 2: Summary of studies on community and social stigma toward persons with TB

Title	Study design	Author(s) (year)	Journal	Key findings
<i>Gender and community views of stigma and tuberculosis in rural Maharashtra, India</i>	EMIC-based community survey (n=160)	Atre et al (2011) [15]	Glob Public Health	Community members endorse distancing behaviours avoiding contact, separate utensils, exclusion from shared spaces); when the patient is a woman, TB is additionally attributed to hereditary family weakness.
<i>TB stigma in India: a narrative review of types of stigma, gender differences and potential interventions</i>	Narrative review	Carwile et al (2025) [4]	PLOS Glob Public Health	Across Puducherry, Gujarat, West Bengal and other states, TB is culturally entangled with poverty, moral failing and sometimes divine punishment, priming anticipated stigma.
<i>Perceptions of stigma among medical and nursing students and TB and diabetes patients at a teaching hospital in southern India</i>	Comparative study	Vaz et al (2016) [16]	PLoS One	Health-professional students held considerably more negative attitudes toward TB patients than toward patients with diabetes, a condition of comparable clinical complexity.
<i>Cross-cultural reliability of the Van Rie TB perceived stigma scale among TB survivors in North India</i>	Cross-sectional validation study (n=400)	Saha et al (2024) [17]	Indian J Tuberc	Community Perspectives Van Rie TB Stigma Scale showed strong psychometric performance in Indian settings (Cronbach's 0.826; McDonald's 0.832).

Perceived Stigma and Its Impact on Treatment Adherence

The influence of stigma on treatment adherence is not limited to a single moment in the care pathway—it operates as a

persistent force from the point at which symptoms first appear through to the completion of the full treatment course. [Table 3]

Table 3: Summary of studies on perceived stigma and its impact on treatment adherence

Title	Study design	Author(s) (year)	Journal	Key findings
<i>Tuberculosis and stigmatization: pathways and interventions</i>	Review	Courtwright & Turner (2010) [2]	Public Health Rep	Fear of what a positive result means socially leads patients to delay care-seeking and postpone confirmatory testing that would trigger treatment.
<i>TB stigma in India: a narrative review of types of stigma, gender differences and potential interventions</i>	Narrative review	Carwile et al (2025) [4]	PLOS Glob Public Health	Concealment creates practical adherence barriers — difficulty taking tablets openly, skipped appointments and higher risk of discontinuation once the emotional cost of secrecy becomes too high.
<i>Exploring manifestations of TB-related stigma experienced by women in Kolkata, India</i>	Qualitative study	Mukerji & Turan (2016) [11]	Ann Glob Health	Women face a disclosure–DOTS dilemma: attending observed treatment usually requires disclosing to a family member, yet disclosure can jeopardise marriage and invite ostracism.
<i>Experiences of patients co-infected with HIV and multidrug-resistant tuberculosis</i>	Qualitative study (lost to follow-up)	Isaakidis et al (2013) [18]	Trop Med Int Health	Social humiliation from neighbours, employers and family members was a central reason for abandoning MDR-TB treatment.
<i>Dual burden of TB and mental ill-health: anxiety and depression among TB patients in Gujarat</i>	Cross-sectional study	Chauhan et al (2024) [13]	J Family Med Prim Care	Stigma-related depression and anxiety further erode patients' capacity to stay engaged with treatment.

<i>Mental health impacts of multidrug-resistant tuberculosis in patients and household contacts</i>	Mixed-methods study	Murugan et al (2024) [14]	Cureus	Psychological consequences of stigma — depression, withdrawal, a diminished sense of self-worth — undermine adherence, especially in MDR-TB.
<i>Depression and stigma among tuberculosis patients in a tertiary care hospital in India</i>	Cross-sectional study	Lytton et al (2025) [12]	Indian J Tuberc	Stigma-related exclusion deepens an already precarious economic situation, reducing patients' ability to prioritise treatment over immediate survival needs.

Interventions to Reduce Perceived TB Stigma in India

Since 2015, India's programmatic response to TB stigma has taken shape primarily through government-led initiatives, community engagement models, and an expanding use of

digital tools. The Nikshay Mitra initiative, which began in September 2022 under the Pradhan Mantri TB Mukht Bharat Abhiyan, takes a more direct approach to the psychosocial dimensions of TB. [Table 4]

Table 4: Summary of studies and programmes on interventions to reduce perceived TB stigma in India

Title	Study design	Author(s)	Journal	Key findings
<i>Nikshay Poshan Yojana: direct benefit transfer for TB patients</i>	Government policy document / scheme	Ministry of Health and Family Welfare (2018) [8]	Government of India	Monthly cash transfer (500, raised to 1,000 from Nov 2024) offsets treatment costs and may reduce the economic vulnerability that stigma feeds on; direct effect on stigma not yet formally evaluated.
<i>Nikshay Mitra: a remarkable initiative in efforts against tuberculosis</i>	Commentary / programme appraisal	Yadav et al (2024) [19]	Cureus	Characterises Nikshay Mitra as a promising, structurally sound model for humanising treatment through nutritional, diagnostic and rehabilitation support; stigma-specific impact not yet measured.
<i>Lessons and updates from India's National TB Elimination Program</i>	Programme review / update	Singh et al (2025) [20]	IJID Reg	More than 100,000 Nikshay Mitra volunteers registered by April 2025, reaching hundreds of thousands of patients nationwide.
<i>Community health workers augment the cascade of TB detection to care in urban slums of two metro cities in India</i>	Implementation study	Potty et al (2021) [21]	J Glob Health	Community health workers strengthen the detection-to-care cascade and show the feasibility of embedding stigma-sensitive messaging into routine TB outreach.
<i>Systematic review of barriers and enablers of TB diagnosis, notification and intervention in tribal communities of India</i>	Systematic review	Satav et al (2025) [22]	J Glob Health	Identifies barriers and enablers and supports customised, community-platform (e.g. Panchayati Raj) intervention packages to reach under-served groups.
<i>Intervention pathways to reduce tuberculosis-related stigma: a literature review and conceptual framework</i>	Literature review / conceptual framework	Nuttall et al (2022) [23]	Infect Dis Poverty	Maps intervention pathways and offers a conceptual framework to guide TB stigma-reduction efforts.
<i>How digital solutions can reimagine TB care</i>	Grey literature / programme report	Jain I, (2023) [24]	PATH	Digital tools (99-DOTS, Video-Observed Therapy, TB Aarogya Sathi) enable remote adherence confirmation and education, reducing the risk of inadvertent disclosure.

DISCUSSION

Taken together, more than a decade of research from across India tells a consistent and sobering story: perceived TB stigma is widespread, structurally embedded, and clinically consequential. Continuing to treat stigma as a background social issue rather than a frontline clinical and programmatic priority is a position that India's TB programme can no longer reasonably maintain. The odds of experiencing stigma are dramatically higher for female patients than for male ones, and the pathways through which this happens are specific and identifiable: cultural norms that tie a woman's social worth to her health and reproductive capacity, family anxieties about marriage prospects, and the expectation that illness

represents a form of personal or familial failure [4,5]. India's TB programme, however, has largely been designed without these gendered pathways in mind. Effective responses will need to move beyond the individual patient and engage the broader social environment, including male family members, in-laws, and community leaders.

The SWOT analysis presented in Table 5 makes clear that India is not starting from nothing. The Nikshay Mitra programme, the established NTEP district infrastructure, the survivor advocacy movement, and the availability of validated stigma measurement tools all represent genuine strengths.

Table 5: SWOT Analysis of TB Stigma Reduction Strategies in India

STRENGTHS	WEAKNESSES
–Nikshay Mitra programme with >100,000 volunteers enrolled [20] –Nationwide NTEP infrastructure at district level [1] –Growing TB Champions and survivor advocacy networks –Validated stigma tools (EMIC, Van Rie) available for Indian settings [17] –Strong political commitment to TB elimination	–No stigma monitoring tool integrated into the Nikshay platform –Limited stigma-sensitive training for ASHA workers –Weak evidence base on which interventions actually reduce stigma –Almost no longitudinal data on stigma trends over time –Gender-neutral programme design despite women's higher vulnerability [4,5]

OPPORTUNITIES

–Nikshay, 99-DOTS, and TB Aarogya Sathi platforms can host stigma screening modules [24]
 –Survivor-led peer support models can be scaled through existing community frameworks
 –Panchayati Raj bodies as platforms for community-level TB awareness campaigns [22]
 –Regional language IEC materials for contextually appropriate messaging
 –Integration of mental health support within routine TB care services [12,13]

***EMIC = Explanatory Model Interview Catalogue; NTEP = National Tuberculosis Elimination Programme; ASHA = Accredited Social Health Activist; IEC = Information, Education, and Communication.**

CONCLUSION

Perceived TB stigma in India is a serious and pervasive problem that has direct, measurable consequences for health outcomes. It delays diagnosis, fractures treatment adherence, and inflicts real psychosocial harm, and its burden is not evenly distributed, falling with particular force on women, people in rural settings, and those living with MDR-TB. India has built real programmatic assets through NTEP, Nikshay Mitra, and community health platforms, and these provide a genuine foundation to work from. But translating those assets into systematic stigma reduction would require standardised measurement tools embedded in national surveillance, longitudinal data to track whether interventions are working, and a gender-responsive programme design. Looking ahead, several priorities emerge from this synthesis: a validated stigma screening instrument, specifically the Community Perspectives Van Rie TB Stigma Scale should be embedded within the Nikshay digital platform so that stigma can be monitored routinely at both the patient and community levels.

Conflict of interests: Authors declare no competing interests.

Funding: None

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THREATS

–Deep-rooted cultural associations between TB, poverty, and moral failure [4]
 –Gender inequity amplifying stigma experienced by women across multiple social domains [5]
 –Rural-urban disparities in healthcare access and programme reach
 –MDR-TB patients facing compounded stigma arising from drug resistance framing [14,18]
 –Risk of increased stigma exposure with intensified active case-finding campaigns

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