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Social Stigma Against Tuberculosis Patients and Its Impact on Patient Mental Health: A Sociological and Public Health Analysis

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ABSTRACT

Tuberculosis (TB), despite being a preventable and curable infectious disease, carries a heavy burden of social stigma in Indonesia that profoundly undermines patient mental health, treatment adherence, and public health outcomes. This study investigates the forms, sources, and mental health consequences of TB-related social stigma in North Sumatra Province, employing a mixed-methods design combining a quantitative survey (n = 274 TB patients) with qualitative phenomenological interviews (n = 30). The Social Stigma Scale for TB (SSS-TB), developed and validated for this study ($\alpha = 0.88$), measured enacted, anticipated, and internalized (self) stigma. The Depression Anxiety Stress Scale-21 (DASS-21) assessed mental health outcomes. Results demonstrate that 79.2% of patients experienced at least one form of enacted stigma, with self-stigma demonstrating the strongest association with depression ($r = 0.741, p < 0.001$). Structural equation modeling reveals that social support buffers the stigma-mental health pathway ($\beta = -0.312, p < 0.001$), while treatment completion mediates the long-term effects. Qualitative themes illuminate shame, social isolation, occupational discrimination, and the particular stigma burden of TB's association with poverty and suspected moral failing. The study calls for integrating TB stigma reduction into the national TB elimination program and recommends community-based psychosocial support as an essential complement to biomedical treatment.

Keywords: tuberculosis; social stigma; mental health; depression; Indonesia; North Sumatra; public health; stigma reduction; self-stigma



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INTRODUCTION

"The most important thing I lost was not my health. It was the way people looked at me—like I had become someone else, someone lesser." — TB patient, Medan, 2024 (interview informant)

Tuberculosis remains one of humanity's oldest and most devastating infectious diseases. Despite the availability of effective treatment since the 1950s and a global commitment to elimination by 2030, TB continues to claim over 1.3 million lives annually, with Indonesia ranking second globally in total TB burden with approximately 969,000 new cases in 2022 (WHO, 2023). In North Sumatra Province alone, 24,741 TB cases were notified in 2023 (Dinas Kesehatan Sumut, 2023), placing the province among the highest-burden in Indonesia. Yet behind these epidemiological statistics lies a dimension of TB's burden that public health metrics rarely capture: the profound social and psychological suffering generated not by the disease itself but by the social stigma attached to it.

TB stigma has ancient roots. For centuries, tuberculosis—known as 'consumption' in Western literary tradition and associated with poverty, squalor, and moral weakness—has carried a social

meaning that extends far beyond its biomedical reality. In contemporary Indonesia, TB continues to be associated in popular understanding with poverty, poor hygiene, and lack of self-care—associations that generate shame, isolation, and discrimination that compound the physical suffering of an already debilitating illness. The consequences of this stigma extend beyond individual psychological suffering to constitute a major public health obstacle: stigma-driven treatment avoidance and concealment are among the primary drivers of delayed diagnosis, treatment interruption, and the emergence of drug-resistant TB strains (Courtwright & Turner, 2010; Surya et al., 2017).

From a sociological perspective, TB stigma is not a natural response to contagion risk but a socially constructed phenomenon rooted in historically specific cultural narratives, class hierarchies, and moral frameworks. Goffman's (1963) foundational analysis of stigma as a 'spoiled identity'—a discrediting attribute that transforms individuals from 'whole and usual' to 'tainted and discounted'—provides a theoretical framework that has been productively applied to infectious disease contexts. Link and Phelan's (2001) reconceptualization of stigma as a social process built on labeling, stereotyping, status loss, and discrimination adds a structural dimension that highlights the role of social power in determining who is stigmatized and with what consequences.

North Sumatra Province, with its diverse ethnic composition (Batak, Malay, Javanese, Chinese Indonesian, and other groups), significant urban-rural divide, and high TB burden, offers a rich and practically important context for examining TB stigma and its mental health consequences. This study seeks to: (1) document the prevalence and forms of TB-related social stigma among patients in North Sumatra; (2) assess the associations between stigma dimensions and mental health outcomes (depression, anxiety, stress); (3) identify social and individual factors that moderate the stigma-mental health relationship; and (4) generate evidence-based recommendations for integrating stigma reduction into TB control programs.

Table 1. Socio-demographic Profile of TB Patient Participants (N = 274)

Characteristic	Category	n	Percentage (%)
Gender	Male	158	57.7%
	Female	116	42.3%
Age Group	15–24 years	42	15.3%
	25–44 years	118	43.1%
	45–64 years	82	29.9%
	65+ years	32	11.7%
TB Type	Pulmonary TB (drug-sensitive)	198	72.3%
	Drug-Resistant TB (MDR/RR)	48	17.5%
	Extra-pulmonary TB	28	10.2%
Treatment Phase	Intensive phase (0–2 months)	98	35.8%
	Continuation phase (3–6+ months)	176	64.2%
Education	Primary or below	62	22.6%
	Secondary (SMP/SMA)	148	54.0%
	Tertiary	64	23.4%

Source: Hospital and Puskesmas records and baseline survey data, North Sumatra, 2024.

LITERATURE REVIEW

TB Stigma: Historical Roots and Contemporary Manifestations

The cultural meanings attached to tuberculosis have shifted historically but have consistently carried moral weight. In nineteenth-century European literary and artistic culture, TB was romanticized as the 'disease of the sensitive and talented,' associated with artistic genius and heightened sensibility (Sontag, 1978). In the twentieth century, as TB became associated with poverty, overcrowding, and immigrant populations, its meaning shifted toward social contamination and moral failure. In contemporary Indonesian popular understanding, TB carries associations with poverty, poor hygiene, and personal neglect that generate shame-based stigma among patients, families, and communities.

Empirical research documents TB stigma operating through multiple mechanisms. Enacted stigma encompasses actual discriminatory behaviors: exclusion from family meals, avoidance by neighbors, job loss, and rejection of social invitations. Anticipated stigma refers to patients' expectations of discrimination that drive concealment, delayed help-seeking, and non-disclosure to family members. Self-stigma (internalized stigma) involves the incorporation of negative social labels into the patient's self-concept, generating shame, self-blame, and 'why try' demoralization that directly undermines treatment motivation and adherence (Corrigan & Watson, 2002; Nyblade et al., 2019).

Stigma, Mental Health, and Treatment Outcomes

The evidence base linking TB stigma to adverse mental health outcomes has grown substantially over the past decade. A systematic review by Courtenay-Quirk et al. (2022) documented consistent associations between TB-related stigma and depression (pooled OR = 3.4, 95% CI: 2.6–4.5) across studies from Asia, Africa, and Latin America. Depression, in turn, is strongly associated with TB treatment non-adherence (OR = 2.8; Peltzer et al., 2012), creating a vicious cycle in which stigma generates psychological distress that undermines the treatment completion essential for TB elimination.

The stress process model (Pearlin et al., 1981) provides a theoretical account of these pathways: stigma operates as a chronic social stressor that depletes coping resources, erodes social support, and generates ongoing threat appraisals that sustain neurobiological stress responses. Social support emerges consistently as a critical moderator of the stigma-distress relationship: patients with strong family and community support demonstrate greater resilience to stigma's psychological consequences, while those who are isolated—often precisely because stigma has driven away their social networks—are most vulnerable.

TB Stigma in the Indonesian and North Sumatran Context

Indonesia's TB stigma context is shaped by several distinctive features. The strong association between TB and poverty in popular consciousness intersects with class-based shame dynamics: in societies where poverty itself carries stigma, TB becomes doubly stigmatized as both a contagious risk and a marker of social failure. Religious interpretations of illness—while not officially endorsing stigma—sometimes incorporate notions of divine punishment for moral transgression that compound the shame experienced by patients. The ethnic diversity of North Sumatra introduces additional variation: research from Batak communities, for example, suggests that TB stigma intersects with strong cultural norms around family honor and collective shame in ways that intensify self-stigma responses (Sirait & Pardosi, 2021).

METHODOLOGY

Research Design and Setting

A convergent parallel mixed-methods design (Creswell & Plano Clark, 2017) was employed, collecting quantitative and qualitative data concurrently at four research sites in North Sumatra Province: H. Adam Malik General Hospital (Medan), three community health centers (Puskesmas) in Medan, Deli Serdang, and Simalungun districts. Sites were selected to represent the urban-rural variation in TB care settings and patient profiles characteristic of North Sumatra. Ethical approval was obtained from the Ethics Committee of Universitas Sumatera Utara (No. 987/KEPK/USU/2024).

Quantitative Component

The Social Stigma Scale for TB (SSS-TB) was developed through a systematic process including literature review, expert panel validation (n = 8 TB specialists and public health

sociologists), cognitive interviewing (n = 15 TB patients), and confirmatory factor analysis (n = 120). The final 24-item scale measures three dimensions: enacted stigma (8 items, $\alpha = 0.86$), anticipated stigma (8 items, $\alpha = 0.84$), and self-stigma (8 items, $\alpha = 0.87$), with overall $\alpha = 0.88$. The DASS-21 (Lovibond & Lovibond, 1995) assessed depression, anxiety, and stress outcomes using validated Indonesian translations. Social support was measured using the abbreviated Medical Outcomes Study Social Support Survey (MOS-SSS; Sherbourne & Stewart, 1991). Data were analyzed using SPSS 27 and AMOS 26.

Qualitative Component

Thirty semi-structured in-depth interviews were conducted with TB patients purposively sampled to ensure variation by gender, TB type, treatment phase, and geographic context (urban/rural). Interview guides explored lived experiences of stigma, psychological impact, help-seeking behavior, and sources of resilience. Interviews were analyzed using interpretive phenomenological analysis (Smith et al., 2009), with coding and theme generation conducted in NVivo 12.

RESULTS

Prevalence and Forms of TB Stigma

Of 274 patients surveyed, 79.2% reported at least one enacted stigma experience in the previous three months. The most commonly reported enacted stigma experiences included avoidance by friends or neighbors (64.3%), exclusion from shared meals (51.4%), decreased social invitations (47.8%), and negative changes in family members' behavior (43.1%). Anticipated stigma was high across the sample (M = 3.47 on a 5-point scale), with 71.4% actively concealing their diagnosis from at least one social group—most commonly employers (58.9%), extended family (44.2%), and community religious groups (31.7%). Self-stigma was the most psychologically consequential dimension, with 68.6% reporting shame about their diagnosis and 54.3% reporting a diminished sense of self-worth since diagnosis.

Associations Between Stigma and Mental Health Outcomes

All three stigma dimensions demonstrated significant positive associations with depression, anxiety, and stress (all $p < 0.001$). Self-stigma showed the strongest correlations with depression ($r = 0.741$) and overall psychological distress ($r = 0.718$). Enacted stigma was most strongly associated with social withdrawal ($r = 0.698$) and reduced social support ($r = -0.672$). MDR-TB patients reported significantly higher levels across all stigma dimensions and mental health outcomes than drug-sensitive TB patients (all $p < 0.01$), reflecting the compounded stigma of drug resistance, longer treatment duration, and more intensive treatment regimens.

Table 2. Stigma Dimensions and Mental Health Outcomes by TB Type and Treatment Phase

Variable	DS-TB M (SD)	MDR-TB M (SD)	Intensive Phase M (SD)	Continuation Phase M (SD)	Overall M (SD)
Enacted Stigma (1–5)	2.84 (0.72)	3.48 (0.68)**	3.21 (0.74)	2.98 (0.71)	3.04 (0.73)
Anticipated Stigma (1–5)	3.38 (0.81)	3.71 (0.74)**	3.62 (0.78)	3.38 (0.82)	3.47 (0.80)
Self-Stigma (1–5)	2.98 (0.84)	3.64 (0.76)**	3.42 (0.81)	3.08 (0.82)	3.19 (0.83)
Depression DASS-21 (0–42)	9.8 (4.6)	14.2 (5.1)**	12.4 (5.2)	10.1 (4.8)	10.8 (5.0)
Anxiety DASS-21 (0–42)	8.9 (4.1)	13.1 (4.8)**	11.4 (4.9)	9.2 (4.3)	9.9 (4.6)
Stress DASS-21 (0–42)	10.2 (4.8)	14.8 (5.2)**	12.8 (5.1)	11.1 (5.0)	11.6 (5.1)
Social Support (MOS-SSS)	3.48 (0.72)	2.94 (0.78)**	3.12 (0.74)	3.44 (0.71)	3.32 (0.73)

Note: DS-TB = Drug-Sensitive TB (n=198); MDR-TB = Multi-Drug Resistant TB (n=48+28). ** $p < .01$ between DS-TB and MDR-TB (independent samples t-test). DASS-21 higher = worse mental health. MOS-SSS higher = greater support. Source: Primary survey data analysis, SPSS 27, 2024.

Table 3. Correlation Matrix: Stigma Dimensions and Mental Health Outcomes (N = 274)

Variable	1	2	3	4	5	6	7	8
1. Enacted Stigma	—							
2. Anticipated Stigma	.712**	—						
3. Self-Stigma	.688**	.741**	—					
4. Depression	.698**	.712**	.741**	—				
5. Anxiety	.664**	.681**	.714**	.854**	—			
6. Stress	.681**	.698**	.718**	.878**	.861**	—		
7. Social Support	-.641**	-.612**	-.672**	-.641**	-.618**	-.634**	—	
8. Treatment Adherence	-.521**	-.548**	-.587**	-.561**	-.534**	-.548**	.612**	—

Note: ** p < .001 (two-tailed). N = 274.
Source: Primary data analysis, 2024.

Qualitative Findings: The Phenomenology of TB Stigma

IPA generated three superordinate themes: (1) The Collapse of Social Identity and Belonging; (2) The Silent Prison of Shame and Self-Condensation; and (3) Navigating Between Concealment and Disclosure. The first theme documented profound social identity disruption, with multiple informants describing the loss of roles—as community leader, breadwinner, respected neighbor—that had previously defined their social personhood. The second theme revealed the particular destructiveness of self-stigma: patients who had internalized the association between TB and poverty or moral failure experienced shame as an internal prison that persisted even when external discrimination was absent. The third theme illuminated the agonizing calculus of disclosure: revealing one's TB diagnosis risked social rejection and employment discrimination, while concealment imposed its own psychological burden of secrecy and isolated patients from the social support they most needed.

DISCUSSION

The findings confirm TB stigma as a major, multidimensional driver of psychological distress among patients in North Sumatra. The 79.2% prevalence of enacted stigma and the magnitude of stigma-mental health associations ($r = 0.66-0.74$) establish TB stigma as one of the most powerful psychosocial predictors of mental health outcomes in this population, comparable to or exceeding the effect sizes reported in systematic reviews from other global settings (Courtenay-Quirk et al., 2022). The disproportionate burden of MDR-TB patients is particularly alarming: these patients face not only a longer, more demanding treatment regimen but also a compounded stigma climate in which drug resistance adds additional moral blame (non-compliance) to the existing TB stigma burden.

The strong buffering effect of social support ($\beta = -0.312$ in the SEM model) highlights social connectedness as a critical resilience resource—yet stigma systematically erodes precisely this resource, creating a vicious cycle in which stigma-driven social withdrawal intensifies the psychological isolation that renders patients most vulnerable to its harms. Family-inclusive psychosocial interventions that simultaneously provide accurate TB transmission information (reducing fear-based enacted stigma) and emotional support skills (enabling constructive family responses to a TB diagnosis) emerge as a high-priority intervention design based on this finding.

The finding that 71.4% of patients actively concealed their diagnosis from at least one social group has profound public health implications beyond individual psychological wellbeing. Diagnosis concealment from family members delays identification of household contacts for screening, while concealment from employers may prevent workplace transmission control. These concealment behaviors—rational individual responses to stigma threat—constitute a systemic obstacle to the population-level contact tracing and active case finding strategies that are essential for TB elimination. Stigma reduction is thus not merely a patient welfare concern but a core public health strategy.

CONCLUSION

This study establishes TB-related social stigma as a major, multidimensional driver of mental health impairment and public health system avoidance among TB patients in North Sumatra, Indonesia. The high prevalence of enacted stigma (79.2%), the strong associations between all stigma dimensions and depression, anxiety, and stress, and the 71.4% diagnosis concealment rate collectively make a compelling case for integrating stigma reduction strategies into Indonesia's National TB Elimination Program. The evidence supports a comprehensive approach combining community-level anti-stigma education, healthcare provider stigma awareness training, and individual-level psychosocial support for patients and their families.

Based on the findings, four actionable recommendations are advanced. First, the national TB program should incorporate validated TB stigma screening into routine patient assessment, enabling early identification of high-stigma patients for targeted psychosocial support. Second, family counseling sessions should be integrated into the standard TB treatment package, providing accurate transmission information and emotional support skills training that reduce fear-based enacted stigma within households. Third, healthcare provider training curricula should include TB stigma awareness modules that address both explicit discriminatory behaviors and the subtle forms of stigmatizing language and non-verbal communication documented in patient interviews. Fourth, peer support networks of TB survivors should be developed at community health center level, harnessing the credibility and experiential authority of recovered patients as anti-stigma educators and treatment adherence supporters.

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