International Journal of Economics, Management and Social Science
Vol 9 No 1 March 2026
E-ISSN: 2614-3828 | P-ISSN: 2614-3887
Open Access: https://journal.salewangang.net/ijemss/index

Social Stigma Against Patients with Infectious Diseases and Its Impact on Patient Mental Health

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Article Info :
Received:
17/02/2026
Revised:
20/02/2026
Accepted:
24/02/2026

ABSTRACT

Social stigma associated with infectious diseases represents a pervasive and damaging phenomenon that undermines the mental health and social wellbeing of affected patients. This study investigates the forms, mechanisms, and mental health consequences of disease-related stigma using a mixed-methods approach combining a structured survey (n = 285) with qualitative interviews among patients diagnosed with tuberculosis (TB), HIV/AIDS, and leprosy in three provincial hospitals in Eastern Indonesia. Quantitative analysis employing the Social Stigma Scale for Infectious Diseases (SSSID) and the Depression Anxiety Stress Scale-21 (DASS-21) revealed significant associations between experienced stigma and elevated levels of depression ($r = 0.684$, $p < 0.001$), anxiety ($r = 0.651$, $p < 0.001$), and social withdrawal ($r = 0.712$, $p < 0.001$). Logistic regression identified enacted stigma, self-stigma, and healthcare provider stigma as independent predictors of clinically significant mental health impairment. Qualitative themes illuminate the social dynamics of isolation, shame, and identity disruption experienced by patients. The findings call for integrating stigma-reduction strategies into infectious disease management protocols and advocate for a sociology-informed public health approach that addresses the structural roots of disease stigma.

Keywords: social stigma; infectious disease; mental health; tuberculosis; HIV/AIDS; public health sociology; stigma reduction

1. INTRODUCTION

Stigma, conceptualized by Erving Goffman as a 'spoiled identity,' fundamentally transforms an individual from a 'whole and usual person to a tainted, discounted one' (Goffman, 1963, p. 3). In the domain of public health, disease-related stigma operates as a social mechanism that assigns moral culpability, fear, and disgust to individuals affected by certain illnesses, with particularly devastating consequences observed in the context of infectious diseases. The historical persistence of stigma associated with conditions such as leprosy, tuberculosis (TB), and HIV/AIDS reflects deep-rooted cultural anxieties about contagion, mortality, and social contamination that transcend specific epidemiological realities.

Indonesia faces a significant burden from infectious diseases with high stigma potential. As of 2023, Indonesia ranks second globally in tuberculosis incidence, with approximately 969,000 new cases annually (WHO, 2023). HIV/AIDS prevalence continues to rise, particularly in eastern Indonesian provinces, with over 550,000 cumulative reported cases (Kemenkes RI, 2023). Leprosy, though reduced in prevalence since the 1990s, remains a significant public health challenge in pockets of Papua, West Nusa Tenggara, and North Maluku, with Indonesia consistently among the top three countries globally for new case detection.

The mental health consequences of disease stigma are well-documented in high-income country contexts but remain substantially understudied in Indonesia and comparable lower-middle-income settings. The limited available evidence suggests that stigma-related psychological distress constitutes a major barrier to treatment-seeking, medication adherence, and social reintegration among infectious disease patients in Indonesia (Tesema et al., 2022; Kipp et al., 2020). This treatment avoidance, paradoxically, contributes to ongoing transmission and worsening epidemiological outcomes, creating a vicious cycle in which stigma undermines the very public health interventions designed to control disease spread.

From a sociological perspective, disease stigma is not a natural or inevitable response to illness but a socially constructed phenomenon rooted in historically specific cultural narratives, power relations, and boundary-drawing practices (Link & Phelan, 2001). Understanding stigma as a social process—rather than a psychological attribute of individuals—reframes the research question from 'how do we help patients cope with stigma?' to 'how do we transform the social conditions that produce and sustain stigmatization?' This sociological reframing has profound implications for intervention design and public health policy.

This study addresses three primary research questions: (1) What are the predominant forms and sources of stigma experienced by infectious disease patients in Eastern Indonesia? (2) To what extent is experienced stigma associated with adverse mental health outcomes? (3) What sociological mechanisms mediate the relationship between stigma and mental health impairment? The answers to these questions are intended to inform both theoretical development in health sociology and practical intervention design in Indonesian public health systems.

Table 1. Participant Demographics by Disease Category

Characteristic	TB (n=105)	HIV/AIDS (n=95)	Leprosy (n=85)	Total (n=285)
Mean Age (years)	38.2 (SD=11.4)	34.7 (SD=9.8)	44.1 (SD=13.2)	38.8 (SD=11.7)
Male (%)	58.1%	62.1%	55.3%	58.6%
Female (%)	41.9%	37.9%	44.7%	41.4%
Rural Residence (%)	43.8%	28.4%	67.1%	45.6%

Formal Education < SMA (%)	52.4%	38.9%	71.8%	54.0%
Duration of Illness (months, mean)	14.3	31.7	48.2	29.6

Source: Hospital medical records and baseline survey data, 2024. TB = Tuberculosis; SD = Standard Deviation; SMA = Senior High School.

2. LITERATURE REVIEW

2.1 Theoretical Frameworks for Disease Stigma

Goffman's foundational stigma framework (1963) identifies three forms of stigmatizing attributes: physical deformities, individual character flaws, and tribal identities. Infectious diseases engage all three: the visible bodily manifestations of leprosy and advanced AIDS engage physical stigma; the perceived recklessness associated with TB transmission and the moral condemnation of sexual behavior linked to HIV invoke character-based stigma; and the ethnic, class, and community associations of disease risk groups activate tribal stigmatization. This multi-dimensional quality of infectious disease stigma renders it particularly resistant to simple informational interventions.

Link and Phelan's (2001) reconceptualization of stigma as a social process built upon the components of labeling, stereotyping, separation, status loss, and discrimination provides a more sociologically precise analytical framework. This model emphasizes that stigma depends fundamentally on social, economic, and political power: those who are stigmatized are typically those who lack the power to challenge, deflect, or resist stigmatizing labels. In the Indonesian context, the intersection of disease stigma with poverty, rural residence, and educational disadvantage amplifies the power dimensions of the stigma process.

2.2 Stigma and Mental Health: Evidence and Mechanisms

The evidence base linking disease stigma to adverse mental health outcomes has grown substantially over the past two decades. Meta-analytic reviews demonstrate consistent associations between HIV stigma and depression (standardized mean difference = 0.81; Rueda et al., 2016) and between TB stigma and treatment non-adherence (OR = 3.2; Somma et al., 2008). Evidence from leprosy-endemic settings in India and Brazil documents severe psychological consequences including social isolation, shame-related suicide ideation, and identity disruption (Sermrittirong & Van Brakel, 2014).

Multiple psychological and social mechanisms mediate the relationship between experienced stigma and mental health outcomes. The stress process model (Pearlin et al., 1981) posits that stigma operates as a chronic social stressor that depletes coping resources, erodes social support, and generates ongoing threat appraisals that sustain neurobiological stress responses. Self-stigma—the internalization of negative social labels—further compounds these effects through shame, self-devaluation, and 'why try' demoralization (Corrigan & Watson, 2002).

2.3 Stigma in the Indonesian Sociocultural Context

Indonesian cultural contexts introduce specific dynamics into disease stigma processes. The concept of malu (shame) occupies a central position in Indonesian social psychology, making self-stigma and concealment particularly prominent responses to stigmatizing diagnoses. The importance of harmonious social relations (kerukunan) and face-saving in Javanese and other Indonesian cultures creates powerful incentives to avoid visible association with stigmatized conditions, even at the cost of treatment access (Good et al., 2007).

Religious interpretations of disease causation also shape stigma dynamics in Indonesia. While mainstream Islamic theological teaching does not support the stigmatization of disease patients, lay understandings frequently attribute illness to divine punishment for moral failings, particularly in the cases of HIV/AIDS and sexually transmitted infections. Community-level religious leaders' attitudes toward stigmatized patients significantly mediate local stigma climates (Ismail et al., 2020).

3. METHODOLOGY

3.1 Study Design and Setting

A convergent parallel mixed-methods design was employed (Creswell & Plano Clark, 2017), collecting quantitative survey data and qualitative interview data concurrently. The study was conducted in three provincial hospitals in Eastern Indonesia: Dr. J. H. Awaloei Hospital (North Sulawesi), Abepura General Hospital (Papua), and W.Z. Johannes Hospital (East Nusa Tenggara). These sites were selected for their high infectious disease case loads and diverse patient populations. Ethical approval was obtained from the ethics committees of Universitas Muhammadiyah Malang and each participating hospital.

3.2 Participants and Sampling

Participants were adult patients (aged 18 and above) diagnosed with tuberculosis (n = 105), HIV/AIDS (n = 95), or leprosy (n = 85), recruited through purposive sampling from outpatient clinics and inpatient wards. Exclusion criteria included acute psychosis, severe cognitive impairment, and inability to provide informed consent. Written informed consent was obtained from all participants. Total sample size of 285 was determined a priori based on power analysis for multiple regression with $\alpha = 0.05$, power = 0.80, and medium effect size ($f^2 = 0.15$).

3.3 Measures

The Social Stigma Scale for Infectious Diseases (SSSID) was developed and validated for this study through a five-stage process including literature review, expert panel review (n = 8), cognitive interviewing (n = 15), and confirmatory factor analysis (n = 120). The final 28-item instrument assesses enacted stigma, self-stigma, healthcare provider stigma, and family stigma dimensions (overall $\alpha = 0.91$). The Depression Anxiety Stress Scale-21 (DASS-21; Lovibond & Lovibond, 1995)

was employed to assess mental health outcomes, using validated Indonesian-language translations (α = 0.89 for the full scale in this sample). Social support was assessed using the Medical Outcomes Study Social Support Survey (MOS-SSS; Sherbourne & Stewart, 1991).

3.4 Analysis

Quantitative data were analyzed using SPSS 27 and AMOS 26. Descriptive statistics characterized the sample. Pearson correlations examined bivariate associations. Hierarchical multiple regression examined the independent contribution of stigma dimensions to mental health outcomes after controlling for demographic variables and disease duration. Binary logistic regression identified predictors of clinically significant mental health impairment (DASS-21 scores in the severe or extremely severe range). Qualitative data from 45 semi-structured interviews (15 per disease group) were analyzed using interpretive phenomenological analysis (IPA; Smith et al., 2009), focusing on participants' lived experiences of stigma and its psychological consequences.

Table 2. Descriptive Statistics for Stigma and Mental Health Variables by Disease Group

Variable	TB M (SD)	HIV/AIDS M (SD)	Leprosy M (SD)	Total M (SD)	F (p)
Enacted Stigma	2.87 (0.74)	3.41 (0.68)	3.62 (0.71)	3.26 (0.76)	28.4 (<.001)
Self-Stigma	2.94 (0.81)	3.58 (0.73)	3.71 (0.77)	3.38 (0.81)	31.7 (<.001)
Healthcare Provider Stigma	2.42 (0.69)	2.89 (0.71)	2.67 (0.74)	2.66 (0.73)	12.8 (<.001)
Family Stigma	2.58 (0.88)	3.12 (0.82)	3.34 (0.86)	2.99 (0.90)	18.9 (<.001)
Depression (DASS-21)	8.4 (4.2)	12.7 (5.1)	13.8 (5.4)	11.5 (5.3)	35.2 (<.001)
Anxiety (DASS-21)	7.8 (3.9)	11.4 (4.8)	12.6 (5.1)	10.5 (4.9)	29.8 (<.001)
Stress (DASS-21)	9.1 (4.4)	13.2 (5.0)	14.1 (5.3)	12.0 (5.2)	32.6 (<.001)

Note: M = Mean; SD = Standard Deviation. DASS-21 subscales scored 0–42 (higher = worse). F statistics from one-way ANOVA.

Source: Primary survey data analysis, SPSS 27, 2025.

4. RESULTS

4.1 Prevalence and Forms of Stigma

Stigma was highly prevalent across all three disease groups, with 84.2% of participants reporting at least one form of enacted stigma in the six months preceding the survey. Leprosy patients reported the highest levels of enacted and self-stigma, followed by HIV/AIDS patients and TB patients. Across disease groups, common enacted stigma experiences included exclusion from family meals and community activities (reported by 67.4%), avoidance by neighbors and acquaintances

(61.8%), rejection of social invitations (54.0%), and loss of employment or educational opportunities (38.6%). Healthcare provider stigma, though less prevalent than community stigma, was reported by 43.2% of participants, with the highest rates among HIV/AIDS patients (52.6%).

4.2 Associations Between Stigma and Mental Health

All four stigma dimensions demonstrated significant positive correlations with depression, anxiety, and stress (all $p < 0.001$). Self-stigma showed the strongest associations with depression ($r = 0.724$) and anxiety ($r = 0.698$), while enacted stigma was most strongly correlated with social withdrawal ($r = 0.712$) and perceived social support ($r = -0.681$). Healthcare provider stigma was uniquely associated with treatment avoidance behavior ($r = 0.644$, $p < 0.001$), a finding with critical implications for disease control outcomes.

Table 3. Pearson Correlation Matrix: Stigma Dimensions and Mental Health Outcomes (N = 285)

Variable	1	2	3	4	5	6	7
1. Enacted Stigma	—						
2. Self-Stigma	.741**	—					
3. Provider Stigma	.589**	.612**	—				
4. Family Stigma	.698**	.721**	.534**	—			
5. Depression	.684**	.724**	.601**	.658**	—		
6. Anxiety	.651**	.698**	.587**	.624**	.841**	—	
7. Stress	.672**	.711**	.594**	.639**	.867**	.852**	—

Note: ** $p < 0.001$ (two-tailed).

Source: Primary data analysis, 2025.

4.3 Predictors of Clinically Significant Mental Health Impairment

Binary logistic regression identified clinically significant mental health impairment (DASS-21 scores ≥ 21 for depression, ≥ 15 for anxiety) in 41.8% of participants. After controlling for age, gender, disease duration, and rural/urban residence, self-stigma (OR = 3.87, 95% CI [2.41, 6.21], $p < 0.001$), enacted stigma (OR = 2.94, 95% CI [1.88, 4.60], $p < 0.001$), and healthcare provider stigma (OR = 2.31, 95% CI [1.47, 3.63], $p < 0.001$) were independent significant predictors of clinically significant impairment. Social support was a significant protective factor (OR = 0.34, 95% CI [0.22, 0.53], $p < 0.001$).

4.4 Qualitative Findings: Phenomenology of Stigma and Psychological Distress

IPA analysis generated three superordinate themes: (1) Social Death: The Collapse of Relational Identity; (2) Internalized Shame and the Fragmentation of Self; and (3) Navigating Institutional Stigma: The Healthcare Setting as Stigma Arena.

Participants across all disease groups described experiences of social exclusion so profound as to constitute what several described as a form of 'social death'—the loss of their pre-illness social

identity, roles, and relationships. A leprosy patient from Papua articulated this experience: 'I used to be the head of the village committee. After my diagnosis, I came to meetings and people moved away from me. Eventually I stopped going. I became nobody.' This narrative of identity disruption resonates with Goffman's concept of the spoiled identity and with sociological theorizations of illness as biographical disruption (Bury, 1982).

Self-stigma emerged as particularly psychologically destructive, operating through mechanisms of shame, self-blame, and anticipated rejection that persisted even in the absence of overt discrimination. HIV-positive participants were especially likely to articulate internalized stigma in ways consistent with the 'why try' effect—a demoralization that undermined both treatment adherence and social reintegration efforts. A 29-year-old HIV-positive man stated: 'I know I should take my medication every day, but sometimes I think, what's the point? Even if I survive, nobody will want to be near me.'

Table 4. Logistic Regression Predictors of Clinically Significant Mental Health Impairment (N = 285)

Predictor	B	SE	OR	p	95% CI
Self-Stigma	1.353	0.241	3.87	<.001	2.41–6.21
Enacted Stigma	1.079	0.228	2.94	<.001	1.88–4.60
Healthcare Provider Stigma	0.838	0.231	2.31	<.001	1.47–3.63
Family Stigma	0.714	0.238	2.04	.003	1.28–3.25
Social Support (MOS-SSS)	−1.079	0.224	0.34	<.001	0.22–0.53
Disease Duration (months)	0.021	0.009	1.02	.023	1.00–1.04
Rural Residence (vs. urban)	0.548	0.241	1.73	.023	1.08–2.77
Model $\chi^2(8) = 187.4$, $p < .001$; Nagelkerke $R^2 = 0.548$; Hosmer–Lemeshow $\chi^2(8) = 7.21$, $p = .514$					

Source: Binary logistic regression analysis, SPSS 27, 2024. OR = Odds Ratio; CI = Confidence Interval.

5. DISCUSSION

This study provides comprehensive evidence that social stigma constitutes a major, multidimensional threat to the mental health of infectious disease patients in Eastern Indonesia. The prevalence of clinically significant mental health impairment (41.8%) substantially exceeds general population rates in Indonesia (estimated at approximately 9.8%; Riskesdas, 2018), and the magnitude of stigma-mental health associations (r = 0.65–0.72) places disease stigma among the most powerful psychosocial predictors of mental health outcomes identified in comparable studies.

The differential stigma burden observed across disease groups—with leprosy and HIV/AIDS patients experiencing more severe stigma than TB patients—reflects the distinctive cultural and moral narratives attached to each condition. Leprosy's centuries-long association with divine punishment and ritual impurity in Indonesian religious traditions creates a particularly potent and resistant stigma

climate. HIV/AIDS stigma is compounded by its association with sexual transgression and drug use, domains subject to intense moral regulation in both Islamic and adat (customary) frameworks. TB stigma, while significant, is partially mitigated by its broader social distribution and the availability of effective, well-established treatment.

The identification of healthcare provider stigma as an independent predictor of mental health impairment is a finding that demands urgent attention from health system administrators. Patients who experience stigmatizing treatment from healthcare workers face not only psychological harm but also the erosion of the therapeutic relationship that is essential for sustained treatment engagement. The concentration of provider stigma among HIV/AIDS patients (52.6%) may reflect inadequate pre-service and in-service training on stigma-aware care practices among health professionals assigned to HIV services—a systemic failure that requires immediate remediation.

The protective effect of social support (OR = 0.34) highlights social connectedness as a critical resilience resource for stigmatized patients. Family-based support was particularly valued by participants, but family members themselves frequently served as stigma sources when inadequately informed about disease transmission realities. This paradox—in which the primary potential source of support also functions as a primary source of stigma—points to the urgent need for family-inclusive stigma-reduction interventions that address both knowledge deficits and emotional responses to infectious disease diagnoses.

Link and Phelan's (2001) power-centered framework for understanding stigma is well illustrated by the intersection of disease stigma with poverty, rural residence, and educational disadvantage observed in this study. Rural patients, who reported higher stigma and worse mental health outcomes, are simultaneously the most geographically isolated from mental health services and the most embedded in close-knit communities where social surveillance and norm enforcement are most intense. Addressing disease stigma in these contexts requires community-based interventions that work within rather than against existing social structures.

6. Conclusion

This study establishes that social stigma constitutes a major, multidimensional driver of mental health impairment among infectious disease patients in Eastern Indonesia. The prevalence of stigma, its diverse forms and sources, and the magnitude of its mental health consequences collectively make a compelling case for integrating stigma assessment and reduction into standard infectious disease care protocols. The findings support a sociology-informed public health approach that addresses the structural, cultural, and institutional roots of disease stigma rather than focusing narrowly on individual patient coping.

The theoretical contributions of this study include an empirical elaboration of Link and Phelan's stigma framework in the Indonesian sociocultural context, the development and validation of

the SSSID instrument, and evidence for the role of healthcare provider stigma as an understudied dimension of disease-related stigma with unique consequences for treatment engagement. Practically, the study calls for community-level stigma-reduction campaigns, healthcare provider training in stigma-aware care, and family-inclusive psychosocial support programs for infectious disease patients and their households.

Future research should employ longitudinal designs to establish the temporal directionality of stigma-mental health relationships, investigate the effectiveness of specific stigma-reduction interventions using rigorous experimental designs, and examine the roles of structural factors such as poverty, gender inequality, and healthcare access in moderating the stigma-mental health pathway. Collaborative research involving community members, patients, healthcare providers, and policymakers in co-designing interventions will be essential for achieving sustainable stigma reduction in Indonesian communities.

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