

## Journal of Resilient and Sustainability for Health (JRSH)

## Quantitative Research Article

## Stigma of Tuberculosis in Indonesia: Systematic Literatur Review

Tasya Lukita Cyndi Pradana<sup>1\*</sup>, Wiwien Sugih Utami<sup>2</sup>

\*Corresponding author: Tasya Lukita Cyndi Pradana

## Abstract

**Background/ problem:** Tuberculosis is an infectious disease that is the second most deadly disease in the world. Many factors that cause tuberculosis cannot be resolved, one of which is the stigma of tuberculosis given by the community

**Objective/ purpose:** To examine the types and impacts of tuberculosis stigma and to explore interventions that can reduce stigma and support the healing process of TB patients.

**Design and Methodology:** This research method uses a systematic literature review with PRISMA guidelines. The databases used were from (Science Direct, and PubMed) with cross-sectional and retrospective cohort study designs for quantitative methods, and Forum Group Discussion (FGD) and in-depth interview methods for qualitative methods. There were 6 articles that fit the inclusion criteria, then the researchers analysed them according to the PICOS method.

**Results:** From the 6 articles reviewed, it was found that tuberculosis stigma can be divided into two things, which are stigma originating from within that causes patients to isolate themselves and stigma given by the community so that patients feel ostracised. The impact of tuberculosis stigma received by patients is anxiety and depression.

**Conclusion and Implications:** Tuberculosis stigma can be stopped by educating patients and the general public about the dangers of tuberculosis stigma and providing education about the prevention of tuberculosis with personal protective equipment (masks) so that the stigma of tuberculosis in the community can decrease and the healing process of tuberculosis patients can increase.

## Author Affiliation

ORCID <https://orcid.org/0009-0009-4964-5516>

<sup>1</sup> Postgraduate Program of Public Health Science, University of Jember

<sup>2</sup>Lecturer (Parasitology Department), University of Jember

\*Corresponding author e-mail: [tasyalukita335@gmail.com](mailto:tasyalukita335@gmail.com)

## Article Information

Received: 18 November 2025

Revised: 19 November 2025

Accepted: 21 November 2025

## Keywords

Tuberculosis stigma, pulmonary tuberculosis, systematic literature review, Indonesia

## Introduction (Heading Level 1)

Tuberculosis is an infectious disease that is still a public health problem in the world and in Indonesia. In 2022 worldwide as many as 28,000 people per day were identified with this disease and as many as 4100 experienced death due to this disease (PAHO, 2022). Based on geographical location, the highest prevalence of cases is in Southeast Asia (45.6%), Africa (23.3%) and the Western Pacific (17.8%) (WHO, 2022), while Indonesia is ranked second (9.2%) after India (27.9%) (Direktorat Jendral Pencegahan, 2023). The prevalence of tuberculosis cases in Indonesia in 2022 was 677,464 cases. This number of cases has increased compared to 2021, which was 397,377 cases (Pusdatin, 2023). Tuberculosis disease is always associated with poverty, limited access to health services, and stigma from the community.

Stigma experienced by tuberculosis patients is called tuberculosis stigma, which has been recognized by the Global Fund and the United Nations as a global public health challenge to achieve case elimination by 2050 (Fuady et al., 2023). Prevalence of tuberculosis stigma around the world geographically can affect around 80% of all tuberculosis patients, causing tuberculosis patients to drop out of treatment and isolate themselves not wanting to meet people (Nuttall et al., 2022). Tuberculosis stigma is divided into two, namely: stigma that is experienced, anticipated and internalized by oneself, making it difficult to control the treatment of tuberculosis. Stigma that already exists and is anticipated, ranging from expectations and fears of discrimination to experiences of stigmatization from others, causing tuberculosis patients to experience delays in seeking health services for diagnosis and treatment (Fuady et al., 2024).

Indonesia is a developing country, and the second ranked country worldwide for the incidence of pulmonary tuberculosis. According to (Fuady et al., 2023), one of the causes of the high incidence of tuberculosis in Indonesia is the stigma of tuberculosis from the surrounding community, although in Indonesia there are still very few studies that can explore the stigma of tuberculosis, so on this occasion the researchers wanted to conduct a literature study related to the stigma of tuberculosis in Indonesia.

## Methods (Heading Level 1)

### Research methods

The research method used in this study is a literature study using the PRISMA (Systematic Review and Meta Analyses) Guidelines, which were published in 2009. With this PRISMA guideline, researchers can increase transparency and reliability, making it easier for readers to interpret all their findings (MJ et al., 2021). The literature search used the PubMed database, and ScienceDirect from 2019-2024. The literature search used selected keywords including: ('tuberculosis' AND ('social stigma' OR ('social' AND 'stigma') OR 'social stigma' OR 'stigma')) AND ('Indonesia'). Study selection in this study used inclusion and exclusion criteria. Inclusion criteria included: studies conducted in Indonesia, articles published from 2019-2024, articles discussing pulmonary tuberculosis, articles with quantitative and qualitative research methods, and articles using cross-sectional and case control study designs. Exclusion criteria included: articles in languages other than English, and duplicate articles.

### PICOS

In the process of determining the research topic, the first step taken by the researcher is to develop a research question using the PICOS framework. Table 1 explains the framework of PICOS

Table 1 Framework of PICOS

PICOS framework	Description	Measurement method
Population	Patients with latent, MDR, and active pulmonary tuberculosis of all ages	Doctor's diagnosis
Intervention	Actions taken to reduce the stigma of tuberculosis found in each article	<ul style="list-style-type: none"> <li>• In-depth interview</li> <li>• Survey</li> <li>• Forum group discussion</li> </ul>
Comparator	Does not use comparators	

PICOS framework	Description	Measurement method
Outcome	The given and perceived outcomes of stigma by patients	Questionnaire instrument: <ul style="list-style-type: none"> <li>• The Van Rie TB Stigma Scale</li> <li>• The Zung Anxiety Self-Assessment Scale Questionnaire</li> <li>• The Zung Self-Rating Depression Scale Questionnaire</li> <li>• Questionnaires prepared by researchers based on previous research</li> </ul>
Study design	Quantitative method: <ul style="list-style-type: none"> <li>• Cross sectional</li> <li>• Cohort retrospective</li> </ul> Qualitative method: <ul style="list-style-type: none"> <li>• In-depth interview</li> <li>• FGD</li> </ul>	

## Results

The selection of studies in this systematic review was carried out by the authors independently through the process of searching the literature in predetermined databases. The results obtained from all articles were 321 consisting of PubMed 27 articles, ScienceDirect 294 articles. The next selection process is to enter all articles into the Rayan.ai application. The Rayan.ai application can facilitate researchers in the process of screening and selecting articles. The first selection is to assess duplication in articles that have been found through the search process. From this process, 50 articles were deleted due to duplication, resulting in 271 articles that could be included in the next stage. The next stage is the screening process, which consists of screening the title, abstract and accessibility of the journal. From this stage, 257 journals were excluded because the title and abstract did not match the research topic, and the remaining articles from the screening stage were 16 articles. From 16 articles, screening was carried out by reading the entire article from the background to the conclusion, and there were 8 articles that were excluded because they used languages other than English in 3 articles, and the content of the article did not match the research topic in 5 articles. From the results of this selection, 6 articles were obtained that were in accordance with PICOS eligibility. The following are the stages of study selection made using the PRISMA flow chart.

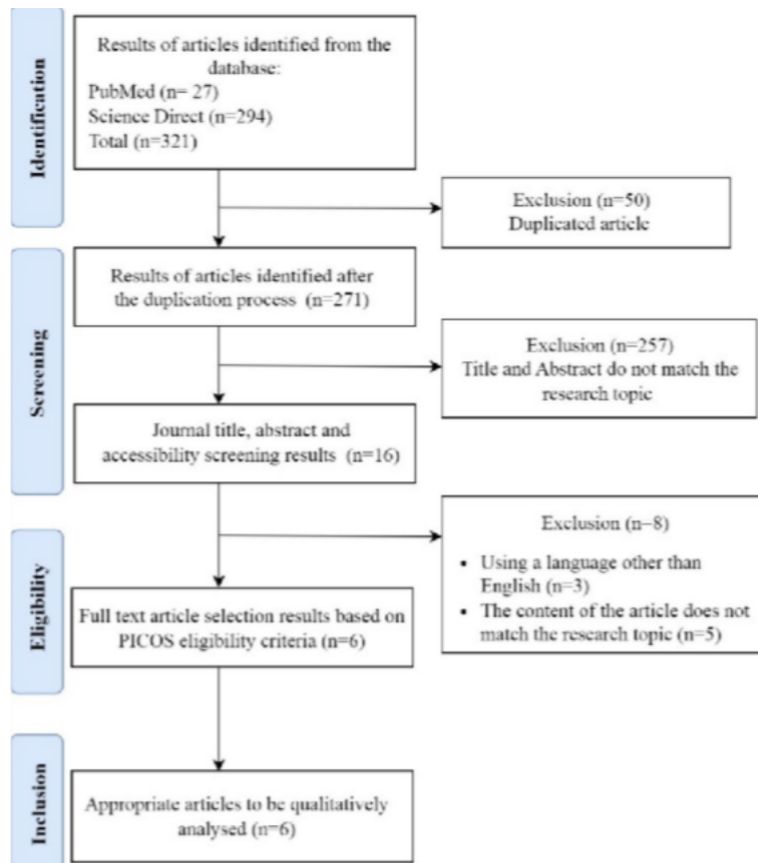


Figure 1.1 Flow of Article Selection Stage

Table 2 Study Characteristics of Pulmonary TB Stigma

Background	Research Methods	Results	Author
Measuring stigma in Indonesia with the Van Rie TB Stigma Scale measurement tools	<ul style="list-style-type: none"> <li>Using Van Rie's TB stigma scale which has been translated and adapted to Indonesian conditions</li> <li>Using a cross-sectional study design</li> <li>410 participants were interviewed.</li> </ul>	TB stigma is divided into 2: <ol style="list-style-type: none"> <li>Patient perspective:               <ul style="list-style-type: none"> <li>feeling guilty</li> <li>disclosure of fear</li> <li>self-isolation</li> </ul> </li> <li>Community perspective:               <ul style="list-style-type: none"> <li>Isolation</li> <li>Ostracised</li> </ul> </li> </ol>	(Fuady et al., 2023)
TB stigma is associated with psychosocial consequences of TB	<ul style="list-style-type: none"> <li>A cross-sectional study using interview based sampling.</li> <li>A total of 612 participants age <math>\geq 18</math> years.</li> <li>Participants were divided into four groups based on the type of primary healthcare facility (public or private) :</li> </ul>	<ol style="list-style-type: none"> <li>Patient perspective:               <ul style="list-style-type: none"> <li>Stigma levels ranged from low, moderate, to high</li> <li>Forms of stigma: reluctance to disclose TB status to people outside the family, being cautious when speaking, fear of being assumed to have HIV/AIDS, fear that others would inform their family about the TB diagnosis</li> <li>Isolation: feeling hurt by others' reactions, losing friends after disclosure, feeling lonely or without support, fear of</li> </ul> </li> </ol>	(Fuady et al., 2024)

<p>a) Group A : TB-DS patients receiving treatment for the first time at a public primary healthcare facility and currently in the intensive phase</p> <p>b) Group B: patient receiving TB treatment at private primary healthcare facilities</p> <p>c) Group C: Respondents diagnosed with TB at a public facility but had not yet started treatment</p> <p>d) Group D: patient receiving TB treatment at their public or private primary healthcare facilities</p> <p>visiting health facilities due to cynical attitudes</p> <ul style="list-style-type: none"> <li>• Guilt: feeling burdensome to the family, believing TB was caused by unhealthy behaviours), worrying about possible HIV/AIDS infection.</li> </ul> <p>b. Community perspective</p> <ul style="list-style-type: none"> <li>• Community stigma levels: moderate, none, low, high.</li> <li>• Isolation behaviours: unwillingness to eat or drink with TB patient, feeling uncomfortable around them, showing different behavior toward TB patients, preventing children from playing with patients, keeping physical distance.</li> <li>• Keeping a distance: perceiving TB patients as unpleasant or “disgusting”, unwillingness to talk to them, fear when encountering TB patients, avoiding physical contact.</li> </ul>			
Measuring stigma in Indonesia with the Van Rie TB stigma scale measurement tool in the workplace	172 participants completed the questionnaire online and offline. Cross-sectional study design	There are two factors that cause stigma among TB patients in the work area: a. Isolation: indicates one's attitudes and perceptions towards TB-positive co-workers to remain employed in the sector. b. Exclusion from the workplace is the perception that a co-worker with TB has a negative impact on the workplace and that the patient should be ostracised.	(Soemarko et al., 2023)
Analyse the details of the transition from fear to awareness in preventing the transmission of pulmonary TB cases in children.	14 participants, qualitative study research method with in-depth interviews	The stigma that often arises in the transmission of paediatric TB cases is fear. The fear of transmitting the disease to other members is felt by parents, the fear of being blamed if other family members contract the disease and ostracised, the fear and worry of physical changes in TB patients and being noticed by neighbours.	(Rakhmawati et al., 2019)
Measurement of anxiety and depression levels of MDR TB patients	102 patients, cross sectional	Due to the stigmatization of MDR TB in the community, it is not uncommon for patients to feel anxiety and depression.	(Susanto et al., 2023)

Exploration of perceived barriers during TB treatment	66 participants, qualitative study with in-depth interviews	Stigmatization of TB patients: a. Identified from the community: patients feel alienated, so they are afraid to make direct contact with their community. b. Family: a husband rejects his wife because she is positive for pulmonary TB, the rejection is triggered by his family so that the wife is expelled and divorced. c. Health services (puskesmas): doctors do not want to inject TB drugs into patients, so patients feel uncomfortable with this treatment.	(Pradipta et al., 2021)
---	---	--	-------------------------

## Discussion

Tuberculosis stigma is one of the determinant factors causing tuberculosis in Indonesia. From the 6 studies summarized by the researchers, all of them mentioned that the stigma of tuberculosis is very dangerous and can cause tuberculosis to stop treatment. The consequence of stopping treatment can lead to multi-drug resistant tuberculosis (MDR-TB) (Fuady et al., 2023, 2024; Susanto et al., 2023). There are two types of stigmas: stigma that is felt by the patient, and stigma that comes from society. Here is an explanation of each stigma:

### 1) Stigma From the Patient's Perspective

Most TB patients perceived stigma in the moderate category (60.6%). However, when associated with gender, most male TB patients received the highest stigma (aB 1.73; 0.59- 2.87) compared to females. Male patients felt the highest stigma because when he suffered from tuberculosis, he would lose his job (aB 2.09; 0.31-3.88). (Fuady et al., 2024). This study is supported by research conducted Soemarko et al., (2023) that the stigma of tuberculosis in the workplace is true. Negative tuberculosis stigma such as “I think coworkers who have tuberculosis cannot do all their work optimally” and “I think coworkers who have tuberculosis will have a negative impact on company finances”. From this statement, there is a gap between tuberculosis patients and healthy co-workers, so that from this statement there is stigmatization among the workplace, and it is not uncommon for companies to dismiss employees who have tuberculosis. In addition to male patients, stigmatization is also felt by female patients, according to research conducted by Pradipta et al., (2021) There was a female patient who was divorced by her husband because she had tuberculosis. Of both cases if associated with research conducted by Fuady et al., (2024) and Rakhmawati et al., (2019) The patients' stigmatization can cause them to choose to isolate themselves because they feel hurt when others find out that they have tuberculosis (25.2%), they start to lose their friends (12.3%), they feel alone and have no friends (15.8%) and they are afraid to go to health services because many people look at them cynically (14.7%). In addition to patients choosing to isolate themselves, there are feelings of guilt from patients. Feelings of guilt were due to the family having the burden of caring for TB patients (45.1%), feelings of guilt for contracting TB from smoking, drinking alcohol and unhealthy behaviors (37.4%) and the fear of contracting HIV/AIDS (34%). Therefore, to avoid feelings of guilt and isolation, patients chose to be careful in their speech (49.2%), did not disclose that they were suffering from tuberculosis to anyone other than family (34%), were afraid of telling others or family that if the patient had tuberculosis, the patient had the potential to get HIV/AIDS (27.6%), and the patient's fear of his family knowing from others that the patient had tuberculosis (18%).

### 2) Stigma From Society's Perspective

According to (Fuady et al., 2024) the majority of stigma received by patients from private health care facilities compared to public health care facilities. In private health care facilities, providers are reluctant to offer tuberculosis services and provide good service due to the stigma of tuberculosis. This study is supported by research conducted Pradipta et al., (2021) stigmatization given by health care facilities such



as health workers (doctors) do not want to inject tuberculosis drugs to patients, so patients feel uncomfortable with this treatment and patients choose to drop out of the drug. In addition to health care facilities, stigmatization can come from close family members such as a husband divorcing his wife because she has tuberculosis. The rejection given by the husband was supported by the man's parents, so the divorce took place. In addition to the immediate family, tuberculosis stigma also comes from the community, where patients feel unwelcome in their community, so patients feel afraid to make direct contact with their community (Pradipta et al., 2021).

The stigmatization given by the community to TB patients included: (1) Isolating tuberculosis patients such as: not wanting to eat or drink together with tuberculosis patients (59.5%), feeling uncomfortable when being next to tuberculosis patients (47.1%), behaving differently from people with tuberculosis (38.2%), not allowing tuberculosis patients to play with their children (58%). Distancing was also practiced by the community when they knew there was a tuberculosis patient. (2) The distancing was done such as: some people considered tuberculosis patients as the most disgusting people (23.7%), some people did not want to talk to people with tuberculosis (27%), some people were afraid to meet tuberculosis patients (39.1%), and some people tried not to touch tuberculosis patients (30.1%). (Fuady et al., 2024). The stigmatization from the community is what makes tuberculosis patients feel anxiety and depression. The level of anxiety in patients is at a severe level of 33.3% and at a moderate level of 46.1%, while the depression felt by patients is at a mildly depressed level of 32.7% and a severe depression level of 9.9% (Susanto et al., 2023)

## Conclusion

Community stigma is the dominant variable that causes TB patients to drop out of treatment and choose to isolate themselves due to embarrassment and being shunned by people who are considered close to TB patients such as; workmates, family, in-laws, and husbands. Therefore, the stigma of tuberculosis can be stopped by providing education related to the dangers of tuberculosis transmission, and prevention tools that can be used from the transmission of tuberculosis.

## Declarations

**Funding:** No external funding was received for this study

**Conflicts of Interest:** The authors declare no conflicts of interest.

## References

- Direktorat Jendral Pencegahan. (2023). Laporan program penanggulangan tuberkulosis tahun 2022. In Sulistyio & A. Y. Kalinda (Eds.), *Kemenkes RI* (1st ed.). Kementerian Kesehatan RI. [https://tbindonesia.or.id/pustaka\\_tbc/laporan-tahunan-program-tbc-2021/](https://tbindonesia.or.id/pustaka_tbc/laporan-tahunan-program-tbc-2021/)
- Fuady, A., Arifin, B., Yunita, F., Rauf, S., Fitriangga, A., Sugiharto, A., Yani, F. F., Nasution, H. S., Putra, Iw. G. A. E., Mansyur, M., & Wingfield, T. (2023). Stigma towards people with tuberculosis: a cross-cultural adaptation and validation of a scale in Indonesia. *BMC Psychology*, 11(1), 1–11. <https://doi.org/10.1186/s40359-023-01161-y>
- Fuady, A., Id, B. A., Yunita, F., Id, S. R., Fitriangga, A., Sugiharto, A., Yani, F. F., Suryani, H., Id, N., Artawan, I. W. G., Id, E. P., Id, M. M., & Id, T. W. (2024). Stigma , depression , quality of life , and the need for psychosocial support among people with tuberculosis in Indonesia : A multi-site cross-sectional study. *Plos Global Public Health*, 4(1), 1–20. <https://doi.org/10.1371/journal.pgph.0002489>
- MJ, P., JE, M., PM, B., I, B., TC, H., & CD, M. et al. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *The BMJ*. <https://doi.org/https://doi.org/10.1136/bmj.n71>
- Nuttall, C., Fuady, A., Nuttall, H., Dixit, K., Mansyur, M., & Wingfield, T. (2022). Interventions pathways to reduce tuberculosis-related stigma: a literature review and conceptual framework. *Infectious Diseases of Poverty*, 11(1). <https://doi.org/10.1186/s40249-022-01021-8>
- PAHO. (2022). *World Tuberculosis Day*. PAHO. <https://www.paho.org/en/campaigns/world-tuberculosis-day-2022>
- Pradipta, I. S., Idrus, L. R., Probandari, A., Lestari, B. W., Diantini, A., Alffenaar, J. W. C., & Hak, E. (2021). Barriers and strategies to successful tuberculosis treatment in a high-burden tuberculosis setting: a qualitative study from the patient's perspective. *BMC Public Health*, 21(1), 1–12. <https://doi.org/10.1186/s12889-021-12005-y>
- Pusdatin. (2023). Profil kesehatan Indonesia tahun 2022. In *Pusdatin.Kemenkes.Go.Id*. <https://www.kemkes.go.id/downloads/resources/download/pusdatin/profil-kesehatan-indonesia/Profil-Kesehatan-2021.pdf>
- Rakhmawati, W., Nilmanat, K., & Hatthakit, U. (2019). Moving from fear to realization: Family engagement in tuberculosis prevention in children living in tuberculosis Sundanese households in Indonesia. *International Journal of Nursing Sciences*, 6(3), 272–277. <https://doi.org/10.1016/j.ijnss.2019.06.002>
- Soemarko, D. S., Halim, F. A., Kekalih, A., Yunus, F., Werdhani, R. A., Sugiharto, A., Mansyur, M., Wingfield, T., & Fuady, A. (2023). Developing a tool to measure tuberculosis-related stigma in workplaces in Indonesia: An internal validation study. *SSM - Population Health*, 21(January), 101337. <https://doi.org/10.1016/j.ssmph.2023.101337>
- Susanto, T. D., Widysanto, A., Cipta, D. A., Tanara, A., Wirawan, G. R., Kosim, A. B., Djoni, C. M., Tantri, E., Kumar, C., & Angelius, C. (2023). Anxiety and depression level of patients with multidrug-resistant tuberculosis (MDR-TB) in two hospitals in Banten province, Indonesia. *Dialogues in Health*, 2(January), 100115. <https://doi.org/10.1016/j.dialog.2023.100115>



WHO. (2022). *2.1 TB inciden*. World Health Organization.  
<https://www.who.int/teams/global-tuberculosis-programme/tb-reports/global-tuberculosis-report-2022/tb-disease-burden/2-1-tb-incidence#:~:text=In 2021%2C eight countries accounted,2>).