

The association of stigma with the incidence of depression in leprosy patients: a systematic review

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ABSTRACT

Introduction: Leprosy is a chronic infectious disease caused by the bacterium *Mycobacterium leprae*. Leprosy causes not only medical problems but also social problems such as stigma. Depression in leprosy patients is thought to be related to stigma from society and from leprosy sufferers, who find it difficult to accept their disability. **Methods:** We conducted this systematic review by gathering articles from the PubMed, ProQuest, and Google Scholar databases. **Results:** At the stage of article collection, 1558 articles were obtained from the databases. After screening, the author finally obtained seven articles for review.

Conclusions: Stigma (enacted, perceived and internalized stigma) is associated with the incidence of depression in leprosy patients.

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INTRODUCTION

Leprosy is a chronic infectious disease primarily caused by the bacterium *Mycobacterium leprae*, which predominantly affects the peripheral nerves and skin (WHO, 2021). In addition to causing medical problems, leprosy affects the social, economic, and cultural life of leprosy patients. The socio-economic problems of leprosy patients are due to the fact that the disease is still stigmatized by the community, the patient's family and some health care workers (Kementerian Kesehatan RI, 2020).

According to World Health Organization (WHO) data, there were 202,256 new cases of leprosy in 2021 from 161 countries in six WHO regions (WHO, 2021). The highest number of cases was found in the Southeast Asia region, with 156,118 cases. India, Brazil and Indonesia now account for the largest number of leprosy cases in the world (WHO, 2021).

The presence of complications in the form of disability, as well as lack of knowledge and fear of infection, has led to the emergence of negative stigma towards leprosy patients. Stigma against leprosy patients is one of the problems hindering the control of the disease (Erni and Dewi, 2018). Stigma experienced by leprosy patients can be divided into three forms: enacted stigma, perceived stigma, and internalized stigma. Enacted stigma (discrimination) is stigma experienced through direct insults. Perceived stigma (anticipated stigma) is stigma in the form of fear of discrimination and negative feelings about what someone will do to them. Internalized stigma (self-stigma) occurs when a person begins to believe what others think and say about them, thus stigmatizing themselves (Voorend et al., 2011).

Depression can arise in leprosy patients due to social stigma. Additionally, these individuals often struggle with accepting their disability, which in turn contributes to feelings of anxiety and hopelessness (Septimar and Sembiring, 2017). A study conducted by van Dorst et al., (2020) in Nepal reported that leprosy patients who experienced stigma had higher levels of depression and lower levels of mental health than the general population. Given the significant impact of stigma and depression, the authors conducted a literature review to explore the relationship between stigmatization and depression incidence in individuals with leprosy.

METHODS

This research utilizes a systematic review design with the aim of providing support for the issues under investigation and presenting relevant theories related to the topic. The study was conducted by collecting sources related to the relationship between stigma and incidence of depression in leprosy patients. Research articles were retrieved from the scientific databases PubMed, Proquest and Google Scholar. The retrieved articles were then selected according to the criteria and reviewed. In this study, articles were searched using the keywords (Leprosy OR "Hansen's Disease" OR "Hansen's Disease") AND (Stigma OR Stigmatization) AND (Depressions OR "Depressive Symptoms" OR "Depressive Symptom" OR "Emotional Depression"). The research steps are illustrated in Figure 1 for reference.

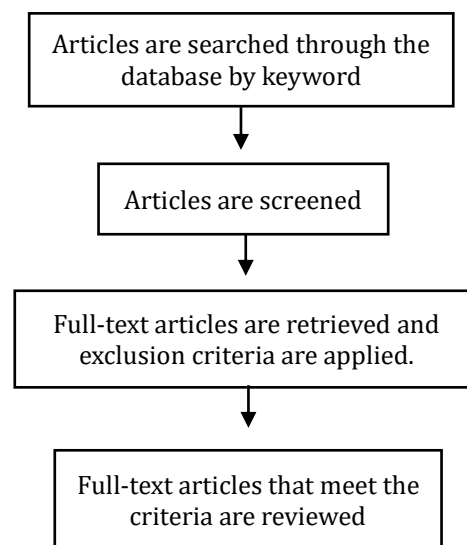


Figure 1. Research steps

RESULTS AND DISCUSSION

The keyword search yielded 1,558 research articles. Next, the data was entered into Ms. Excel and there were 144 duplicate articles, which then excluded. The next step was to select titles and abstracts, which resulted in 1,386 articles that did not meet the criteria. An additional 28 articles underwent full text review and restriction criteria. There were 20 articles that did not meet the restriction criteria and one journal that did not have the full text available, so in the end the literature review was conducted on seven articles (Figure 2).

Of the seven articles that underwent literature review, six of them reported an association between stigma and the incidence of depression in leprosy patients (van Dorst et al., 2020,

Nishida et al., 2006, Tsutsumi et al., 2004, Frota da Rocha Morgado et al., 2020, Mangeard-Lourmea et al., 2020, Weiss et al., 1992). In addition, a study by Wiyaniputri (2015) reported that out of 49 leprosy patients, all experienced depression, with 57.1% of patients experiencing moderate depression and 42.9% experiencing mild depression. Each article used a different instrument to measure stigma (Table 1). However, the questionnaires used were reported to be valid and reliable. Therefore, it can be concluded that the measurement results of stigma and depression using these instruments are acceptable.

Based on our review, enacted stigma is the most common stigma among leprosy patients. This is due to ignorance about leprosy, misconceptions, and the role of the government in forcing leprosy patients to undergo forced isolation and sterilization (Nishida et al., 2006). The physical differences between leprosy patients and the rest of society lead the general public to shun and discriminate against leprosy patients (Weiss et al., 1992). In addition, leprosy patients who experience discrimination may experience perceived stigma, where patients feel afraid and assume that others do not know what they are experiencing (Frota da Rocha Morgado et al., 2020, Weiss et al., 1992). Perceived and actual stigma can cause patients to feel different from others, discriminated against, ostracized, and burdened by their disability, resulting in decreased self-esteem. This is also referred to as internalized stigma or stigma internalized by the patient (Tsutsumi et al., 2004, Wiyaniputri, 2015).

Seven articles included in this study reported that stigma makes it difficult for leprosy patients to live their lives because they experience discrimination, fear of being excluded from society, feeling different from others, and decreased self-esteem, resulting in psychological problems and often depression. There are several factors associated with the level of depression such as female gender, disability level, and stigma (van Dorst et al., 2020, Mangeard-Lourmea et al., 2020). Moreover, the level of stigma is one of the independent factors of depression development in leprosy patients (van Dorst et al., 2020, Akul Islam et al., 2004).

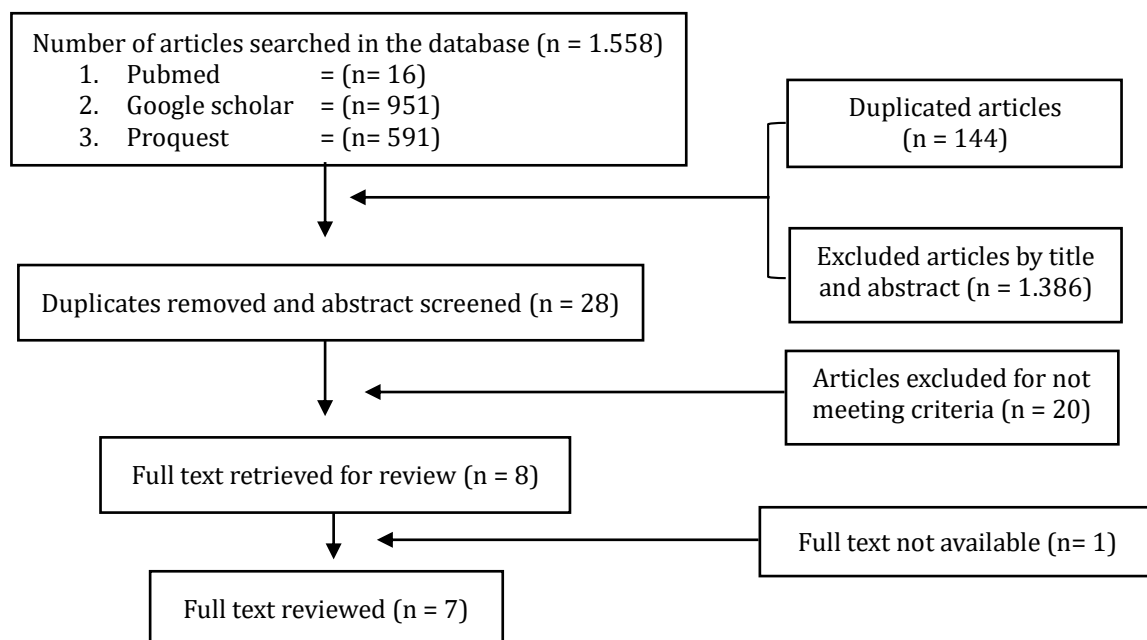


Figure 2. PRISMA flowchart

Table 1. Research Summary

Author	Title	Research type	Form of Stigma	Study Subject	Outcome
van Dorst et al (2020)	Depression and mental wellbeing in people affected by leprosy in southern Nepal	Cross-sectional study	Enacted stigma	Sample: 196 samples (142 leprosy patients and 54 as control group) Instruments: 5-QSI-AP and PHQ-9 questionnaires.	Patients with leprosy had higher levels of depression compared to the control group. The mean depression score of leprosy patients was significantly higher than that of the control group (7.54 vs. 3.61, $p < 0.001$). Gender, level of disability, and level of stigma were independently associated with depression severity.
Nishida et al (2006)	Prevalence and characteristics of depression in a Japanese leprosarium from the viewpoints of social stigmas and ageing. A preliminary report	Case control study	Enacted stigma	Sample: 20 samples of leprosy patients and 20 samples of control group. Instruments: TMIG-Index and GDS-SF questionnaires	There was a significant difference ($p < 0.001$) in depression between leprosy patients and control group.
Tsutsumi et al (2004)	Depressive status of leprosy patients in Bangladesh: association with self-perception of stigma	Cross-sectional study	Internalized stigma	Sample: 275 samples (140 leprosy group and 135 control group) Instruments: CES-D score questionnaire and self-perception of stigma.	Depression status in leprosy patients was greater than in the general population ($p < 0.001$). There was an association between stigma and the incidence of depression in leprosy patients as evidenced by 3 significant questionnaire results, namely: 'I have been physically attacked by people' $p = 0.024$; 'I feel people regard me strange' $p = 0.015$; 'I have been refused the purchase of something by a shopkeeper' $p = 0.035$.

Wiyani Putri (2015)	Relationship between Self-Concept and Depression Level in Leprosy Patients at Alverno Leprosy Hospital Singkawang	A cross sectional study	Internalized stigma	Sample: 49 leprosy patients Instrument: Personal concept questionnaire and Zung Self-Rating Depression Scale (ZSDS)	All leprosy patients suffered from depression, with 57.1% of patients suffering from moderate depression and 42.9% from mild depression.
Weiss et al (1992)	The Explanatory Model Interview Catalogue (EMIC) Contribution to Cross-cultural Research Methods from a Study of Leprosy and Mental Health	A cross cultural study	Perceived stigma, internalized stigma.	Sample: 56 people with leprosy Instruments: EMIC questionnaire and DSM III-R interview and combined Hamilton Depression and Anxiety Rating Scale.	There is a significant relationship between perceived stigma and internalized stigma with the incidence of depression (Diminished self-esteem $p = 0.0001$; community stigma $p = 0.002$; self-stigmatizing belief $p = 0.003$; adversely affects marital life $p = 0.01$).
Frota da Rocha Morgado, et al (2020)	Psychometric assessment of the EMIC Stigma Scale for Brazilians affected by leprosy	Cross sectional study	Perceived stigma, enacted stigma.	Sample: 180 leprosy patients Instruments: EMIC questionnaire and BDI score	There was an association between stigma and incidence of depression in leprosy patients with p value <0.001 .
Mangard-Lourme et al (2020)	Depression and anxiety in people affected by leprosy and lymphatic filariasis: a cross-sectional study in four States in India	Cross sectional study	Enacted stigma	Sample: 3706 samples (1404 men and 2302 women with leprosy). Instruments: WGMH questionnaire and interviews by accredited community health workers.	The results of this study indicate that there is a significant relationship between discrimination (stigma) and the incidence of depression, where the p -value is <0.05 .

CONCLUSION

Our systematic review leads us to the conclusion that there exists a strong association between stigma (including enacted, perceived, and internalized stigma) and the incidence of depression in leprosy patients. Nevertheless, the studies we examined exhibited limitations related to sample size and the absence of diverse samples. It is imperative to emphasize the necessity of obtaining a heterogeneous and representative sample, particularly given that the countries with the highest prevalence of leprosy cases (such as India, Brazil, and Indonesia) are culturally diverse nations. Moreover, from our literature search, we did not find enough evidence to demonstrate an association between different types of stigma with levels of depression. Therefore, we encourage further studies to explore these fields in leprosy patients.

REFERENCES

- Akul Islam, M. D., Uddin Amed, J., Nakahara, S., Takagi, F., & Wakai, S. (2004). Depressive status of leprosy patients in Bangladesh: association with self-perception of stigma. In *Lepr Rev* (Vol. 75). <https://doi.org/https://doi.org/10.47276/lr.75.1.57>
- Astutik, E., & Gayatri, D. (2018). Perceived stigma in people affected by leprosy in leprosy village of Sitanala, Banten, Indonesia. *Kesmas*, 12(4), 178–186. <https://doi.org/10.21109/kesmas.v12i4.1756>
- Frota da Rocha Morgado, F., Kopp Xavier da Silveira, E. M., Pinheiro Rodrigues do Nascimento, L., Sales, A. M., da Costa Nery, J. A., Nunes Sarno, E., & Illarramendi, X. (2020). Psychometric assessment of the EMIC Stigma Scale for Brazilians affected by leprosy. *PloS One*, 15(9), e0239186. <https://doi.org/10.1371/journal.pone.0239186>
- Kementerian Kesehatan RI. (2020). *Pedoman Nasional Pelayanan Kedokteran Tata Laksana Kusta*.
- Mangeard-Lourmea, J., Arquera, G. R. de, Parasab, J., Singhb, R. K., Satleb, N., & Mamhidi, R. (2020). Depression and anxiety in people affected by leprosy and lymphatic filariasis: A cross-sectional study in four states in India. *Leprosy Review*, 91(4), 367–382. <https://doi.org/10.47276/lr.91.4.367>
- Nishida, M., Nakamura, Y., & Aosaki, N. (2006). *Prevalence and characteristics of depression in a Japanese leprosarium from the viewpoints of social stigmas and ageing. A preliminary report*. <https://doi.org/https://doi.org/10.47276/lr.77.3.203>
- van Dorst, M. M. A. R., van Netten, W. J., Waltz, M. M., Pandey, B. D., Choudhary, R., & van Brakel, W. H. (2020). Depression and mental wellbeing in people affected by leprosy in southern Nepal. *Global Health Action*, 13(1). <https://doi.org/10.1080/16549716.2020.1815275>
- Vooreend, C., Angermeyer, M., Fuzikawa, P., Pakasi, T., Rensen, C., Stevelink, S., Dejong, I., Ramdas, S., Heijnders, M., & Van Brakel, W. (2011). *ILEPstigmaguidelines-2_web*. https://www.researchgate.net/publication/260662429_Guidelines_to_reduce_stigma_how_to_assess_health-related_stigma
- Weiss, M. G., Doongaji, D. R., Siddhartha, S., Wypij, D., Pathare, S., Bhatawdekar, M., Bhawe, A., Sheth, A., & Fernandes, R. (1992). The Explanatory Model Interview Catalogue (EMIC). Contribution to cross-cultured research methods from a study of leprosy and

- mental health. *British Journal of Psychiatry*, 160(JUNE), 819–830.
<https://doi.org/10.1192/bjp.160.6.819>
- WHO. (2021). *Global leprosy (Hansen disease) update, 2020 impact of COVID-19 on the global leprosy control*. 421–444.
- Wiyani Putri, C., Wicaksono, A., Studi Pendidikan Dokter, P., Untan, F., Ilmu Kesehatan Jiwa, D., & Khusus Jiwa Sungai Bangkong Pontianak, R. (2016). Hubungan Konsep Diri terhadap Tingkat Depresi pada Pasien Kusta di Rumah Sakit Kusta Alverno Singkawang.
- Zahrah, M., & Rista Sembiring. (2017). Hubungan Dukungan Keluarga Dengan Depresi Penderita Kusta Di Ruang Rawat Penyakit Dalam Kusta Rumah Sakit Kusta Dr. Sitanala Tangerang. In *Jurnal Ilmiah Kesehatan: Vol. XII*.