JILS
Journal of Interdisciplinary Lifestyle Studies
DOI: https://doi.org/10.19141/jils.v14ilifestyle.2123

UNASP
CENTRO UNIVERSITÁRIO ADVENTISTA DE SÃO PAULO

STIGMA AND SOCIAL EXCLUSION IN LEPROSY IN VULNERABLE POPULATIONS: INTERDISCIPLINARY ANALYSIS THROUGH INTEGRATIVE REVIEW

Beatriz Neves Guedes[1]
Andressa de Souza Batista[2]
João Victor dos Santos Carvalho[3]
Nayane Pereira Silva[4]
Thayslane de Oliveira Brandão[5]
Cicera Hellen Cavalcante Gonçalves[6]

ABSTRACT: Objective: This study aims to explore the available scientific evidence on stigma and social exclusion related to leprosy in vulnerable populations, considering the associated social, cultural, and economic impacts. **Method:** An integrative literature review was conducted in the LILACS (via BVS) and MedLINE (via PubMed) databases, using descriptors related to social stigma, social exclusion, and leprosy. Original articles published between 2020 and 2025, in Portuguese and English, were included. **Results:** A total of 19 articles were identified, with the highest number of publications in 2021, followed by 2020. All studies were conducted in Brazil, particularly in the Northeast region. Cross-sectional studies predominated, accounting for approximately 60% of the publications. The evidence indicates that leprosy remains strongly associated with social vulnerability, low education, and limited access to healthcare services, contributing to late diagnosis, social stigma, and exclusion of affected individuals. **Conclusion:** Stigma and social exclusion related to leprosy are closely linked to social inequalities and vulnerability, negatively affecting quality of life, mental health, and social participation of affected

* **Corresponding author:** Beatriz Neves Guedes. E-mail: beatriznevesguedes@gmail.com
1 Centro Universitário Adventista de Ensino do Nordeste (UNIANE), Bahia, BH (Brazil). E-mail: beatriznevesguedes@gmail.com
2 Universidade Estadual de Feira de Santana (UEFS), Bahia, BH (Brazil). E-mail: souzabatistaandressa@gmail.com
3 Universidade Estadual do Maranhão (UEMA), Maranhão, MA (Brazil). E-mail: joaovictorsantosdossantos3@gmail.com
4 Universidade Estadual do Maranhão (UEMA), Maranhão, MA (Brazil). E-mail: nayanesilvaenfer@gmail.com
5 Universidade Estadual do Maranhão (UEMA), Maranhão, MA (Brazil). E-mail: thayslanebrandao5@gmail.com
6 Centro Universitário Maurício de Nassau de Juazeiro do Norte (UNINASSAU), Ceará, CE (Brazil). E-mail: hcavalcante523@hmail.com

Submitted: 28/03/2026
Accepted: 18/06/2026
ISSN: 3086-5336

Editors: Prof. Dr. Elias Porto e Profa. Dra. Natália Cristina de Oliveira (Centro Universitário Adventista (UNASP), São Paulo.

How to cite: Guedes, B. N., de Souza Batista, A., Carvalho, J. V. dos S., Pereira Silva, N., Brandão , T. de O., & Gonçalves, C. H. C. (2026). O Estigma e Exclusão Social na Hanseníase em Populações Vulneráveis: Análise Interdisciplinar por Revisão Integrativa. *Journal of Interdisciplinary Lifestyle Studies, 14*(lifestyle), e02123. https://doi.org/10.19141/jils.v14ilifestyle.2123

individuals. The findings highlight the need for health education, early diagnosis, and public policies aimed at reducing stigma and social disparities.

Keywords: Social exclusion; Leprosy; Social vulnerability.

O Estigma e Exclusão Social na Hanseníase em Populações Vulneráveis: Análise Interdisciplinar por Revisão Integrativa

RESUMO: Objetivo: Este estudo visa explorar as evidências científicas disponíveis acerca do estigma e da exclusão social relacionados à hanseníase em populações vulneráveis, considerando os impactos sociais, culturais e econômicos envolvidos. **Método:** Realizou-se uma revisão integrativa nas bases LILACS (BVS) e MedLINE (PubMed), utilizando descritores relacionados a estigma social, exclusão social e hanseníase. Foram incluídos artigos originais publicados entre 2020 e 2025, em português e inglês. **Resultados:** Foram identificados 19 artigos, com maior concentração de publicações em 2021, seguido de 2020. Todos os estudos foram realizados no Brasil, com destaque para a região Nordeste. Predominaram estudos de delineamento transversal, correspondendo a cerca de 60% das publicações. **Conclusão:** O estudo evidenciou que o estigma e a exclusão social relacionados à hanseníase estão associados às desigualdades sociais e à vulnerabilidade, influenciando o diagnóstico tardio e a manutenção do preconceito. Esses fatores impactam negativamente a qualidade de vida, a saúde mental e a participação social das pessoas acometidas.

Palavras-chave: Exclusão social; Hanseníase; Vulnerabilidade social.

Estigma y Exclusión Social en la Lepra en Poblaciones Vulnerables: Análisis Interdisciplinario Mediante una Revisión Integrativa

RESUMEN: Objetivo: Este estudio tiene como objetivo explorar la evidencia científica disponible sobre el estigma y la exclusión social relacionados con la lepra en poblaciones vulnerables, considerando los impactos sociales, culturales y económicos asociados. **Método:** Se realizó una revisión integradora de la literatura en las bases de datos LILACS (a través de la BVS) y MedLINE (a través de PubMed), utilizando descriptores relacionados con el estigma social, la exclusión social y la lepra. Se incluyeron artículos originales publicados entre 2020 y 2025, en portugués e inglés. **Resultados:** Se identificaron 19 artículos en total; el mayor número de publicaciones correspondió al año 2021, seguido por el 2020. Todos los estudios se llevaron a cabo en Brasil, particularmente en la región Nordeste. Predominaron los estudios transversales, que representaron aproximadamente el 60% de las publicaciones. La evidencia

indica que la lepra sigue estando fuertemente asociada a la vulnerabilidad social, el bajo nivel educativo y el acceso limitado a los servicios de salud, factores que contribuyen al diagnóstico tardío, al estigma social y a la exclusión de las personas afectadas. **Conclusión:** El estigma y la exclusión social relacionados con la lepra están estrechamente vinculados a las desigualdades sociales y a la vulnerabilidad, afectando negativamente la calidad de vida, la salud mental y la participación social de las personas afectadas. Los hallazgos subrayan la necesidad de implementar educación sanitaria, diagnóstico precoz y políticas públicas orientadas a reducir el estigma y las disparidades sociales

Palabras clave: Exclusión social; Lepra; Vulnerabilidad social

INTRODUCTION

Leprosy is a chronic infectious disease caused by the pathogen *Mycobacterium leprae*, a resistant bacillus that replicates slowly, primarily affecting the skin and peripheral nerves, and later involving the upper respiratory tract, lymph nodes, internal organs, testicles, and eyes. It is transmitted through direct and prolonged contact with an infected person who is not undergoing treatment and has a high bacterial load, using droplets of saliva and nasal secretions expelled during coughing or sneezing (Brasil, 2022).

In the Brazilian epidemiological landscape, the North, Northeast, and Central-West regions have the highest prevalence of the disease, with 19,635 new cases reported in 2022 and a detection rate of 9.67 per 100,000 inhabitants. This disease is intrinsically linked to conditions of poverty and is typical of developing countries such as Indonesia, Brazil, and India, which face weaknesses in infrastructure, housing, nutrition, and access to healthcare. In this global context, Brazil ranks second in terms of the highest number of cases, surpassed only by India (Brasil, 2024).

Its complexity reveals that vulnerability extends beyond factors such as socioeconomic status, manifesting itself in structured and systemic ways. Structural vulnerability, rooted in historical patterns of social devaluation, exacerbates the situation of affected individuals, undermining their citizenship and access to basic rights. At the same time, programmatic vulnerability, evidenced by operational failures in health care and surveillance, as well as by deficiencies in the management, planning, and evaluation of control measures,hinders early diagnosis and adherence to treatment (Jesus et al., 2023).

Controlling the disease, particularly in primary health care (PHC), is essential to addressing this persistent public health challenge, especially in developing countries. Ongoing training for health care professionals is essential for early diagnosis, epidemiological surveillance, and health education, all of which are crucial for reducing transmission and mitigating the impact of the disease (Guimarães et al., 2024).

In line with its goals and with the aim of eliminating leprosy worldwide, the World Health Organization (WHO) launched the National Strategy Plan for the Control of Leprosy 2024–2030 in 2021, proposing targets aligned with the Sustainable Development Goals (SDGs), particularly SDGs 3, 10, and 17, which address well-being, reducing inequalities, and partnerships. In line with the WHO strategy, the Ministry of Health (MOH) will launch the National Strategy to Combat

Leprosy in 2024, aiming to decrease the incidence of cases among children and reduce severe cases (Brasil, 2024).

The significance of this study lies in the persistence of leprosy as an indicator of social inequality and a public health challenge in Brazil. The historical stigma associated with the disease remains a significant barrier to diagnosis, treatment, and social inclusion of vulnerable populations. Understanding its dimensions is essential for aligning health practices with national and global strategies to combat the disease, contributing to the reduction of new cases and the promotion of patients dignity.

In light of the above, this study aims to explore the available scientific evidence regarding stigma and social exclusion related to leprosy in vulnerable populations, taking into account the social, cultural, and economic impacts involved.

METHODS

A literature review, also known as a bibliographic review or theoretical framework, is a research method dedicated to exploring, analyzing, and synthesizing established knowledge from academic and scientific sources (Cavalcante; Oliveira, 2020). Among its approaches, the integrative review stands out, as it systematizes knowledge by integrating both theoretical and empirical studies. Its distinguishing feature is its interpretive view of the evidence, which makes it flexible enough to include research that employs diverse methodologies (Rodrigues; Sachinski; Martins, 2022).

The search was conducted using the Latin American and Caribbean Health Sciences Literature (LILACS) database, using the Virtual Health Library (VHL), and the Medical Literature Analysis and Retrieval System Online (MEDLINE), using PubMed. In addition, the use of Health Sciences Descriptors/Medical Subject Headings (Decs/MeSH) was combined using the Boolean operators AND and OR.

Table 1 below shows the cross-reference between Boolean operators and MeSH/DeCS terms in the databases searched.

Table 1. Search strategy broken down by database.

Base de Dados	Descritores e Operadores Booleanos
LILACS using BVS	(Social stigma/estigma social) OR (Social exclusion/exclusão social) AND (Hansen's disease/hanseníase).
MedLINE using PubMed	(social stigma/estigma social) AND (Social exclusion/exclusão social) AND (Hansen's disease/hanseníase) OR (Vulnerable populations/populações vulneráveis)

Source: Prepared by the authors, 2026.

To guide the methodological process in selecting the articles, the following guiding question was used: "What is the scientific evidence regarding stigma and social exclusion among people affected by leprosy in contexts of social, economic, and cultural vulnerability?" The formulation of this question was based on the PICo strategy. In this context, P (Population) was defined as

people affected by leprosy, I (Interest) as stigma and social exclusion, and finally, Co (Context) as populations in situations of social, economic, and cultural vulnerability.

The inclusion criteria established were original articles, available in full and free of charge, in Portuguese or English, published between 2020 and 2025, and explicitly addressing stigma and/or social exclusion related to leprosy. The studies were selected manually; no automated tools were used to exclude records.

Conversely, editorials, conference abstracts, books, and book chapters were excluded. Studies that addressed leprosy exclusively from a pathophysiological, pharmacological, or genetic perspective were also excluded. In addition, publications that lacked a clear description of data collection or analysis procedures, making it impossible to understand the methodology used, were excluded.

The selection of studies was conducted in two stages. In the first stage, titles and abstracts were reviewed for initial screening. In the second stage, the full texts of the articles that met the eligibility criteria were reviewed. Figure 1 below shows the flowchart for the selection of studies.

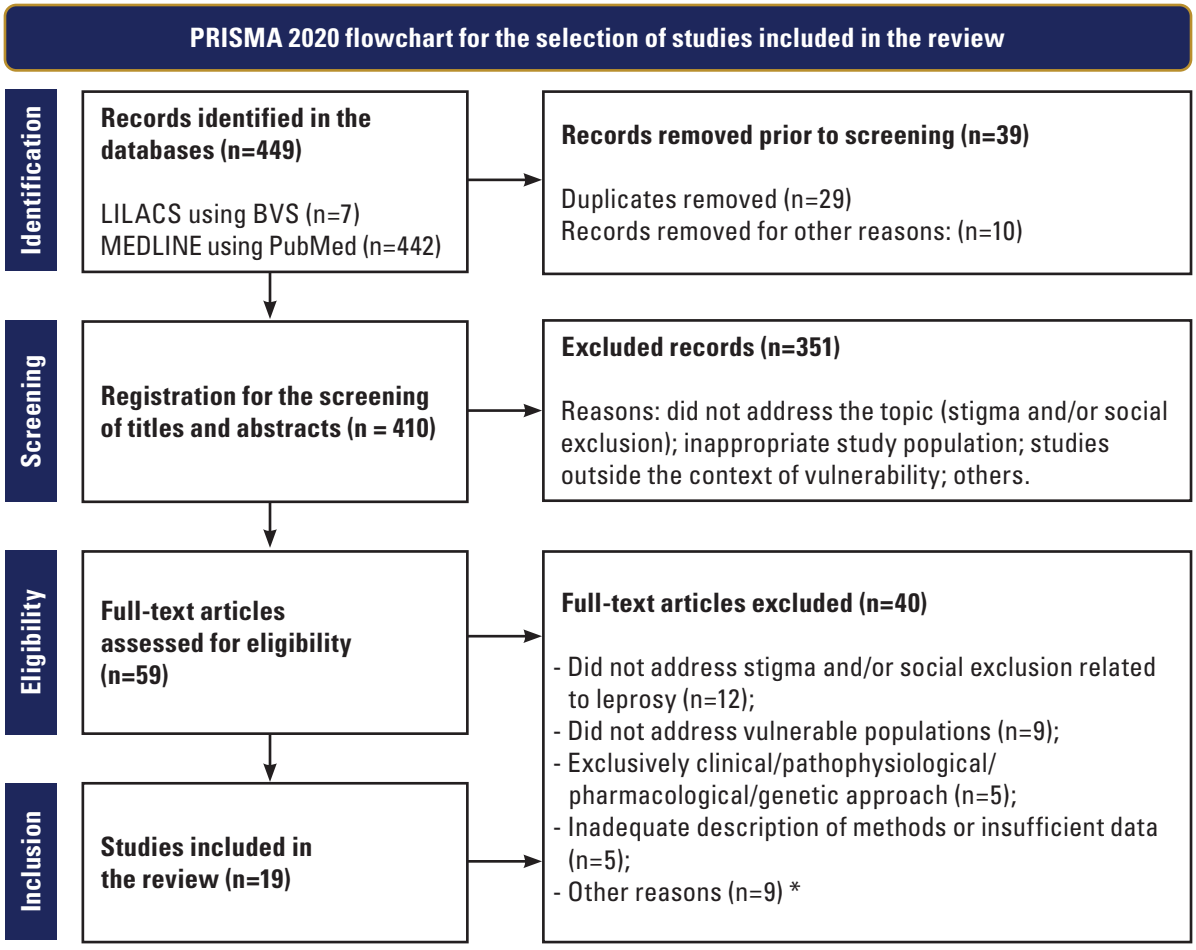

Figure 1. Flowchart of the selection process for the included studies.

Source: Prepared by the authors, 2026.

Finally, to further analyze the findings, a descriptive quantitative synthesis of the main thematic areas identified was conducted. Each included study was categorized based on the presence

or absence of these outcomes. Based on this categorization, the prevalence proportion of each impact relative to the total sample was calculated. To ensure the statistical accuracy of the synthesis, the proportions were presented using a forest plot, accompanied by their respective 95% confidence intervals (95% CI), calculated using the Wald method.

RESULTS

The scientific evidence identified through the search strategy totaled 19 articles. A higher concentration of publications was observed in 2021, accounting for 30% of the studies, followed by 2020 with 25%. Regarding the location, 100% of the studies were conducted in Brazil, with a particular focus on the Northeast region, highlighting the endemic nature of leprosy in this region and its relevance as a national public health issue.

With regard to methodological design, cross-sectional studies predominated, accounting for approximately 60% of the publications. Table 2 below provides a detailed overview of the studies and their descriptions.

Table 2. Summary of the studies, presenting data on the authors, year of publication, study design, and main results (n=19).

N	Authors (year)	Title	Methodological Design	Number of participants	Main Results
1	Antas et al. (2022)	Quality of life and clinical condition of individuals with leprosy	Cross-sectional Study	96 participants.	Factors such as a lack of leisure activities, limited financial resources, and negative emotions reduced average well-being scores, while self-esteem and personal support scored higher.
2	Batista et al. (2022)	Stigma of leprosy by community health workers: associated factors	Cross-sectional Study	301 participants.	It was found that 22.92% of community health workers still stigmatize patients with leprosy, incorrectly recommending the separation of personal belongings and isolation. A lack of training and professional experience were key factors contributing to these attitudes.
3	Finotti et al. (2020)	Common mental disorders and associated factors amongpeople with leprosy: cross-sectional analysis in Cuiabá,Brazil, 2018	Cross-sectional Study	206 participants.	It was found that 70.4% of people with leprosy and treatment-related complications suffer from common mental health disorders. This condition is primarily associated with women, people of working age (26 to 60 years old), and those with low incomes.
4	Fortunato et al. (2024)	Quality of life, functionality and self-esteem of people in the post-discharge period due to leprosy cure	Epidemiological study	131 participants.	A study conducted in João Pessoa involving 131 individuals who had been discharged after being cured of leprosy revealed that the predominant profile consists of men (65.6%) in the working-age group of 41 to 60 years old, with low household income. Quality of life was most affected in physical terms, particularly among those with no formal education and who were economically vulnerable.

N	Authors (year)	Title	Methodological Design	Number of participants	Main Results
5	Lima et al. (2021)	Therapeutic itinerary of people with leprosy: Paths, struggles and challenges in search of care	Descriptive study	224 cases.	The main challenge faced by patients is access to diagnosis, which leads to delayed detection and the development of visible deformities. Local healthcare facilities are under-resourced and lack the necessary procedures and protocols for comprehensive treatment.
6	Morais et al. (2024)	Profile of knowledge about leprosy among patients at a university hospital	Cross-sectional Study	500 participants.	Although approximately 92% of respondents had heard the terms "hanseníase" or "leprosy," less than half knew that both refer to the same disease. Only 50.4% had any actual knowledge of the disease, with the identification of skin lesions (99.2%) being the most commonly recognized symptom.
7	Nascimento et al. (2024)	Creation and development of support groupsfor leprosy self-care in a state in the northeastof Brazil	Exploratory study	50 participants.	The main motivation for its creation was the need to expand care beyond physical aspects, incorporating emotional and social dimensions, as well as optimizing professionals' work time through group care.
8	Nascimento et al. (2020)	Activity limitation and restriction of social participation in people with leprosy: cross-sectional analysis of magnitude and associated factors in a hyperendemic municipality of Piauí, 2001 to 2014	Cross-sectional Study	263 participants.	There is a direct correlation between impairment of the eyes, hands, and feet and difficulty integrating into the community, with multibacillary cases tending to be more severe and carry a higher risk of exclusion.
9	Passos e Araújo (2020)	Social representations of a former colony hospital: a study of its residents	Exploratory study	16 participants.	Residents of a former leprosy colony in the Northeast view the place positively, seeing it as a peaceful refuge. They remain there after being cured due to a lack of resources and emotional attachment, seeking protection from prejudice.
10	Pinheiro et al. (2021)	Profile of patients who completed multidrug therapy treatment for leprosy	Cross-sectional Study	90 participants.	It primarily affects women and people in vulnerable situations (low income and low educational attainment). Treatment is highly centralized in referral centers (97.8%). Clinically, the presence of physical disabilities at the end of therapy and serious gaps in official records indicate that the disease is diagnosed late.
11	Pinto et al. (2021)	Factors associated to quality of life in patients with leprosy	Cross-sectional Study	63 participants.	A higher quality of life is associated with being white, while a lower quality of life is linked to a lower level of education. Women, people without a partner, and those who do not receive visits from health workers report lower levels of well-being.
12	Rocha et al. (2020)	Epidemiological characteristics of leprosy inelderly Brazilians and comparison withother age groups (2016-2018)	Cross-sectional Study	81.205 cases.	Men, Black individuals, and those with low levels of education account for the largest proportion of multibacillary cases (81.3%), indicating delayed diagnoses and a higher potential for transmission. Paradoxically, detection through contact tracing is the lowest among all age groups (4.9%), highlighting a failure in active surveillance.

N	Authors (year)	Title	Methodological Design	Number of participants	Main Results
13	Santos et al. (2025)	Clinical-epidemiological profile of leprosy cases in the states of the Northeast region of Brazil in the period 2018-2022	Ecological study	147.617 cases.	Maranhão has the highest prevalence of leprosy, while Rio Grande do Norte has the lowest. The epidemiological profile is characterized by a predominance of men (57.4%), people of mixed race (64.9%), and adults of working age (20–59 years), generally with low levels of education. Clinically, multibacillary cases are predominant (76.94%).
14	Silva et al. (2023)	Social stigma and leprosy: identification of knowledge as a health education strategy	Descriptive study	112 participants.	Knowledge about leprosy remains limited and riddled with contradictions, particularly regarding transmission, as 59.4% mistakenly believe that the disease is spread through skin-to-skin contact. Although the majority (51.8%) claim to know the modes of transmission, 48.2% still hold the misconception that people with the disease should not handle food.
15	Soares et al. (2021)	Sociodemographic and clinical factors of leprosy cases associated with the performance of the evaluation of their contacts in Ceará, 2008-2019	Cross-sectional Study	23.675 participants.	Only 65.4% of new leprosy cases had all their contacts screened. This gap in surveillance is concentrated among socially and clinically vulnerable groups, being more common among men, Black or Brown individuals, those with low levels of education, rural residents, and multibacillary cases.
16	Sousa et al. (2023)	Patients' perception of the search for a diagnosis of leprosy and care in health care networks	Exploratory study	15 participants.	The process of diagnosing leprosy is long and challenging. Initially, patients have difficulty recognizing the symptoms, often mistaking them for skin or bone problems. This journey leads to multiple visits to the doctor and misdiagnoses, which significantly delays the start of proper treatment.
17	Sousa et al. (2023)	Difficulties in coping with leprosy in treatment and after discharge	Cross-sectional Study	53 participants.	The participants were predominantly male (58.5%), with a mean age of 53 years, low educational attainment (62.3% with only elementary school education), and low income (66% earning between 1 and 2 minimum wages). During treatment, prejudice was reported by 41.5% of participants, dropping to 15.1% in the post-discharge period.
18	Souza et al. (2021)	Quality of life of patients diagnosed with leprosy in a municipality in Piauí	Cross-sectional Study	46 participants.	It was observed that the employment variable had a negative impact on mental health and overall health, while functional capacity was impaired by factors such as low educational attainment and the presence of other conditions, such as hypertension and diabetes. In addition, the study highlighted that gender influenced social aspects and mental health.
19	Souza et al. (2020)	Leprosy and social deprivation: definition of priority areas in an endemic state of northeastern Brazil	Ecological study	42.227 casos.	Municipalities with better living conditions have the highest rates of leprosy detection due to easier access to health services, a phenomenon known as “pseudo-risk.” In contrast, areas with very high levels of social deprivation (60.4% of the state) suffer from hidden prevalence, where poverty acts as a barrier to diagnosis and keeps transmission active.

Source: Prepared by the authors, 2026.

The main finding of the quantitative synthesis, as shown in the forest plot in Figure 2, reveals that social stigma is the most prominent impact associated with leprosy, present in 74% of the studies analyzed (95% CI: 0.54–0.94), numerically surpassing other impacts such as barriers to care (68%) and economic impact (63%).

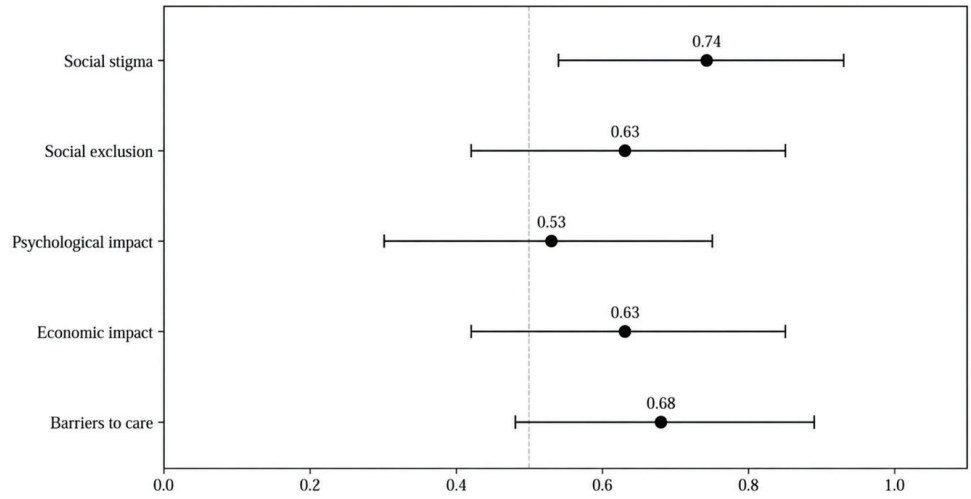

Figure 2. Forest plot summarizing the proportions of the main impacts associated with leprosy.
Source: Prepared by the authors, 2026.

In addition, a comparative analysis of the studies was conducted, revealing a concentration in the Northeast (100%), with a predominance of cross-sectional designs (60%), followed by qualitative (25%) and ecological (15%) studies. The most affected population was adults of working age (75%), particularly in contexts of social vulnerability, with greater severity among the elderly (10%) and few studies involving healthcare professionals (5%), highlighting regional inequalities and gaps in scientific output. These comparisons can be seen in table 1.

Table 1. Internal comparison of the studies analyzed, considering region, study design, and study population, with corresponding numbers, percentages, and main findings.

Comparison criteria	Number of studies	% Percentage of studies	Key findings
Region			
Northeast	19	100%	High prevalence and concentration of scientific output.
Study type			
Cross-sectional	11	60%	Predominance of epidemiological analyses.
Exploratory/qualitative	5	25%	Emphasis on stigma and perceptions of the disease.
Ecological	3	15%	Relationship with social determinants.
Population			
Adults (ages 20–59)	15	75%	Higher prevalence among the working-age population.
Elderly	2	10%	Greater severity and delayed diagnosis.
Healthcare professionals	1	5%	The presence of stigma and lack of awareness.

Source: Prepared by the authors, 2026.

Finally, Table 2 highlights the main aspects related to the economic impacts of leprosy, emphasizing its strong association with conditions of social vulnerability. It is observed that low educational attainment (70%) and low income (60%) stand out as the main factors associated with leprosy. Also noted are high social vulnerability (65%), difficulties in accessing diagnosis (50%), and work disability (45%), in addition to institutionalization (15%).

Table 2. A summary of the economic impacts described in the included studies, presenting the variables, the number and percentage of studies, and the main associated findings.

Economic variable	Number of studies	% Percentage of studiess	Key findings
Low income	12	60%	Predominance of incomes at or below 1–2 minimum wages.
Low educational attainment	14	70%	Associated with a lower quality of life.
Work disability	9	45%	Limitations on employment.
Social vulnerability	13	65%	Direct link to the occurrence of the disease.
Institutionalization	3	15%	Persistence due to lack of resources.
Inequality in access	10	50%	Barriers to diagnosis and treatment.

Source: Prepared by the authors, 2026.

DISCUSSION

This study demonstrated that the stigma and social exclusion associated with leprosy remain strongly linked to contexts of socioeconomic vulnerability, posing persistent barriers to disease control. The profile of affected individuals overlaps with social risk factors, such as low educational attainment, limited income, and restricted access to health services, reinforcing the understanding of leprosy as a socially determined condition. Thus, the disease goes beyond the biological dimension and reflects historically constructed structural inequalities that interfere with prevention, early detection, and continuity of care (Souza et al., 2020; Rocha et al., 2020).

The predominance of men of working age, of mixed-race descent, and with low educational attainment was associated not only with a higher risk of illness but also with significant social and economic repercussions. Lower male demand for health services, often related to informal employment and the need to maintain family income, contributes to late diagnosis and the perpetuation of the transmission chain. As a result, there is a high proportion of multibacillary cases and individuals with grade 2 physical disability at the time of diagnosis, which exacerbates discriminatory processes and psychosocial impacts (Soares et al., 2021; Pinheiro et al., 2021).

With regard to social perceptions of leprosy, the disease is still marked by negative symbolic associations, historically influenced by the term "leprosy." The persistence of this imagery is linked to conceptual confusion regarding terminology and a lack of knowledge about modes of transmission, treatment, and cure. This scenario fosters the spread of myths and misconceptions, fueling practices of rejection within family, community, and workplace settings. Even with effective and free treatment provided by the Unified Health System (SUS), such conceptions continue to impact the social lives of those affected (Silva et al., 2023; Morais et al., 2024; Souza et al., 2021).

These symbolic constructs have a direct impact on daily life, interfering with self-image and interpersonal relationships. Concealing clinical signs and delaying the search for care are recurring strategies to avoid situations of exposure and discrimination. In many cases, social withdrawal occurs as a self-protection mechanism. The internalization of these stigmas manifests as feelings of shame, fear, and worthlessness, compromising self-esteem, emotional well-being, and treatment adherence, even after the start of care (Finotti et al., 2020; Pinto et al., 2021).

Institutional discrimination was identified, particularly in primary health care (PHC). Although it occupies a strategic position as the gateway to the system, PHC faces challenges related to the decentralization of care, insufficient professional training, and the fragility of care pathways. These limitations reduce its capacity to effectively address the disease and its social impacts. Strengthening primary care, in conjunction with active contact tracing and longitudinal care, is essential for early diagnosis and the prevention of disabilities (Lima et al., 2021; Sousa et al., 2023; Sousa et al., 2023).

Inappropriate conduct by some professionals, such as misguided advice regarding home isolation and the separation of personal belongings, highlights gaps in technical training and continuing education. These practices compromise humanized care and reinforce exclusionary processes within the health services themselves. The literature indicates that institutional failures can reproduce historically constructed stereotypes, amplifying the suffering of affected individuals (Batista et al., 2022; Rocha et al., 2020).

Institutional weaknesses are also reflected in prolonged and fragmented treatment pathways. Multiple appointments, successive referrals, and misdiagnoses—particularly in primary care—lead to delays in the start of treatment and clinical deterioration. This exhausting process intensifies emotional distress and undermines trust in the healthcare system. Furthermore, it reinforces the perception of institutional neglect, especially among individuals who are more socially vulnerable (Sousa et al., 2023; Lima et al., 2021).

Social exclusion related to leprosy persists even after discharge due to cure, demonstrating that clinical resolution does not end its impacts. Impairments in functionality, self-esteem, and quality of life are observed, especially among people with lower levels of education and income. Physical sequelae, combined with the symbolic marks of the disease, continue to influence social relationships and labor market integration. Thus, biological cure alone proves insufficient to ensure full rehabilitation, requiring continuous follow-up and psychosocial support (Fortunato et al., 2024; Antas et al., 2022).

This situation is even more evident among residents of former colonial hospitals, where prolonged institutionalization reflects the historical exclusion experienced by this population. Studies on social representations in these spaces demonstrate that, although they functioned as places of care, they also contributed to the construction of identities marked by segregation and institutional dependence (Passos and Araújo, 2020; Nascimento et al., 2020). The persistence of these institutions highlights limitations in social reintegration policies and in the guarantee of rights.

Within the scope of coping strategies, Self-Care Support Groups (GACs) stand out as relevant initiatives for strengthening autonomy and reframing the disease. These spaces promote mutual support, the exchange of experiences, and the encouragement of self-care. However, their sustainability still faces challenges related to the structural precariousness of services and the lack

of continuous institutional support, which limits their transformative potential (Nascimento et al., 2024; Sousa et al., 2023).

Overall, the findings indicate that discrimination against people with leprosy does not stem solely from clinical manifestations, but is rooted in persistent structural inequalities and institutional weaknesses. The lack of educational initiatives is a central factor in perpetuating misconceptions about transmission and coexistence. This gap affects not only the general population but also students and healthcare professionals, revealing shortcomings in initial training and continuing education (Santos et al., 2025; Batista et al., 2022; Souza et al., 2021).

Finally, overcoming social exclusion related to leprosy requires a paradigm shift in how the disease is socially understood. Recognizing affected individuals as rights-holders and protagonists of their own care is fundamental to breaking historically stigmatizing narratives. The promotion of collective spaces, social participation, and community strengthening constitute powerful strategies for the symbolic reconstruction of the disease. Thus, addressing leprosy requires not only technical actions but also an ethical and political commitment to equity, social justice, and human rights, in line with national control guidelines (Souza et al., 2020).

CONCLUSION

Therefore, the study showed that the stigma and social exclusion associated with leprosy remained linked to social, historical, and institutional inequalities, especially among vulnerable populations. It was found that the disease extended beyond the biological realm, being influenced by social determinants that contributed to late diagnosis and the perpetuation of stigma.

It was also observed that stigma negatively affects the quality of life, mental health, and social participation of those affected, even after cure, and is reinforced by misinformation, historical perceptions, and discriminatory practices. We also identified weaknesses in primary health care related to early diagnosis, the organization of care, and professional training, highlighting the need for interdisciplinary strategies and public policies aimed at reducing inequalities and promoting human rights.

STATEMENT ON THE USE OF ARTIFICIAL INTELLIGENCE

The author(s) used ChatGPT Plus for grammatical review. All intellectual and scientific decisions regarding the content of the manuscript are the sole responsibility of the authors.

REFERENCES

Antas, E. M. V., Silva, M. R., & Souza, L. S. (2022). Qualidade de vida e condição clínica de indivíduos com hanseníase. *Revista Mineira de Enfermagem, 26*, e1466. https://doi.org/10.35699/2316-9389.2022.40403

Batista, S. O., Santos, F. S., & Almeida, R. C. (2022). Estigma da hanseníase por agentes comunitários de saúde: Fatores associados. *Hansenologia Internationalis, 47*, 1–17. https://doi.org/10.47878/hi.2022.v47.37913

Brasil. Ministério da Saúde. (2022). *Protocolo clínico e diretrizes terapêuticas da hanseníase*. Ministério da Saúde.

Brasil. Ministério da Saúde. (2024). *Estratégia nacional para enfrentamento à hanseníase 2024–2030*. Ministério da Saúde.

Cavalcante, A. K. S., & Oliveira, L. C. (2020). Revisão da literatura como método científico.

Finotti, R. F. C., Souza, M. A., & Lima, D. R. (2020). Transtornos mentais comuns e fatores associados entre pessoas com hanseníase: Análise transversal em Cuiabá, 2018. *Epidemiologia e Serviços de Saúde, 29*(4), e2019279. https://doi.org/10.5123/S1679-49742020000400006

Fortunato, C. N., Pereira, A. L., & Costa, M. S. (2024). Qualidade de vida, funcionalidade e autoestima de pessoas no pós-alta por cura de hanseníase. *Cogitare Enfermagem, 29*, e92092. https://doi.org/10.1590/ce.v29i0.92092

Guimarães, A.S.A.N., Siqueira, A.B.S., Machado, A.V.S., Júnior, D.D.A., Nascimento, E.T.B., Passos, J.V.S., Alencar, P.J.F.A., Soares, R.S.L., Santos, R.G.S., Filho, T.W.A., & Frana, A.R.S. (2024). estratégias de controle da hanseníase na atenção primária à saúde: uma revisão de escopo. *Revista ft*. https://doi.org/10.69849/revistaft/ni10202411212032

Jesus, I.L.R., Montagner, M.I., Montagner, M.A., Alves, S.M.C., & Delduque, M.C. (2023). Hanseníase e vulnerabilidade: uma revisão de escopo. *Ciência e Saúde Coletiva*. https://doi.org/10.1590/1413-81232023281.09722022

Lima, E. O., Santos, J. P., & Oliveira, R. S. (2021). Itinerário terapêutico das pessoas com hanseníase: Caminhos, lutas e desafios em busca do cuidado. *Revista Brasileira de Enfermagem, 74*(1), e20200532. https://doi.org/10.1590/0034-7167-2020-0532

Morais, R. X. B., Almeida, T. S., & Costa, F. L. (2024). Perfil de conhecimento sobre hanseníase entre pacientes de um hospital universitário. *Hansenologia Internationalis, 49*, e37421. https://doi.org/10.47878/hi.2024.v49.37421

Nascimento, D. S., Silva, R. A., & Souza, P. H. (2020). Limitação de atividade e restrição à participação social em pessoas com hanseníase: análise transversal da magnitude e fatores associados em município hiperendêmico do Piauí, 2001 a 2014. *Epidemiologia e Serviços de Saúde, 29*(3), e2019543. https://doi.org/10.5123/S1679-49742020000300012

Nascimento, R. D., Oliveira, M. C., & Santos, L. F. (2024). Criação e desenvolvimento de grupos de apoio para o autocuidado em hanseníase. *Physis: Revista de Saúde Coletiva, 34*, e34012. https://doi.org/10.1590/S0103-7331202434012

Passos, Á. L. V., & Araújo, L. F. (2020). Social representations of a former colony hospital: A study of its residents. *Psicologia: Teoria e Prática, 22*(2), 234–249. https://doi.org/10.5935/1980-6906/psicologia.v22n2p234-249

Pinheiro, M. G. C., Santos, D. A., & Lima, F. R. (2021). Perfil de pacientes que concluíram o tratamento poliquimioterápico da hanseníase. *Ciência, Cuidado e Saúde, 20*, e58386. https://doi.org/10.4025/ciencuidsaude.v20i0.58386

Pinto, G. F., Oliveira, A. L., & Costa, R. S. (2021). Fatores associados à qualidade de vida em pacientes com hanseníase. *Einstein (São Paulo), 19*, eAO5936. https://doi.org/10.31744/einstein_journal/2021AO5936

Rodrigues, A. B., Sachinski, R. T., & Martins, L. F. (2022). Contribuições da revisão integrativa para a pesquisa qualitativa em educação. *Linhas Críticas*. https://doi.org/10.26512/lc28202240627

Rocha, M. C. N., Souza, A. C., & Lima, P. R. (2020). Características epidemiológicas da hanseníase nos idosos. *Cadernos de Saúde Pública, 36*(9), e00048019. https://doi.org/10.1590/0102-311X00048019

Santos, M. D. B., Oliveira, J. R., & Costa, H. L. (2025). Perfil clínico-epidemiológico dos casos de hanseníase no Nordeste. *Hansenologia Internationalis, 50*, e40505. https://doi.org/10.47878/hi.2025.v50.40505

Silva, T. M. A., Ferreira, L. R., & Santos, C. A. (2023). Estigma social e hanseníase: Identificação de conhecimento como estratégia de educação em saúde. *Estudos Interdisciplinares em Psicologia, 14*. https://doi.org/10.5433/2236-6407.2023.v14.48115

Soares, G. M. M. M., Costa, A. P., & Lima, J. S. (2021). Fatores sociodemográficos e clínicos de casos de hanseníase. *Epidemiologia e Serviços de Saúde, 30*(3), e2020585. https://doi.org/10.1590/S1679-49742021000300015

Sousa, J. N., Oliveira, F. C., & Santos, M. R. (2023). Dificuldades no enfrentamento da hanseníase no tratamento e pós-alta. *Revista de Enfermagem da UFPI, 12*, e3383. https://doi.org/10.26694/reufpi.v12i1.3383

Sousa, J. N., Almeida, R. S., & Costa, D. F. (2023). Percepção dos pacientes sobre a busca pelo diagnóstico da hanseníase. *Hansenologia Internationalis, 48*, e39333. https://doi.org/10.47878/hi.2023.v48.39333

Souza, C. D. F., Silva, M. A., & Oliveira, J. P. (2020). Hanseníase e carência social. *Revista Brasileira de Epidemiologia, 23*, e200007. https://doi.org/10.1590/1980-549720200007

Souza, Z. C. P., Ferreira, A. L., & Santos, R. M. (2021). Qualidade de vida em pacientes com hanseníase. *Revista de Enfermagem da UFPI, 10*, e1020. https://doi.org/10.26694/reufpi.v10i1.1020