

EPIDEMIOLOGY OF LEPROSY AND THE RELATIONSHIP WITH SOCIAL DETERMINANTS AND SUSTAINABILITY



<https://doi.org/10.56238/arev7n3-138>

Submitted on: 14/02/2025

Publication date: 14/03/2025

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ABSTRACT

Leprosy is an infectious, communicable, notifiable disease, considered a public health problem, with a high morbidity rate, whose etiological agent is *Mycobacterium leprae*, an acid-fast bacillus. Thus, the objective of this study was to carry out a bibliographic survey on the impact of leprosy in Brazil and its main implications for public health. This is an Integrative Literature Review. The search process took place by crossing the exact descriptors in health sciences: "leprosy; social vulnerability", with the Boolean operator

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AND. The crossing of descriptors in the selected databases returned 30 studies. Of these, 17 were in LILACS, 03 in BDEF, 05 in MEDLINE and 05 in SCIELO. A total of 18 studies were submitted to the full reading process. Of the studies included, all were in the area of epidemiology and public health. Sustainability, as it was well explained in the course of the research, is anchored in environmental impact, climate change, uncontrolled urbanization and environmental degradation can influence the transmission of the disease; sustainability of control programs, with prioritization of promotion, prevention, treatment and rehabilitation actions, with equity in health services and social sustainability, through the involvement of the community with disease control actions in a social and economic way.

Keywords: Leprosy. Social Vulnerability. Epidemiology. Public health.

INTRODUCTION

Leprosy is a chronic, infectious, transmissible disease, considered a serious public health problem in Brazil with a high prevalence and incidence rate, affecting people of any age group with progressive and slow evolution. Caused by *Mycobacterium leprae* or *M. lepromatosis*, with wide symptoms, it is responsible for a high rate of morbidity and mortality, with transmission through the upper airways, especially in patients with a high bacillary load (MS, 2016; MS, 2020).

Epidemiological data from the World Health Organization (WHO) show that 208,619 new cases of the disease were registered in 2018 worldwide. Of these, 30,957 occurred in the Americas region and 28,660 (92.6% of the total of the Americas) were reported in Brazil (WHO, 2019).

The control and elimination of leprosy is a global public health goal. The prevalence target is configured in cases of records less than 1 per 10,000 inhabitants. However, even with the WHO control goals, in Brazil, public health articulated with important points of capture and considered the main entrance to the health system, primary care, has shown a decrease in the experience of professionals in the care and management of leprosy, pointing out that Brazil is experiencing a hidden endemic in the country, even in non-endemic areas (Frade *et al.*, 2017).

Thus, it is emphasized that living standards vary according to regions, population groups and vulnerabilities faced. With this, we think about the need to think about the quality and sustainability of human development. Referring to this, this chapter will have as its main objective to articulate the main concepts of leprosy, epidemiological aspects and their relationship with the social determinants of health and social sustainability.

The main weakness pointed out in the studies by Macinko *et al.* (2017) demonstrates that the sustainability of the control of Leprosy Control Actions (HCA) still faces challenges for the expansion of care in primary health care. Therefore, in order to achieve the proposed objective, a literature review will be carried out to theoretically substantiate the themes exposed above.

THEORETICAL FRAMEWORK

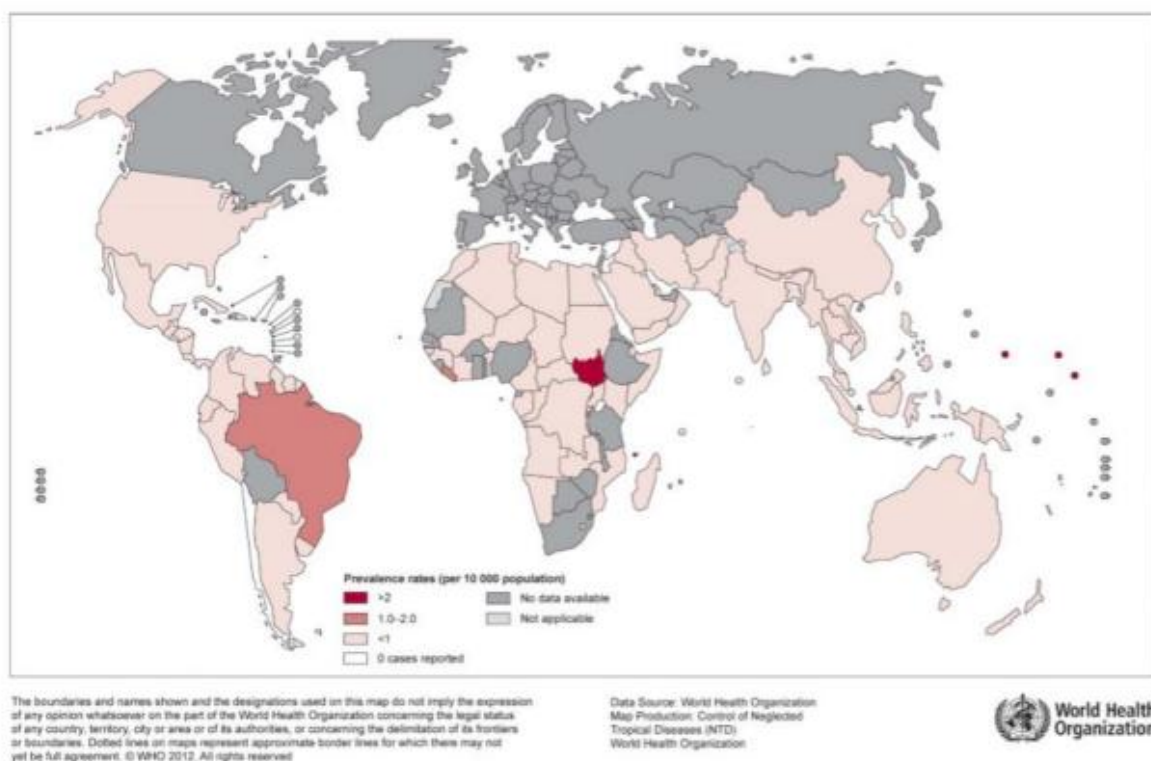
LEPROSY TRAJECTORY AND EPIDEMIOLOGICAL ASPECTS

Leprosy, a disease caused by *Mycobacterium leprae* (*M. leprae*), despite advances, continues to be a highly relevant public health problem, with a high burden on the

government. Among the clinical manifestations, dermatoneurological are the most present, with the appearance of red or brown spots and loss of painful, tactile and thermal sensitivity. Statistical data from the World Health Organization (WHO) reported 115 new cases of the disease in 2013, with a higher incidence in Southeast Asia, Latin America and the African continent (WHO, 2013; WHO, 2014).

With regard to epidemiology at the global level, the countries considered endemic according to data from the WHO (2014) are: Brazil, China, India, Angola, Ethiopia, Indonesia and ten other countries. In the period from 2005 to 2010, a decrease of 23% in cases of the disease was recorded. In 2012, an average of 232 thousand cases were registered, with 189 thousand cases identified at the end of the first half of 2013 (WHO 2013; WHO 2014).

Figure 1 - Global leprosy prevalence rate in 2012.



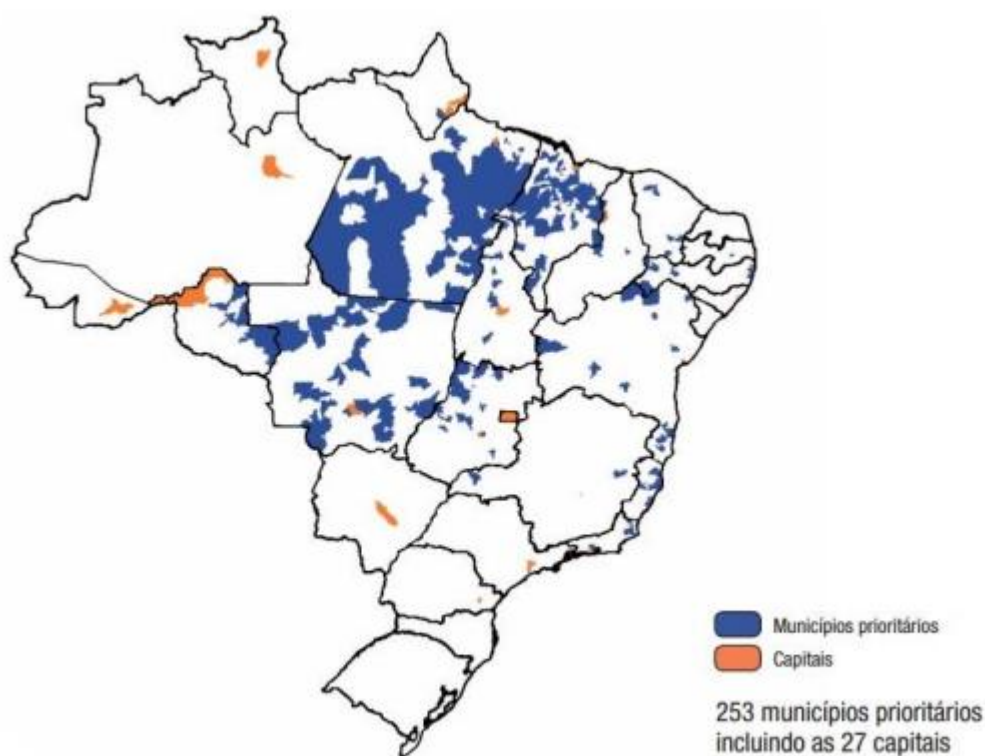
Source: WHO, 2014.

In an analysis of published material regarding the history of epidemiology, the WHO promoted the 44th World Health Assembly in 1991 with the objective of eliminating leprosy. The goal, however, was not met, and it was necessary to revalidate the commitment to eliminate leprosy by 2005, but again without success, and in 2006 a new national elimination plan was established by the year 2010, with the indicator of detection of new

cases (Brasil, 2008).

In 2009, faced with the failure to meet the goal, Brazil abandoned the WHO goal and created a specific action for the country with the objective of eliminating the disease by 2015. The main indicator that supported this coping planning was based on the early detection and cure of diagnosed cases. Geographic areas at risk of greater endemicity, represented by a set of 253 municipalities, were listed as priority targets, as these municipalities registered 56% of new cases diagnosed in 2010 and 67% of new cases in children under 15 years of age (Brasil, 2012).

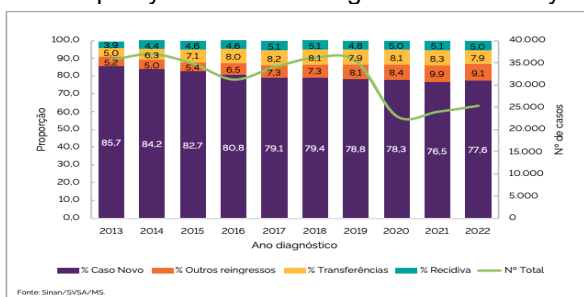
Figure 2 - Priority municipalities for leprosy surveillance in 2010.



Source: BRASIL, 2012.

In increasing context, during 2013 to 2022, 316,182 cases of leprosy were reported in Brazil, with a reduction of 28.9% in the number of cases. In the years before the covid-19 pandemic (2013 to 2019) there was a reduction of 0.8%. In the period from 2019 to 2022, the reduction was 28.4% (Brasil, 2024).

Figure 03 – Proportion of leprosy cases according to mode of entry – Brazil, 2013 to 2022.



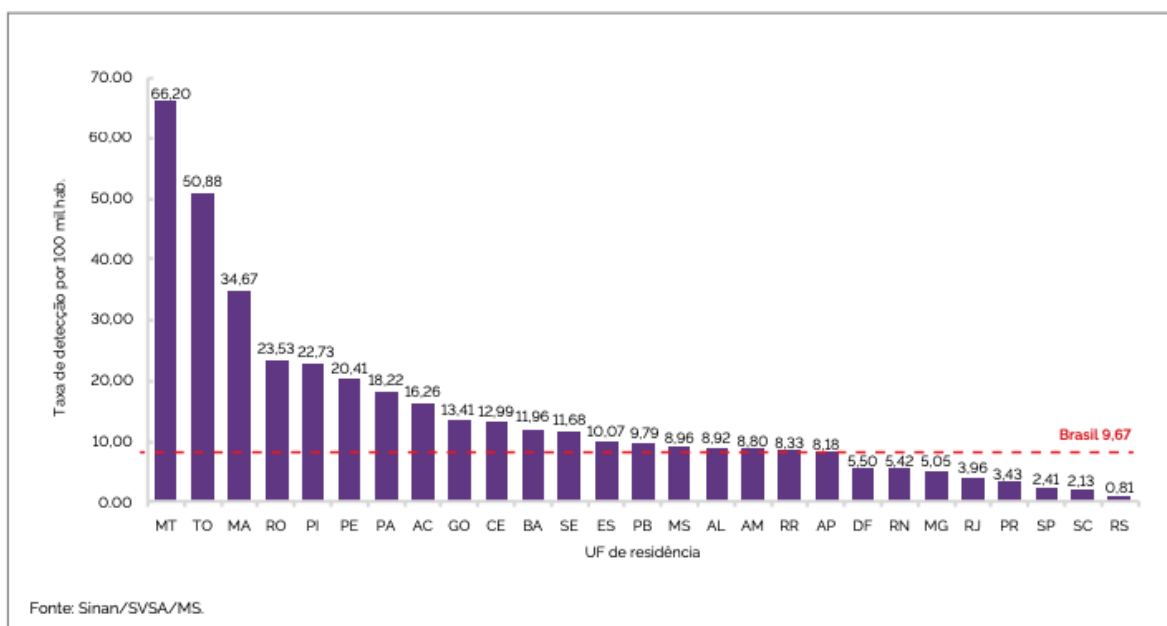
Source: Brazil, 2024.

Recent data from the WHO show that in 2021, 106 countries reported 140,594 new cases of the disease in the world, this represents an increase of 10.2% compared to 2020. The country that reported the most new cases was India, with about 53.6% of the global total. In the Americas region, 92.4% of the cases were registered in Brazil. At this juncture, Brazil ranks second among the countries with the highest number of cases in the world, followed by Indonesia. Of the global total registered, India, Brazil, and Indonesia are the countries that reported the most new cases, corresponding to 74.5% (WHO, 2022; Brazil, 2023).

A major public health concern in 2021 was the notification of 9,052 new cases diagnosed in children under fifteen years of age. Regarding the degree of disability, 8,492 (6%) new cases of the disease were diagnosed with grade 2 disability, with more severe injury to the eyes, hands, and feet (WHO, 2022).

In 2022, 174,087 new cases of leprosy were registered worldwide, corresponding to 21.8 cases per 1 million inhabitants. Regarding cases in Brazil in 2022, (9.67) new cases were identified per 100 thousand inhabitants. The states of Mato Grosso and Tocantins were the ones with the highest reported cases: 66.20 new cases per 100 thousand inhabitants and 50.88 new cases per 100 thousand inhabitants, respectively (Brasil, 2022; Brazil, 2024).

Figure 04 - Overall detection rate of new leprosy cases (per 100 thousand inhabitants) by Federation Unit of residence – Brazil, 2022.



Source: Brazil, 2024.

GEOPROCESSING AND SPATIAL ANALYSIS

Within the social sciences, geoprocessing and spatial analysis have contributed to the understanding of ecological studies, since it enables spatial relationships and biological events, in addition to subsidizing statistical analyses for the detection of the variability of a phenomenon. Diseases such as leprosy, which are chronic, infectious and transmissible, when using geoprocessing and spatial analysis, provide subsidies for the formulation of effective public policies (Pereira, 2006; Barcellos et al., 2008; Pereira *et al.*, 2015).

Geoprocessing has become indispensable in the spatial analysis of communicable diseases that present epidemiological patterns that are related to the environment. Through geoprocessing, the analysis of much information available in a database has become faster with the probability of integrating epidemiological data with cartographic bases (Chiaravalloti-Neto, 2017).

Pereira *et al.* (2018) reiterates that the thematic maps used in the health area provide the visualization of the spatial distribution of the diseases and allow us to ensure the association of the event with factors that are adjusted by the conditions of the local environment and can help in the formulation of hypotheses about the etiology of the disease. In the context of the spatial analysis of diseases, Ribeiro (2014) mentions that "maps continue to be his most expressive language, but they are only one of the stages of research, important for the formulation of etiological hypotheses and for the establishment

of spatial relationships.

RELATIONSHIP BETWEEN LEPROSY AND SOCIAL DETERMINANTS AND SUSTAINABILITY SOCIAL CAPACITY

Analyzing the social determinants of health and social sustainability and their relationship with leprosy emerges the discussion of understanding the recognition of social vulnerability in people diagnosed with leprosy and the population at risk. Characterized as a chronic disease, strongly conditioned by the social context and closely associated with the socioeconomic precariousness of the affected populations, it is expressed in the spatial distribution of the disease in poorer and underdeveloped countries (Pinheiro, 2007).

Social Determinants of Health 'are the circumstances in which people are born, grow, live, work and age, as well as the systems established to combat disease'. These circumstances 'are configured by a broader set of forces: economic, social, normative and political'. In this sense, living conditions [...] are 'determined' by the 'place that each one occupies in the social hierarchy'; This includes the degree of individual vulnerability to health problems and their consequences. (WHO, 2008 apud TAMBELLINI; SCHÜTZ, 2009, p. 374-375).

The context in which individuals are inserted in the health-disease process goes beyond the biological dimension and is directly related to political, cultural and socioeconomic aspects. Therefore, individuals need to be seen holistically, valuing their singularities and strengthening the autonomy of these subjects (Fleury-Teixeira, 2009).

Studies focused on the analysis of the social determinants of health promote reflection on equity in the provision of care, valuing individualities, integration of the service and management, and strengthening of preventive, curative, and rehabilitation actions.

In this context, social vulnerability is inserted in this discussion as spaces for the emergence of diseases and the relationship between natural risks linked to health. As pointed out by Katzam apud Brasil, 2007, p. 14-15, a situation of social vulnerability is characterized by:

[...] Situations of social vulnerability must be analyzed based on the existence or not, on the part of individuals or families, of available assets capable of facing certain risk situations. Therefore, the vulnerability of an individual, family or social group refers to the greater or lesser capacity to control the forces that affect their well-being, that is, the possession or control of assets that constitute the resources required to take advantage of the opportunities provided by the State, market or society. These assets would be ordered as follows: (i) 'physical', which would involve all the essential means for the pursuit of well-being. These could be further divided into [...] (land, animals, machines, housing, durable goods relevant to social reproduction); or [...] involving savings and credit, as well as forms of insurance and protection; (ii) 'human', which would include work as the main asset and the value

added to it by investments in health and education, which would imply greater or lesser physical capacity for work, qualification, etc.; (iii) 'social', which would include networks of reciprocity, trust, contacts and access to information. Thus, the condition of vulnerability should consider the situation of people based on the following elements: insertion and stability in the labor market; [...] the degree of regularity and quality of access to public services or other forms of social protection. (KATZAM apud BRASIL, 2007, p. 14-15).

In line with the relationship between leprosy and social sustainability, it is extremely relevant to discuss which sustainable development goals are related to this theme. Thus, we point out here three objectives that are implicitly related to the theme of this research. Goal 3 mentions that one must "ensure a healthy life and promote well-being for all, at all ages"; Goal 4 cites that it should "ensure inclusive and equitable quality education, and promote lifelong learning opportunities for all" and goal 13 cites that "urgent action should be taken to combat climate change and its impacts".

The 2030 agenda is an important action plan for people seeking to secure human rights. With regard to goal 3, the agenda recommends that by 2030 epidemics such as AIDS, tuberculosis, tropical and communicable diseases, such as leprosy, be eradicated from the world. In addition, "reduce premature mortality from noncommunicable diseases by one-third through prevention and treatment, and promote mental health and well-being" (UN, 2015).

The promotion of inclusive and equitable education for all ages is one of the objectives of the agenda through providing learning scenarios in all life cycles. Another relevant issue is "by 2030, eliminate gender disparities in education and ensure equal access to all levels of education and vocational training for the most vulnerable, including persons with disabilities, indigenous peoples and children in vulnerable situations" (UN, 2015).

With regard to climate change and its impacts, the 2030 agenda emphasizes the need to "integrate climate change measures into national policies, strategies and planning" and "improve education, increase awareness and human and institutional capacity on global climate mitigation, adaptation, impact reduction, and early warning of climate change" (UN, 2015).

Figure 05- Sustainable Development Goals



Source: UN, 2015.

METHODOLOGY

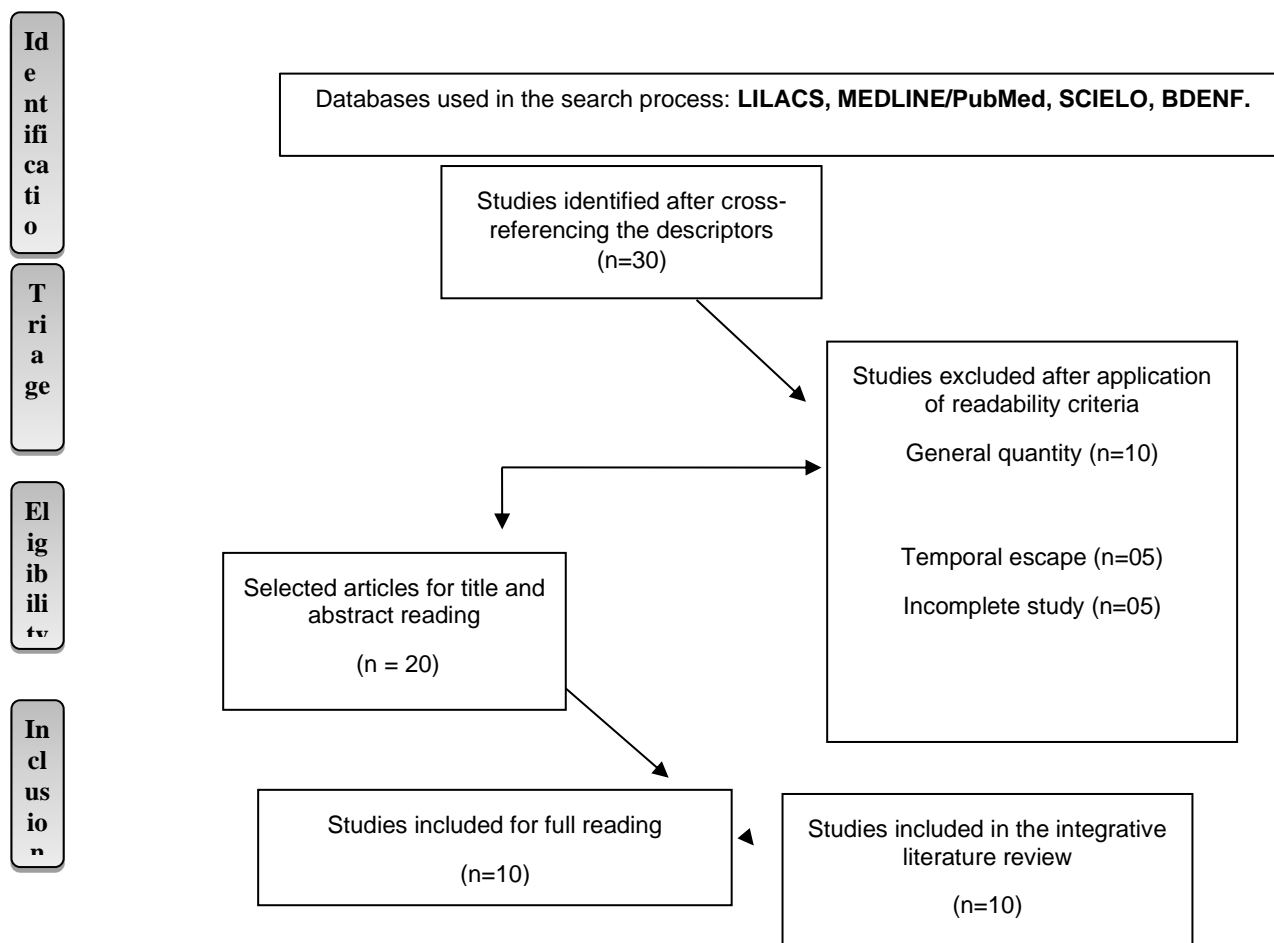
This is an Integrative Literature Review (RIL), of a descriptive nature, developed to analyze and synthesize studies on the subject (Souza; Silva; Carvalho, 2010). Original articles available in full, as well as dissertations, theses, and manuals of the Ministry of Health, in any language indexed in the CAPES journal portal and the Virtual Health Library Portal (VHL) during the month of July 2024, were searched. The search process took place by crossing the exact descriptors in health sciences: "leprosy"; "epidemiology"; "social determinants of health", with the Boolean operator AND. The articles included in the study were published in the period from 2014 to 2024.

RESULTS AND DISCUSSIONS

The cross-referencing of the descriptors in the selected databases returned 30 studies. Of these, 17 were in LILACS, 03 in BDNF, 05 in MEDLINE and 05 in SCIELO. After applying the eligibility criteria, 10 studies were excluded because they did not fit the established criteria, 5 studies were incomplete, and 5 were time-slippery; 20 articles were submitted to the title and abstract reading process. After reading the title and abstract, 10 studies were excluded, 03 studies of another nature (review articles, dissertations and theses), 03 duplicated and 04 with escape from the proposed theme. A total of 10 studies were submitted to the full reading process. After a new analysis, 10 articles answered the research question and composed the final sample of the integrative review.

The stages of study selection are presented in Figure 1, an adaptation of the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) flowchart as presented by Moher et al., (2009).

FIGURE 1 - Flowchart for the selection of studies, adapted according to Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA).



Source: Prepared by the authors, 2024.

Of the studies included, all were in the area of epidemiology and public health. Regarding the language, they were published in Portuguese and covered: quantitative cross-sectional study, exploratory study with qualitative approach, ecological study and cross-sectional study.

After applying the eligibility criteria and excluding 18 studies, 30 articles were submitted to reading the title and abstract. In the subsequent stage, with the exclusion of 35 articles (of other natures, duplicates or with deviations from the theme), the sample was reduced to 18 studies. Finally, after reading in full, 13 articles with presentation of the final

sample, with the highest value observed 17 studies (in the LILACS database) and the lowest value 05 studies (in MEDLINE), reflecting the diversity of studies available in different databases and the selection process rigorously, studies throughout the selection process, with the final sample consisting of 10 studies, that met the established inclusion criteria and were considered relevant to the research.

The data were organized in a table prepared by the researcher containing relevant aspects of the included studies, such as: author/year, type of study, sample size, origin of the study and results (Table 1).

TABLE 1 - Qualitative analysis of the studies included in the review.

| AUTHOR/YEAR/TY PE OF STUDY | SAMPLE SIZE | FINDINGS |
|---|---|--|
| Boigny <i>et al.</i> , (2020). Cross-sectional study | 233 cases of leprosy | Of the 233 leprosy cases analyzed, 154 (66.1%) belonged to family networks with 3 or more leprosy cases. |
| Olivério <i>et al.</i> , (2021). Cross-sectional study | Available cases of leprosy from 2014 to 2019. | Leprosy predominated in the northern regions and, especially, in the northeast region. |
| Assis <i>et al.</i> , (2021). Descriptive exploratory study | 41 participants from a basic health unit in Macéio. | The clinical manifestations of leprosy have an impact on quality of life, living in society and damage to self-image, in addition to the prevalence of these factors in populations in situations of social vulnerability. |
| Soares <i>et al.</i> , (2021). Cross-sectional study | New cases of leprosy residing in the state of Ceará, Brazil, from 2008 to 2019. | There were higher cases of multibacillary leprosy and individual and social vulnerability influences the unsatisfactory performance of the contact assessment. |
| Martorelli J. <i>et al.</i> , (2023). Ecological study | Cases of leprosy in children under 15 years of age reported in the Notifiable Diseases Information System, between 2008 and 2018 | Risk clusters for leprosy were identified in the north, west, east and south regions of Cuiabá, |
| Silva, A. <i>et al.</i> , (2020). Cross-sectional study | 200 patients | Identification of high rates of leprosy in peripheral communities due to social vulnerability. |
| Kumar, R. <i>et al.</i> , (2020). Cohort study | 300 patients | Study on the relationship between social vulnerability and leprosy in marginalized areas of India. |
| Tran, D. <i>et al.</i> , (2021). Qualitative study | 40 participants | The impact of health education on the early diagnosis of leprosy in vulnerable populations in Thailand. |
| Hara, M. <i>et al.</i> (2021). Intervention Study | 100 patients | Implementation of public health policies to reduce the prevalence of leprosy in vulnerable communities in Japan. |
| Patel, S. <i>et al.</i> , (2020). Observational study | 120 patients | Study on the prevalence of leprosy in Uganda and the challenges in accessing treatment in rural areas. |

An analysis of leprosy and its relationship with social vulnerability, present in several geographical contexts, reveals the complexity of this disease and the challenges for its control. Studies conducted in Brazil, Vietnam, India, Thailand, and Japan provide a comprehensive perspective on the social determinants that influence the prevalence of leprosy, highlighting poverty, social stigma, and unequal access to health services as determinant factors for the spread of the disease.

Silva *et al.* (2020) point out that the prevalence of leprosy in peripheral communities in Brazil is closely linked to socioeconomic conditions, such as low income level and restricted access to adequate health services. The research shows that social vulnerability, manifested mainly in urban and peripheral areas, favors the spread of leprosy, since this situation faces difficulties both in early diagnosis and in continuous treatment of the disease. The lack of adequate infrastructure and the social stigma associated with leprosy are additional obstacles to treatment adherence, creating a cycle of exclusion and worsening health in vulnerable communities.

In a similar study, Santos *et al.* (2019) investigated leprosy in low-income communities in Brazil, focusing on the relationship between poverty and the increase in cases of the disease. The cohort study showed that, in areas with high rates of social vulnerability, the prevalence of leprosy is more pronounced, due to the difficulty of access to medical care and the delay in diagnosis. Social vulnerability, therefore, not only perpetuates the disease, but also aggravates the negative effects of leprosy, such as stigma and social exclusion.

Costa *et al.* (2017) deepen the discussion on the social stigma related to leprosy, especially in the peripheral regions of Brazil. The qualitative study revealed that people suffering from leprosy often face discrimination, which makes it even more difficult to access treatment and social reintegration. The stigma associated with the disease is a crucial factor that prevents adherence to treatment and contributes to the invisibility of leprosy as a public health problem.

In an international context, Nguyen *et al.* (2019) investigated the social determinants of leprosy in rural areas of Vietnam, revealing that poverty and lack of health education are critical factors that hinder prevention and early diagnosis of the disease. The study highlighted that rural landscapes face even more significant barriers to access to specific treatments, resulting in higher incidence of the disease in these regions.

Kumar *et al.* (2020), in turn, analyzed the relationship between social vulnerability and leprosy in marginalized communities in India. The study pointed out that poor living conditions, lack of resources and limited access to health services are determining factors for the prevalence of leprosy among the poorest populations in India. The research also underlines the need for more effective public policies to ensure early diagnosis and appropriate treatment in these communities.

No studies by Tran *et al.* (2021) on the impact of health education on the early detection of leprosy in Thailand, it was found that educational initiatives are essential to raise awareness about the disease, especially in rural communities. The study suggests that health education can be a powerful tool to overcome barriers such as stigma and lack of knowledge about leprosy symptoms.

Finally, Hara *et al.* (2021) discuss leprosy control strategies in Japan, focusing on the implementation of public policies in public communities. Although Japan has an efficient health system, the study highlights the importance of adapting public policies to reach more vulnerable communities, which still face difficulties in terms of access to treatment.

In short, leprosy remains a global public health problem, with social vulnerability playing a crucial role in its prevalence. The combination of factors such as poverty, social stigma, barriers to access to healthcare, and lack of health education contributes significantly to the perpetuation of the disease, especially in marginalized regions. It is therefore necessary to adopt intersectoral approaches that involve health education, inclusive public policies, and the reduction of social inequalities to effectively address leprosy.

The persistence of leprosy in endemic regions and its relationship with social vulnerability are widely discussed in studies carried out in Brazil and in other locations. From the aforementioned references, it is possible to observe different approaches to the factors that perpetuate leprosy and the inequalities associated with it, both in terms of access to health and in terms of the occurrence of complications such as disability.

Boigny *et al.* (2019) address the persistence of leprosy in household networks, evidencing the overlapping of cases and the vulnerability of the population in endemic regions. This study demonstrates that, in many areas of Brazil, leprosy transmission continues to occur within the family circle, which can be explained by factors such as lack of information about the disease, social stigma and delay in diagnosis. The home

environment, where coexistence is closer and health care is often limited, is configured as a risk space for the spread of the disease. This scenario reveals the importance of health education strategies and more effective public policies for early diagnosis and prevention.

Olivério *et al.* (2021) discuss the importance of epidemiological data to understand the dynamics of leprosy in Brazil, highlighting the disparities in incidence rates and case characteristics, including the higher prevalence among populations in situations of social vulnerability. Data is crucial for driving public policy, but the study suggests that despite progress in controlling the disease, there are still many gaps, especially in hard-to-reach areas and marginalized populations. The lack of health infrastructure and trained professionals to diagnose and treat the disease effectively contributes to the continuity of leprosy in these social groups.

Regarding inequalities related to leprosy, Martoreli Júnior *et al.* (2021) reveal that the disease continues to vary unevenly, with groups such as women, children, and people with disabilities being more vulnerable to complications from leprosy. The study carried out in a hyperendemic metropolis in Brazil highlighted how gender inequality, age and the presence of disabilities affect the evolution of the disease. This study reinforces the idea that leprosy is not only a health issue, but also a social justice issue, since structural inequalities are reduced to a greater burden of morbidity in certain populations.

Assis *et al.* (2020) analyzed the risk conditions for disability associated with leprosy in the border region between Brazil, Paraguay, and Argentina. The study showed that areas at risk for disability are often associated with poor socioeconomic conditions, such as poverty and lack of adequate access to health services. The proximity of transit in vulnerable situations, with cross-border trade and migratory movements, further complicates the task of controlling the disease in this region. The research highlights the need for an integrated regional approach, which takes into account the geographical, social and cultural characteristics of the affected populations.

Soares *et al.* (2021) highlight the relationship between sociodemographic and clinical factors in leprosy cases in Ceará, showing that the evaluation of patient contacts is essential to interrupt the chain of transmission. The study points out that, among the main factors associated with the performance of the evaluation of contacts, are education, income and access to the health system. The identification and monitoring of contacts are essential for the early detection of the disease, but the lack of adequate follow-up and the fear of social stigma still represent significant barriers.

In short, the persistence of leprosy in endemic regions in Brazil and in other countries is a direct reflection of conditions of social vulnerability, lack of access to health services, and continuity of transmission within family and social networks. The studies presented show that, despite advances in the control of the disease, social inequality continues to be a determining factor for the prevalence of leprosy, and it is crucial that public policies are more effective to address this issue in a comprehensive way. The promotion of health education, the strengthening of support networks, and the intersectoral approach are essential strategies to reduce the impact of leprosy on the most vulnerable populations.

CONCLUSION

Studies on the epidemiology of leprosy are extremely relevant, especially when considering the social determinants of health and sustainability. The study of the epidemiology of leprosy is crucial in the monitoring and control of the epidemiological patterns of the disease, providing important data for the formulation of public health policies and planning of specific interventions for the target population.

It is noteworthy that leprosy has an important relationship with the social determinants of health, therefore, the study of conditions such as housing, education, basic sanitation, access to information are crucial to understand the magnitude, incidence and prevalence of the disease. Among the determinants, community education is presented as a strengthener of early diagnosis and coping with the stigmas permeated between people.

Finally, sustainability, as it was well explained in the course of the research, is anchored in environmental impact, climate change, uncontrolled urbanization and environmental degradation can influence the transmission of the disease; sustainability of control programs, with prioritization of promotion, prevention, treatment and rehabilitation actions, with equity in health services and social sustainability, through the involvement of the community with disease control actions in a social and economic way.

ACKNOWLEDGMENTS

I would like to express my deep gratitude to the Coordination for the Improvement of Higher Education Personnel (CAPES) for the fundamental support in my academic career. The incentive provided through scholarships and research promotion programs was

essential for the development of my work and for the expansion of knowledge in my area of study.

CAPES' commitment to education and research in Brazil is of enormous value, enabling students and researchers to be able to dedicate themselves fully to scientific production and the advancement of knowledge. This support not only strengthens academic training, but also contributes significantly to the country's development.

I am immensely grateful to CAPES for the opportunity and for the investment in education and science. The impact of this work is invaluable and reflects directly on the construction of a more promising future for all.

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