



Leprosy surveillance and health care in the State of São Paulo

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ABSTRACT

OBJECTIVE

To identify leprosy surveillance and health care actions in the State of São Paulo.

METHODS

Narrative literature review. The databases consulted were Scielo, Scielo Saúde Pública, Lilacs, and PubMed, from 1990 to 2022. The keywords used were leprosy, *Mycobacterium leprae*, São Paulo and SP, and leprosy and Hansen's disease. The terms were matched using the Boolean operators AND or OR. The research included studies that involved people affected by leprosy who referred to actions of surveillance, care and control of the disease. In the data analysis, the content analysis technique was adapted and thematic categories were created.

RESULTS

Seven thematic categories were found: 1. Social impact and quality of life; 2. Demographic data and social disadvantage; 3. Importance of health care network; 4. Epidemiological surveillance; 5. Prophylaxis and pharmacovigilance; 6. Need for training; 7. Laboratory tests and treatment. It was noted that an important number of articles addressed the relations between mental health and the symptoms that weaken users. The need for training of health teams to deal with the challenges of leprosy was also observed.

CONCLUSIONS

The importance of multidisciplinary and integrated approaches in the control and care of leprosy is emphasized, seeking to improve early detection, contact surveillance, appropriate treatment, quality of life of patients and overcoming barriers that impact treatment adherence.

KEYWORDS

Leprosy; *Mycobacterium Leprae*; Primary Health Care; Epidemiologic Surveillance; Brazil.

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INTRODUCTION

Leprosy is a chronic granulomatous infectious disease caused by *Mycobacterium leprae*, mainly transmitted through contact with nasal secretions and droplets released during speech, coughing, or sneezing by an infected individual.¹

It primarily affects superficial skin nerves and peripheral nerve trunks, which can lead to physical disabilities, and may also compromise the eyes and internal organs. If not treated in the early stages, the disease almost always progresses, becoming transmissible. Individuals of any age or sex may be affected. There are two main forms: paucibacillary, characterized by up to five skin lesions with few or no bacilli detected in laboratory tests, and multibacillary, with more than five lesions and a high bacillary load.²

Although it has high infectivity, its low pathogenicity in the general population is remarkable. Genetic, environmental, and nutritional factors, as well as the degree of exposure to *M. leprae*, make the approach and control of this disease a complex challenge.¹

From a public health perspective, leprosy has been a concern for centuries, with historically ineffective therapeutic approaches leading to an increase in cases over time.³ In the State of São Paulo, the fight against the disease faced challenges until the implementation of multidrug therapy (MDT) in 1981, as established by Law No. 1582.⁴

However, it was only after 2010 that new guidelines for leprosy surveillance, care, and control gained strength nationwide, with the establishment of the National Leprosy Control Program (NLCP). This program aims to guide and strengthen health services, emphasizing early diagnosis, treatment of confirmed cases, and household contact surveillance to hold transmission under control.⁵ Leprosy is a compulsory notifiable disease.⁶

Despite the decline in the number of registered active cases in the city of São Paulo over the past 10 years, leprosy remains a public health issue. Data indicate that low case detection rates do not necessarily reflect a reduction in transmission, especially in municipalities with low endemicity, where intensified surveillance may result in higher detection.⁷

Although international policies implemented since the 2000s have contributed to reducing the detection of new cases at the national level, regional disparities in disease distribution persist. Areas of high endemicity have been more frequently studied by the scientific community, while regions of low endemicity or with stable incidence seem to be neglected, which may compromise transmission control efforts.⁷

Ultimately, people affected by leprosy face challenges that go beyond the physical limitations imposed by the disease. The planning and implementation of health interventions are crucial to provide better care for affected individuals and their families, addressing not only clinical aspects but also the social and economic issues associated with the disease.⁷ In this context, the objective of this study was to identify leprosy surveillance and health care actions in the State of São Paulo.

METHODS

A narrative literature review was conducted. Data collection was carried out in the online databases SciELO, SciELO Public Health, LILACS, and PubMed. Scientific materials published between January 1990 and June 2022 were considered.

The starting period was chosen due to the new health policies developed by the National Division of Sanitary Dermatology,⁴ which aimed at the decentralization, integration, and systematization of health services.

The inclusion criteria comprehended studies linked to people affected by leprosy from the perspective of surveillance, control, and health care actions. The descriptors used were: in Portuguese, hanseníase, *Mycobacterium leprae*, São Paulo, SP; and in English, leprosy and Hansen's disease. The Boolean operators AND and OR were applied.

The articles were organized and analyzed in two stages. In the first stage, a table was completed with the following data: authorship, title, year and place of publication, research method, variables used, main results, and conclusions.

In the second stage, the content analysis method⁸ was adapted. The researchers performed a pre-analysis through a skim reading of the aforementioned table. The goal was to process the evidence from the table in order to define significant excerpts, with the purpose of composing thematic categories. These categories were built from the most recurrent topics addressed in the articles studied and discussed in light of theoretical frameworks and health policies related to the theme.

RESULTS AND DISCUSSION

Table 1 presents the seven thematic categories (column 1) and highlights the object of importance (column 2) to address the objective of this study.

Table 1. Thematic categories with details of the study objects.

Thematic category ¹	Object of importance for the present study addressed in the articles
Social impact and quality of life	Women's mental health, ^{9,10} depressive symptoms, ¹¹ stigma and unemployment, ⁹ fear and anxiety, ¹² multibacillary patients have greater suffering than paucibacillary, ¹³ skin appearance impairment ^{13,14}
Demographic data and social disadvantage	Low education and low income among people affected by leprosy, ^{15,17} male population aged 30-59 years ^{16,17}
Importance of the Health Care Network	Primary Care, ¹⁸ Specialized Care ¹⁹
Epidemiological surveillance	Importance of notifications, ²⁰ frequency of occurrence, ^{7,20-22} active contact tracing ²⁶
Prophylaxis and pharmacovigilance	BCG vaccine, ^{23,24} use of rifampicin, ²⁴ adverse effects of dapsone ²⁵
Need for training	Community health workers (CHWs), ⁹ health professionals, ^{9,12,27} community ²⁸
Laboratory tests and treatment	Rapid test to detect anti-PGL-1 IgM antibody, ²⁹ CD31 and CD105 markers, ³⁰ treatment ^{5,12,27,29,30}
BCG: Bacillus Calmette-Guérin	

Source: Authors

A total of 22 scientific studies were analyzed, with some articles addressing more than one theme presented in Table 1.

Six articles discussed issues concerning the social impact and

¹The categorized themes do not necessarily reflect the central idea addressed in the articles.

quality of life of people affected by leprosy, particularly the relations between mental health and symptoms that weaken patients^{9,14}. Three studies showed the relation between sex and social disadvantage in certain regions of the State of São Paulo.^{7,16,17} Four articles highlighted the importance of the health care network, emphasizing primary¹⁸ and specialized services.^{12,18,19,27} Several relevant aspects of health surveillance were found (seven articles), particularly epidemiological surveillance,^{7,20,22} drug monitoring,^{24,25} prophylaxis actions,^{23,24} and active contact tracing.²⁶

Finally, four studies pointed to the need for training and capacity building^{9,12,27,28} of health teams to deal with the challenges of leprosy.

The studies identified were subsequently described and analyzed within each of the thematic categories listed in Table 1.

Social Impact and Quality of Life

The difficulty in dealing with the mental health of people affected by leprosy stood out in the studies analyzed, as it may harm their quality of life in daily social interactions. In fact, two studies addressed the mental health of women affected by leprosy, highlighting that not only do they suffer physically but also psychologically. These studies raised concerns about the difficulties that the disease can cause in work and daily activities, as well as social isolation and lack of support. Hence, understanding the experiences of these women is crucial to provide better care and support, emphasizing both their physical and psychological needs, and offering assistance tailored to the specific demands of this group.^{9,10}

Moderate to severe depressive symptoms, regardless of the presence of physical disabilities, accounted for 43.1% of the cases evaluated. The most common symptoms included somatic concerns, irritability, fatigue, self-blame, tendency to cry, sleep disturbances, decreased libido, sadness, and loss of interest in previously pleasurable activities.¹¹

Moreover, prejudice, stigma, pain, and disabilities generated by leprosy contribute to the high prevalence of mental health problems in this group of patients.⁹ The historical stigma and the pejorative use of the term “leprosy” represent an additional challenge for affected individuals.^{4,18} Furthermore, it was found that 28.6% of patients became unemployed after diagnosis, 15.5% retired, and 14.1% applied to leave the National Institute of Social Security (INSS).⁹

Overall, patients perceive the therapeutic journey as an emotional struggle, relying on medication, knowledge, self-care, and the search for an accurate diagnosis as resources to cope with the disease. Although they follow medical recommendations, those actions are permeated by fear and anxiety, suggesting the need to strengthen educational actions within leprosy care services. This would foster greater integration and partnership between patients and health professionals, adjust patient expectations regarding treatment, promote a realistic view of medication effectiveness, and enable a reinterpretation of the challenges faced as part of a broader journey of resilience.¹²

These concerns may cause significant harm to the quality of life of people affected by the disease. This is further reinforced by findings showing that multibacillary patients experience worse physical function and greater bodily pain, reflected in lower scores in functional assessments, as well as greater interference of skin damage in daily activities compared to paucibacillary patients.¹³

Patients without reactions, who reported less bodily pain and less skin-related impact, also showed less embarrassment when choosing clothing. Approximately one-third of the changes in quality of life were attributed to skin conditions.¹³ Skin problems have a significant impact on social life, psychological

well-being, and daily routines, resulting in profound effects on interpersonal relationships and emotional health. Such findings were demonstrated in a comparative study between the ABC region of São Paulo and the Amazon region. Although São Paulo presented a more favorable scenario (despite skin problems) compared to the Amazon population, the state still shows endemic presence and precarious socioeconomic conditions.¹⁴

Similarly, only 19% of individuals affected by leprosy in the region of Santo André/SP reported poor quality of life, compared to 76.9% ($p < 0.001$) of residents in Amazonas/AM.¹⁴ While the authors concluded that the unfavorable results in the Amazon could be attributed to failures in early diagnosis, poor health care, and lack of trained professionals—resulting in poor prognosis, especially for multibacillary patients—on the other hand, one may infer that such aspects were better structured in Santo André/SP.

Demographic data and social disadvantage

It is extremely challenging to infer that low education and low income affect certain populations more than others with higher education and income. However, one study indicated that a significant proportion of patients had low educational levels, with 10% being illiterate and 65% having dropped out of school.¹⁶

A study conducted in Ribeirão Preto/SP between 2006 and 2016 also showed that low educational attainment and income of one to two minimum wages were associated with an increase in cases. The authors emphasized that the factors linked to the rise in leprosy cases in this city are similar to those observed in hyperendemic regions of Brazil, highlighting social inequality as a key determinant, even in areas of low endemicity. This suggests the presence of hidden endemicity in the city and underscores the strong association between the disease and social disparities, emphasizing failures in early detection by health services and reinforcing the connection between leprosy and social inequities.¹⁷

It is argued that disadvantaged and marginalized populations have less access to health services, which can hinder early diagnosis. Moreover, limited access to information contributes to reduced health-seeking behavior, resulting in delayed diagnosis.¹⁶ These aspects converge with data from another study that also characterized the socioeconomic and demographic profile of people affected by leprosy.¹⁵ Furthermore, low levels of education were associated with a higher proportion of multibacillary cases, suggesting that education acts as a risk factor for leprosy transmission. These individuals were also more likely to present disabilities both at diagnosis and at the end of treatment, indicating the need to improve early diagnosis and care delivery in health services.^{7,16}

Regarding patient age, the majority were between 30-59 (55.5%) and over 60 (26.3%).⁷ Whereas in childhood and adolescence it was reported that patients aged between 13-18 may present low school performance. Additionally, 15% of these patients had at least one musculoskeletal manifestation. The study inferred that the reduction in school performance could be associated with neuropathy and/or difficulties in writing caused by chronic joint pain.³¹

As for sex, a higher proportion of men (60.9%) compared to women (39.1%) was observed.⁷ Men of economically active age were more frequently affected by multibacillary forms. This age group is significant because it represents the population on which health services should focus preventive measures and interventions to minimize the disease's impact.^{7,16}

Importance of the health care network: primary and specialized care

In this dimension, the focus was on care management, which is mainly carried out in primary health care, the frontline in combating and preventing the disease. Educational actions, surveillance, and early detection are fundamental tools to progressively reduce the incidence of leprosy. In addition, treatment and physical and psychosocial rehabilitation should also be addressed in primary care, especially in less complex cases such as paucibacillary leprosy. Therefore, health teams must be trained and prepared to manage these cases.¹⁸

In specialized care, leprosy is treated in referral services and specialized hospitals, where care management is centered around the diagnosis and treatment of complex cases, including multibacillary forms, leprosy reactions, and neurological complications. This care requires a multidisciplinary approach, in which health professionals such as dermatologists, infectious disease specialists, neurologists, physiotherapists, psychologists, and social workers work together to provide integrated care.¹⁹

Epidemiological surveillance: notifications, frequency of occurrence, and active contact tracing

Variations in disease notifications were observed over the study period. In 2016, a municipality in the interior of São Paulo State experienced a significant increase of 18.8% in notifications, in contrast to a slight decline of 3.05% in the state as a whole. At the national level, Brazil recorded a small increase of 5.70%, while the global scenario showed a sharp decrease of 36.14%. These data highlighted that municipal records continue to show fluctuations compared to state and national trends.²⁰

A high proportion of people diagnosed with leprosy were found to present some degree of physical disability, along with a significant share of multibacillary cases. In this municipality, the estimated hidden prevalence was 23.90 cases per 10,000 inhabitants.²⁰

High levels of hidden prevalence have also been reported in São Paulo State, such as in the municipality of Jardinópolis. In this region, 12 cases were diagnosed during emergency medical visits and eight additional cases during a two-day mobile clinic campaign. Spatial analysis revealed a concentration of cases in the northwestern area of the city. The detection rate increased to 42.8 per 100,000 inhabitants after the study. Recommendations included strengthening disease control, training health professionals, conducting active surveillance, and raising community awareness about leprosy.²¹

At the state level, São Paulo reported 7,163 new leprosy cases between 2009 and 2012, ranging from zero to 983 per municipality. Although some areas had high detection rates, no significant spatial pattern was observed. Regions with high incidence were identified in the western part of the state and in the metropolitan area, where social inequalities were evident.²²

Regarding the clinical forms of the disease, there was a predominance of multibacillary cases (732; 82.2%), with most individuals aged between 30 and 59 years. The findings pointed to an increasing trend in detection rates from 2006 to 2016. This suggests that, even in a low-endemicity scenario, transmission of the disease remains high.⁷

Active case-finding activities were also reported in the literature. With respect to contact surveillance, changes were noted in Brazil over the years, with the follow-up period being reduced from five to two years. In São Paulo, however, intrahousehold contact surveillance of multibacillary cases was

maintained for five years to identify potential future cases. In this context, intradermal BCG vaccination is recommended for all contacts, regardless of the type of index case. Moreover, one study proposed expanding the concept of "contacts" and emphasized the importance of continuous interventions such as epidemiological surveillance, laboratory testing, vaccination, treatment, and educational activities directed towards patients, families, and the community to reduce leprosy incidence.²⁶

Prophylaxis and pharmacovigilance

One possible intervention for leprosy prevention is prophylaxis with the BCG vaccine. Although this vaccine is primarily known for preventing tuberculosis, it may also provide some degree of protection against leprosy.²⁴ BCG vaccination can reduce the risk of developing leprosy in children. While it does not offer complete protection, it remains an important strategy to reduce incidence in endemic areas.²³

Chemoprophylaxis is another preventive approach. The administration of single doses of rifampicin or other antimicrobial drugs to individuals exposed to *M. leprae* can prevent disease development or reduce transmission risk. This strategy is particularly useful in outbreak or epidemic settings.²⁴

Only one study specifically addressed the importance of pharmacovigilance in therapeutic framework, highlighting the occurrence of adverse effects of dapsone in a city located in northern São Paulo State.²⁵

Importance of training

Four of the studies reviewed addressed the importance of training as a tool for leprosy control and prevention.

In fact, training community health workers (CHWs) was shown to be important in assisting with the identification and dissemination of leprosy signs and symptoms. In addition, primary health care professionals play a fundamental role by using the Leprosy Suspicion Questionnaire (LSQ) to screen people at risk, with positive results. Training and dedicated identification of cases by skilled professionals capable of recognizing all clinical manifestations of the disease—including subtle presentations—are essential for interrupting transmission and demonstrating effective leprosy control in municipalities.³²

Professional training and health education actions aimed at both health professionals and the community are also critical to strengthen surveillance strategies. This is essential to improve diagnosis and treatment of leprosy, particularly early diagnosis, since initial lesions may go unnoticed by less experienced professionals.¹² Moreover, training contributes to improving the work processes of professionals involved in leprosy care, for example, enhancing the management of logistics related to the storage, transport, and identification of material collected for confirmatory diagnostic tests.²⁷

With regard to health education, raising community awareness about the symptoms of leprosy, its forms of contagion, and preventive measures are among the strategies that may help identify cases earlier and reduce disease dissemination. Health professionals and community leaders can play a key role in disseminating this information and encouraging people to seek health services for diagnosis and treatment.²⁸

Laboratory tests and treatment

The laboratory tests identified in the literature as supporting tools for leprosy diagnosis focused on rapid testing and on cell surface markers expressed in the endothelium of blood and lymphatic vessels.

Indeed, diagnosis proved to be more effective with the use

of the rapid test to detect anti-PGL-1 IgM antibodies in screening contacts of patients with leprosy, even in the absence of typical clinical lesions. However, it was emphasized that a positive result does not confirm the diagnosis, making it necessary to proceed with bacilloscopy in positive cases. It was also highlighted that diagnostic equipment must be made available in all health services, in addition to improving diagnostic skills and raising awareness about the disease to reduce delays in starting treatment.²⁹

Regarding cell surface markers, the presence of blood vessels reactive to CD31 and CD105 markers was demonstrated in patients with different forms of leprosy. A significant increase in vessels reactive to the D2-40 marker was also observed in patients with tuberculoid (paucibacillary) leprosy compared to both the control group and patients with lepromatous (multibacillary) leprosy.³⁰

As for leprosy treatment, the most common intervention is multidrug therapy (MDT), which was reported in some of the studies analyzed.^{12, 27, 29, 30} MDT involves the combination of antimicrobial drugs such as rifampicin, clofazimine, and dapsone to kill *M. leprae* and prevent drug resistance. MDT is highly effective in treating leprosy, and most patients recover fully with appropriate therapy.

It is essential, however, to ensure that treatment is carried out to completion, even if symptoms have disappeared, in order to prevent relapse. Health teams must also provide adequate care and follow-up to patients during and after treatment to ensure full recovery and prevent complications.⁵

National leprosy policies

The data retrieved from the scientific literature, although showing that leprosy still appears relatively neglected in some regions of São Paulo State, are consistent with the main national health policies related to the disease.

Indeed, the collection, processing, analysis, and interpretation of data are part of the epidemiological surveillance process for leprosy cases and their contacts. Surveillance can be implemented at all levels of complexity within the Health Care Network and is responsible for providing information on the distribution, magnitude, and burden of the disease across different geographic areas. New leprosy cases are actively detected through contact investigation and community-based examinations, such as surveys and campaigns, as well as passively through spontaneous demand and referrals. Patient follow-up is conducted through the Notifiable Diseases Information System (SINAN), which monitors cases via the Leprosy Follow-up Bulletin. These data are submitted monthly by health units to municipal epidemiological surveillance, where they are analyzed and subsequently forwarded to the state surveillance service.³³

Similarly, the findings of this study align with the recommendations of the National Leprosy Strategy (2019-2022) regarding primary care. This document is an adaptation of the Global Leprosy Strategy (2016-2020) and has as its overall objective the reduction of leprosy burden. The program is structured around three core pillars, involving specific objectives such as political and financial strengthening of the program, encouragement of scientific production, community-based action to raise public awareness, and promotion of treatment adherence and completion. It also emphasizes intensified support for people affected by leprosy, either through direct or indirect measures, such as social and financial support services, or by facilitating access to social and health services.³⁴

In this sense, the importance of national health policies for leprosy is highlighted, particularly those aimed at addressing psychological impacts: the role of health teams in providing adequate approaches to foster acceptance, resilience, and

treatment adherence. This approach should begin at diagnosis, continue throughout treatment, and, if necessary, extend into post-cure follow-up.^{5, 35-38}

Study limitations

It is important to acknowledge that the approach used may have introduced bias in the interpretation of evidence. Systematic or integrative literature reviews, with more robustly defined inclusion and exclusion criteria and a more specific selection of different methodological approaches, would certainly minimize bias and fill potential gaps.

The scarcity of studies specifically addressing municipalities in São Paulo State with low notification rates—based on the best of our knowledge—also represents an important gap for understanding the actual magnitude of the disease in areas of presumed low endemicity.

CONCLUSION

Surveillance, control, and care actions highlight the importance of multidisciplinary and integrated approaches in the care of patients affected by leprosy, aiming to improve early detection, contact surveillance, appropriate treatment, patients' quality of life, and the overcoming of physical and mental health barriers that may impact treatment adherence. Furthermore, health education initiatives seem to serve as a bridge between the health needs of affected individuals and health services, particularly within primary health care.

Future studies are needed to provide more precise data and to support more effective strategies for prevention, control, and care, considering the specific needs of the local population.

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