LEPROSY: CLINICAL PROFILE AND KNOWLEDGE OF PATIENTS

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Abstract

The present study aimed to evaluate the clinical profile and previous knowledge of patients about leprosy in the municipality of Tangará da Serra, Mato Grosso, Brasil. The sample consisted of 70 patients undergoing leprosy treatment or post-discharge, followed up at the Regionalized Specialized Leprosy Care Outpatient Clinic. Data collection consisted of clinical information regarding the data from the information system and questions about previous knowledge in leprosy. The most frequent clinical form was dimorphic with 78.57%, for leprosy reactions type II was 10%. The degree of physical disability with GIF 1 was 38.57%. The data reinforce that leprosy continues to be a public health challenge, especially in areas of greater social vulnerability with high bacillary loads. The study shows the importance of health education strategies, early detection and appropriate treatment to reduce the burden of leprosy.

Keywords: Leprosy; Clinical profile; Knowledge; Health promotion.

1 Introduction

Leprosy is an infectious, transmissible, and chronic disease that remains a public health issue in Brazil. It was first described in 1873 by the Norwegian Amauer Hansen (Araújo, 2003). The disease affects people of all genders and age groups, and it can develop slowly and progressively. If left untreated, it may cause physical deformities and disabilities, often irreversible (Brazil, 2017).

In 2020, 127,396 new cases of leprosy were reported worldwide to the World Health Organization (WHO). Of these, 19,195 (15.1%) occurred in the Americas, and 17,979 were reported in Brazil, accounting for 93.6% of the new cases in the Americas. Brazil, India, and Indonesia each reported more than 10,000 new cases, collectively representing 74% of all new cases detected globally in 2020. In this context, Brazil ranks second among countries with the highest number of cases, following India. In 2022, the state of Mato Grosso reported the highest number of new leprosy cases in Brazil (WHO, 2023; Brazil, 2023).

Among the new cases diagnosed in Brazil, 878 (4.8%) occurred in children under 15 years of age. Regarding the degree of physical disability (GIF), 7,198 new cases were diagnosed with Grade 2 disability (GIF 2) across 64 reporting countries worldwide. India and Brazil were the only countries to diagnose over 1,000 new cases with GIF 2 at the time of diagnosis, with 1,572 and 1,504 cases, respectively (WHO, 2023). The proportion of new leprosy cases diagnosed with GIF 2 is an important indicator of late diagnosis, reflecting a higher degree of physical impairment (Brazil, 2022).

Neural involvement, which can occur even with early diagnosis and adequate treatment, results in disabilities and deformities that are highly characteristic and peculiar to each affected nerve. These may be reversible or irreversible, depending on the degree observed (Alves et al., 2014; Brazil, 2002). The physical disabilities and deformities caused by the disease lead to several issues, such as reduced work capacity, social life limitations, and psychological problems (Brazil, 2002).

In this context, the formulation of specific health promotion actions for leprosy, such as the *Global Leprosy Strategy* for 2021–2030, represents a significant shift in the approach to combating leprosy worldwide. Brazil is a signatory to this strategy, which has the following goals: Reduce the rate of new leprosy cases in children under 15 years of age by 55% by 2030; Reduce the absolute number of new cases with GIF 2 at diagnosis by 30% by 2030; Address 100% of reports of discriminatory practices related to leprosy submitted to the Unified Health System Ombudsman (Brazil, 2023).

Given the above, this study is important as it can contribute to a better understanding of the clinical profile of patients undergoing leprosy treatment and assess whether these patients have prior knowledge about the disease. Thus, this research aims to evaluate the clinical profile and prior knowledge of leprosy patients in the municipality of Tangará da Serra, Mato Grosso, Brazil.

2   Methodology

This is a quantitative, cross-sectional, descriptive, and analytical study. The project was approved by the Research Ethics Committee of Cesumar University, in accordance with Resolution 466/2012, under opinion number 6,661,739. The study population consisted of 70 individuals undergoing treatment or in post-treatment for leprosy, attended at the Regionalized Specialized Care Outpatient Clinic for Leprosy (AAER) in the municipality of Tangará da Serra, Mato Grosso. Individuals at the start of treatment, those with diagnostic errors, and individuals under 18 years of age were excluded.

For data collection, the notification form from the Sistema de Informação de Agravos de Notificação (SINAN) was used to obtain clinical data on leprosy patients, including clinical form, degree of physical disability (GIF), leprosy reactions, and bacilloscopy results. Additionally, a questionnaire with six questions about the patients' prior knowledge of leprosy was administered. The questionnaire was applied by the researcher during the patients' monthly evaluation (conducted every 30 days when the patients visit the outpatient clinic for medication and

guidance) and to post-treatment patients seeking medical attention for symptoms of leprosy reactions.

The data were compiled into spreadsheets using Microsoft Excel, where quantitative variables were analyzed. Statistical analysis was performed using SPSS software, version 21. The results were presented as absolute (n) and relative (%) frequencies.

3   Results and discussion

Below are the registration form data related to the clinical information and the patients' prior knowledge about leprosy, as reported by the research participants.

3.1 Clinical profile of participants related to leprosy

Regarding the clinical characteristics of the study participants related to leprosy, it was observed that the clinical form in most cases is dimorphic (78.57%), followed by lepromatous (17.14%). The majority of the patients studied, classified as multibacillary, accounted for 95.17%, consistent with the overall operational classification of 2022, which reported 81.2% multibacillary cases (Brazil, 2024).

The dimorphic form is the most disabling clinical form of leprosy, especially when diagnosed late, and it is the most common presentation of the disease (Brazil, 2022; Brazil, 2017). It typically occurs after a long incubation period (about 10 years or more) due to the slow multiplication of the bacillus (which takes an average of 14 days). The multibacillary forms of the disease are more susceptible to developing sequelae and/or reactions caused by leprosy, which makes Hansen's bacillus infection more noticeable and, consequently, increases discrimination (Filgueira et al., 2020). Among the clinical forms in Brazil, there has been a 22.6% increase in new cases of the dimorphic form and a reduction of 40.3% and 35.4% in the tuberculoid and indeterminate forms, respectively (Brazil, 2024). In the present study, paucibacillary cases accounted for 4.29%, with 1.43% being indeterminate and 2.86% tuberculoid cases.

In Brazil, the Madrid classification is adopted, and for operational classification, patients should be categorized for treatment purposes according to the criteria defined by the WHO (2018), as follows: paucibacillary (PB) - cases with up to five skin lesions and/or only one affected nerve trunk; and multibacillary (MB) - cases with more than five skin lesions and/or more than one affected nerve trunk. Additionally, a positive bacilloscopy automatically classifies the case as multibacillary, regardless of the number of lesions (Araújo, 2003). This classification considers two stable and opposite poles of the disease (tuberculoid and lepromatous forms), interpolar and unstable clinical forms (dimorphic leprosy), and an initial form with mild clinical manifestations of the disease (indeterminate form) (Talhari; Penna; Gonçalves, 2014).

An important indicator for monitoring leprosy is the degree of physical disability. When physical disability is not detectable through inspection or visual acuity tests but there is a reduction in protective sensitivity or muscle strength in the hands, feet, and/or eyes, the case is assigned a degree of physical disability - GIF 1 (Brazil, 2022). In the present study, the GIF 1 rate was 38.57%.

In comparison, the GIF 1 proportion in Brazil was observed to be 3.1% from 2009 to 2018, revealing a significant difference. This suggests deficiencies in early diagnosis of leprosy in the studied population (Brazil, 2022; Brazil, 2020).

The degree of physical disability GIF 2 includes cases presenting visible physical deformities or blindness resulting from Hansen's neuropathy, observed exclusively in patients with high bacillary loads (Mi; Liu; Zhang, 2020). The percentage of GIF 2 cases found in this study was 10%, which is approximately equivalent to national data from the Ministry of Health (Brazil, 2022), where among 23,843 patients evaluated at the time of diagnosis, 2,351 (9.9%) presented GIF 2. This similarity suggests that physical disability is a common and significant challenge in Brazil, requiring continuous attention in health policies. Monitoring GIF 2 in newly diagnosed cases is among the specific strategies implemented to achieve the goal of zero leprosy cases. This action aims to qualify data and investigate the occurrence of GIF 2 to develop and implement preventive measures to reduce late diagnosis of leprosy and promote rehabilitation initiatives for patients. The rate of newly diagnosed leprosy cases with GIF 2 at the time of diagnosis, per 1 million inhabitants, was highest in the state of Tocantins (66.16%), followed by Mato Grosso (58.76) (Brazil, 2023).

The proportion of participants with degree of physical disability GIF 0 was 32.86%. Degree zero is assigned to patients who do not present any of the aforementioned signs and, therefore, do not exhibit any problems caused by leprosy in the hands, feet, or eyes (Lehman, 1997). However, the number of cases not evaluated for the degree of disability was 18.57%, drawing attention to this issue. This highlights the disparity in system records, making it impossible to build reliable indicators and compromising the epidemiological situation.

According to Santana et al. (2018), early diagnosis and treatment during the initial phase of bacillus activity in the superficial portions of the nerves can significantly reduce nerve involvement, decreasing the occurrence of physical disabilities in patients. The delay in diagnosis has been attributed to various factors, including a lack of knowledge and awareness among healthcare providers. Health professionals must be aware of the increased risk of delayed diagnosis and physical disability during active case finding and contact tracing to ensure that secondary cases are not missed (Dharmawan et al., 2022).

For leprosy reactions, 25.71% of participants reported having experienced Type I leprosy reactions, 10% had Type II reactions, and 5.71% had both Type I and Type II reactions. The total percentage of participants who had some form of leprosy reaction suggests that a significant portion of the patients (approximately 41.42%) experienced some type of leprosy reaction. This aligns with other studies, which indicate that up to 50% of leprosy patients may experience reactions at some point, and approximately 30-50% of patients may develop reactional episodes (Brazil, 2022; Teixeira; Silveira; França, 2010; Saunderson, 2007; Alves, 2014).

Leprosy reactions are acute inflammatory phenomena marked by exacerbation. Although reactional episodes can occur in any clinical form, they are rarer in the milder cases of the disease (Brazil, 2022; Foss, 2003). Health services must monitor patients and manage leprosy reactions to prevent disabilities. If neural involvement is not treated, it can cause disabilities and deformities due to loss of sensation in areas innervated by affected nerves (Brazil, 2002).

In this context, the bacilloscopy index (BI), which estimates the patient's bacillary load, showed that 30% of participants had a positive BI, 38.57% had a negative BI, 28.57% were not evaluated for bacilloscopy, and 2.86% were classified as unknown. High bacillary loads and the presence of leprosy reactions are risk factors for the development of physical disabilities in individuals affected by leprosy, in addition to delayed treatment (De Paula et al., 2019; Brazil, 2022). Regarding the achievement of goals to reduce the leprosy burden in priority countries, Nittsuma et al. (2021) emphasize that isolated strategies may not suffice to reduce the risk of illness in vulnerable populations. Universal health coverage and strengthening leprosy control actions are necessary.

3.2 Prior knowledge of participants about leprosy

Table 1 shows the participants' prior knowledge about leprosy. It was observed that 84.3% had some knowledge of leprosy before undergoing treatment, while 15.7% of participants were unaware of the disease. Most participants (68.6%) lacked prior knowledge about how leprosy treatment is conducted, while only 31.4% stated they had prior knowledge about leprosy treatment before initiating treatment. This indicates a significant gap in knowledge about leprosy and its therapeutic management. Timely treatment of leprosy is hindered by stigma and discrimination associated with fear and a lack of knowledge about the disease (Brazil, 2022).

Table 1 – Prior knowledge of participants about leprosy.

Questions	n	%
A) Before starting treatment for leprosy, had you heard about this disease?		
Yes	59	84.3
No	11	15.7
B) Did you already know how leprosy is treated?		
Yes	22	31.4
No	48	68.6
C) Did you already know where to seek treatment for Leprosy?		
Yes	40	57.1
No	30	42.9
D) Do you find it difficult to take the medication?		
Yes	10	14.3
No	37	52.9
General discomfort	6	8.6
Difficulty swallowing pills	3	4.3
Nausea, vomiting, and stomach pain	10	14.3
Weakness	3	4.3
Medication rejection/allergy	1	1.4

E) When you noticed the first symptoms of leprosy, did you seek healthcare services promptly?		
Yes	35	50
No	35	50
E.1) If delayed, how much time passed since the appearance of the first symptom?		
Did not delay	30	42.9
1 to 4 months	11	15.7
5 to 8 months	9	12.9
9 to 12 months	6	8.6
More than 1 year	14	20

Regarding knowledge about where to seek treatment for leprosy, 57.1% of participants stated they already knew where to seek treatment, while 42.9% did not have information about where to obtain assistance for the disease. It can be considered that people with prior knowledge about leprosy are more likely to seek health services when necessary and to access appropriate treatment. According to Jesus et al. (2023), creating inclusive spaces, shifting paradigms towards education and health promotion, is crucial so that this knowledge reaches schools and spreads among adolescents and children, who then bring this awareness home. One of the pillars of the Global Leprosy Strategy 2021–2030, "Towards Zero Leprosy," is to expand leprosy prevention along with integrated active case detection. This is fundamental to ensuring that patients receive timely and appropriate medical care (WHO, 2023).

Regarding the perception of the initial symptoms of leprosy, 50% of participants reported seeking health services promptly. However, a significant portion reported delays in seeking health services and obtaining a diagnosis after suspecting the first symptoms. Specifically: 15.7% delayed 1 to 4 months, 12.9% delayed 5 to 8 months, 8.6% delayed 9 to 12 months and 20% delayed more than 1 year for diagnosis. As a result, these patients received late diagnoses. These data are consistent with findings from a study on factors associated with delays in leprosy screening, which revealed that leprosy diagnosis was confirmed in 68.11% of cases more than six months after symptom onset (Gnimavo et al., 2022). Diagnosis delays are concerning as they can lead to disease progression and an increase in complications.

The delay in seeking health services by leprosy patients is also demonstrated in a study by Santos et al. (2024), which analyzed factors associated with late leprosy diagnosis in an endemic area of Northeast Brazil. The authors reported that health system-related factors are the main contributors to delayed leprosy diagnosis, such as the lack of immediate care at the first health service sought, especially when access to a doctor was unavailable, excessive referrals, and the need for three or more consultations to confirm the diagnosis. However, the signs and symptoms of the disease can be subtle, particularly in its early manifestations and paucibacillary forms, often going unnoticed by healthcare professionals and the patients themselves (Brazil, 2022).

Early diagnosis and appropriate treatment of leprosy patients are essential conditions to interrupt transmission, prevent disease progression, and reduce the physical and social

consequences caused by the disease (Santos et al., 2007). In the guidelines for control, both the Ministry of Health (Brazil, 2022) and the World Health Organization (WHO, 2023) emphasize the importance of early diagnosis and timely treatment as strategic priorities for reducing the disease burden. Thus, health education activities for the population and active case-finding are essential strategies for case detection and should be carried out periodically, particularly in endemic areas (Brazil, 2022).

When analyzing the data, it is observed that the majority of participants, representing 52.9%, do not experience difficulty taking the medication for leprosy. However, some participants reported experiencing side effects or difficulties related to the medication: 14.3% of participants reported experiencing nausea/vomiting/stomach pain, 8.6% reported general discomfort while taking the medication, 14.3% mentioned difficulty taking the medication due to these side effects. Specific difficulties were also reported, such as trouble swallowing pills (4.3%), weakness (4.3%), and medication rejection or allergy (1.4%). These data suggest that, although most participants do not encounter challenges with the medication, there is still a significant proportion experiencing side effects or obstacles to adhering to leprosy treatment.

Multidrug therapy for leprosy involves the combination of three antimicrobials (rifampicin, dapsone, and clofazimine), achieving a cure rate of up to 98% in treated cases. This treatment presents a low relapse rate, estimated internationally at around 1% of treated cases over a five- to ten-year period. The therapeutic regimen for PB (paucibacillary) cases is defined as six months, while for MB (multibacillary) cases, it is 12 months, which can extend to 24 months if necessary (Lockwood, 2019; Brazil, 2020).

According to Temoteo et al. (2023), adverse drug reactions are among the main factors contributing to treatment abandonment in leprosy. For example, the Clofazimine may cause skin pigmentation, which should not be considered a criterion for discontinuing the medication, except in cases of extreme patient dissatisfaction. The Rifampicin can lead to hepatotoxicity, with mild transient increases in liver transaminases, though such reactions are rare at the prescribed dosage. Dapsone is generally well tolerated at recommended doses but may cause hemolysis and, more rarely, significant anemia, highlighting the importance of monitoring hematological levels during the initial months of treatment (Brazil, 2022). In a study of 753 leprosy patients, the most frequent complaints were skin pigmentation (21.7%) and xerosis (16.9%). Laboratory tests revealed hemoglobin levels below 10 g/dL in 23.3% of patients, aspartate transaminase (AST) above 40 U/L in 29.5%, and alanine transaminase (ALT) above 40 U/L in 28.5% (Cruz et al., 2018).

According to the World Health Organization (2023), several actions are necessary to build and maintain the capacity of clinical and public health service teams across all aspects of leprosy prevention, screening, diagnosis, treatment, complication management, self-care, rights of those affected by leprosy and their families, and program management. Considering the need for early diagnosis and prevention, it is crucial to provide training and capacity-building for various healthcare professionals, including doctors, nurses, community health workers, nursing technicians, and psychologists. This ensures care reaches the populations in need, enabling effective diagnosis and treatment of leprosy while promoting sensitive communication with patients.

Self-care is essential for actions aimed at preventing physical disabilities in leprosy and depends not only on the multidisciplinary team but also requires that the individual affected by the disease actively participate in the care of their health, developing skills and risk awareness that contribute to the prevention and reduction of harm (Brazil, 2022). For the prevention of leprosy, contact examination is the most productive tool for identifying new cases. Patients suspected of having leprosy should be thoroughly evaluated for the autonomic, sensory, and motor functions of the peripheral nerves (Brazil, 2020).

Case-finding campaigns should be accompanied by innovative and well-targeted community information and awareness activities that combat myths and encourage early self-referral and positive attitudes toward people affected by leprosy (WHO, 2023). Engaging community leaders and local groups to promote education on leprosy, providing information on how to approach this issue in an educational manner. This information can be disseminated in schools, churches, and community centers, helping to spread accurate knowledge.

The implementation of support groups and individual counseling can be very beneficial, as well as developing rehabilitation programs to help patients reintegrate into society and the labor market. Investment in research and technology is essential for overcoming and improving leprosy diagnosis and treatment, in addition to ensuring that diagnostic and treatment services are accessible, free, and available in endemic areas. Mobile health units can be used to reach remote communities, aiming to ensure equal access to health services (Brazil, 2022).

According to the WHO (2023), there are ongoing efforts to reduce discrimination. It is crucial to challenge myths and prejudices, working with the media to spread positive stories of overcoming the disease and inform about the non-contagious nature of leprosy after the initiation of treatment. It is necessary to implement anti-discriminatory policies: reinforcing laws and policies that prohibit discrimination against people with leprosy. Protecting patients' rights is crucial to reduce social stigma, foster social and labor inclusion, and ensure that children and adults with leprosy have equal access to education and employment, free from discrimination.

Additionally, supporting public policies that strengthen the health system for better leprosy management, including adequate funding, research, and the development of new diagnostic and treatment technologies. Intersectoral collaboration, involving different sectors such as health, education, and work, in coordinated initiatives to combat leprosy and its stigma. In summary, forming partnerships with non-governmental organizations and international organizations is crucial to share resources, knowledge, and best practices in the fight against leprosy, with all spheres of health and their levels—federal, state, and municipal—working together, considering the specificities of each locality.

4   Conclusion

The study on the clinical characteristics of participants affected by leprosy reveals crucial information about the prevalence and impact of the disease. Most cases present the dimorphic clinical form, which is the most disabling form of the disease. The predominance of multibacillary cases highlights patients' vulnerability, with sequelae and leprosy reactions being significant risk factors for the development of physical disabilities. The analysis also shows a high proportion of patients with Grade 1 physical disability (GIF 1), suggesting shortcomings in early diagnosis. Comparatively, the rate of Grade 2 physical disability (GIF 2) aligns with national data, emphasizing the need for continuous and effective health policies for disease management.

The analysis of prior knowledge, delays in seeking healthcare services, and lack of information reported by a considerable proportion of participants contribute to diagnostic delays, compromise treatment adherence, and hinder the cure of leprosy. Although most participants had some knowledge of leprosy, a significant portion was unaware of critical aspects, such as treatment and where to seek assistance. Despite the effectiveness of multidrug therapy, it poses challenges that may lead to treatment abandonment, underscoring the importance of rigorous monitoring and medical follow-up.

The need to improve awareness and education about leprosy, both among the general population and healthcare professionals, stands out. The data reinforce that leprosy remains a significant public health challenge, particularly in areas of greater social vulnerability. Leprosy reactions, present in a considerable proportion of patients, and high bacillary loads underscore the urgency for effective intervention strategies. In conclusion, the study highlights the importance of health education strategies, early detection, and appropriate treatment to reduce the burden of leprosy. Implementing health policies that ensure universal coverage and strengthen leprosy control actions is imperative to achieve better outcomes in managing the disease.

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