

ORIGINAL ARTICLE

Leprosy, Stigmatization, and Social Isolation: A Case Report

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Abstract

Introduction: this case report highlights the unique and severe impact of social stigma on the clinical course of leprosy. It presents the story of a 63-year-old patient diagnosed with indeterminate leprosy who lived in social isolation for over 30 years and ultimately died due to multiple health complications. The case illustrates how stigmatization can substantially aggravate the biopsychosocial burden of a condition that is potentially controllable with early diagnosis and adequate treatment.

Case Report: the main clinical features included progressive physical and psychological deterioration, compounded by self-isolation and lack of social support. Despite the availability of treatment, the patient experienced a therapeutic failure attributed mainly to delayed diagnosis, social neglect, and the absence of coordinated follow-up.

Method: this retrospective, descriptive report was based on data extracted from medical records and analyzed qualitatively.

Results: The findings reveal that operational and sociocultural barriers, such as incomplete patient records, stigmatizing attitudes, and limited involvement in the self-care process, contributed to the deterioration of the patient's clinical condition and a reduced quality of life.

Discussion: the case highlights the importance of a comprehensive care approach in leprosy management, extending beyond pharmacological treatment. Early diagnosis must be accompanied by psychosocial support and strategies to combat stigma and promote inclusion. One of the main findings of this case is that therapeutic success in leprosy is intrinsically related to social determinants of health; in the absence of effective strategies to address stigma and longitudinal, integrated follow-up, even clinically treatable conditions can progress to adverse outcomes.

Conclusion: The limiting factor of this report was the sparse chronological documentation in the medical records. Beyond pharmacotherapy, the active involvement of the patient's social network is essential in mitigating stigma, preserving self-esteem, promoting treatment adherence, and supporting social inclusion.

Keywords: Neglected Tropical Diseases, Mycobacterium leprae, social exclusion, stigma.

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Authors summary

What was the main finding of the study?

Social stigmatization can seriously compromise the clinical outcome of leprosy, even in cases with a favorable prognosis, by causing isolation, refusal of treatment, and physical and psychosocial deterioration.

How was the study conducted?

This is a descriptive, retrospective, and qualitative study presented as a case report based on the analysis of medical records and clinical records of a patient followed by the Municipal Health Department of Feijó, Acre, Brazil.

How do the results change people's lives?

The results highlight the need to integrate psychosocial care into leprosy treatment, which can prevent treatment abandonment, promote adherence, and improve patients' quality of life.

How do the results change what was already known in the field?

The case reinforces and exemplifies, in a concrete way, how social stigma remains a critical factor in the negative evolution of leprosy, highlighting the inadequacy of exclusively biomedical approaches.

What happens in light of the results/conclusions?

There is a clear need for intersectoral and multidisciplinary strategies that involve families, communities, and health professionals in addressing stigma and humanizing care for leprosy.

How can the results be applied to decision-making?

They can guide strategic decisions in the Brazilian Unified Health System (SUS), such as:
 Strengthen active surveillance for early detection and follow-up.
 Integrate psychosocial support into leprosy care.
 Promote education and communication to reduce stigma.
 Prioritize vulnerable and underserved areas.

INTRODUCTION

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae*, predominantly affecting the skin and peripheral nerves. Despite the availability of effective treatment, the disease remains a serious public health concern in endemic regions such as Brazil, where social determinants – like poverty, low education, and inadequate sanitation – amplify its burden. The pathogen primarily invades the human body through the respiratory tract, with a predilection for Schwann cells, leading to preferential involvement of superficial cutaneous nerves and peripheral nerve trunks in regions such as the face, neck, upper limbs, knees, eyes, and internal organs.

Beyond the physical consequences, leprosy is strongly associated with psychosocial impacts, including stigma, discrimination, and social exclusion. These factors can delay diagnosis, hinder treatment adherence, and lead to irreversible complications and loss of quality of life¹. Clinically, leprosy presents in several forms, classified according to the number of skin lesions, bacillary load, and degree of peripheral nerve involvement. The traditional classification includes: Indeterminate Leprosy (paucibacillary), Tuberculoid Leprosy (paucibacillary), Borderline Leprosy (multibacillary), and Lepromatous Leprosy (Virchowian; multibacillary)^{1–3}.

Despite being one of the oldest known diseases, with references found in biblical texts, leprosy remains a significant public health concern in many parts of the world. In 2018, 22 countries reported high prevalence rates, with India ranking first, followed by Brazil and Indonesia⁴. Beyond the physical and functional impairments caused by the disease, such as deformities and sensory losses, leprosy is profoundly associated with psychosocial burdens. Affected individuals often experience stigma and discrimination, which can lead to social isolation, loss of employment, and a reduced

quality of life. In addition, this stigma related to leprosy can result in emotional distress, restricted participation in community life, and impaired well-being⁵. By reducing delays in diagnosis and treatment, the complications of the disease can be controlled, and the transmission within communities can be prevented⁶.

This case report is unique because it documents the extreme biopsychosocial impact of stigma in a patient with indeterminate leprosy who lived in social isolation for over 30 years. Her story illustrates how persistent neglect, lack of follow-up, and absence of social support can result in therapeutic failure, even in a form of leprosy typically associated with a better prognosis. By sharing this narrative, the report contributes to the understanding of stigma's role in disease progression and underscores the importance of integrating psychosocial care into leprosy management, especially in vulnerable populations.

METHODS

This is a descriptive, retrospective study with a qualitative approach, presented as a clinical case report, developed by analysing the patient's medical records made available by the Municipal Health Department of the municipality of Feijó, state of Acre, in May 2021. Sociodemographic information, personal history, clinical evolution, diagnostic hypotheses, therapeutic approaches, complementary exams, drug prescriptions, and other therapeutic procedures recorded during the patient's follow-up were collected. The preparation of this report followed the guidelines recommended by the Case Report Guidelines (CARE)⁷ (Supplementary Material S1).

The research was conducted based on reports from Mrs. Rozilene Oliveira da Silva, who was invited to participate as a volunteer in her capacity as legal representative of the deceased patient. After being

duly clarified by the researcher and confirming her understanding of the explanation, she consented to participate in this research project, as evidenced by her signature on the Informed Consent Form (ICF).

Patient information

The patient, identified by the initials M.L.O.S., was a white, single woman residing in a small municipality in the interior of the state of Acre, Brazil. Her medical history began in 1975, at the age of 20, when she was diagnosed with indeterminate leprosy. At that time, she was prescribed Dapsone (sulfone) at a dosage of 250 tablets per year and maintained follow-up with a local dermatology service until 1978. After this period, there are no records of continued treatment, and over time, she gradually entered social isolation. The patient died at the age of 63 due to multiple health complications, after approximately 30 years of social isolation.

■ CASE REPORT

Ten years later, in 1988, without any recorded medical follow-up during the intervening period, she was re-evaluated during a home visit at the age of 33 and diagnosed with the vichowian form of leprosy, a multibacillary form of the disease, with the presence of slight hypotrophy in both hands and ulcerations on the right leg. However, there is no documentation of any therapeutic intervention at that time. Afterwards, the patient's medical records show that in 1995, at the age of 40, a new home visit by a doctor who "no clinical symptoms and negative baciloscopic test", but again, there is no record of the therapeutic proposal. From that point forward, there were no entries in her medical records for 23 years.

In 2018, local health authorities were alerted by community members about a patient in urgent need of medical attention. Health – the team identified the patient, now 63 years old, living in severe social isolation since her previous medical contact in 1988.

At the time of the visit, the patient "was lucid, with organized speech and good memory, amid low body weight

and refusal to eat, in addition to the reported fact that she had not had a bowel movement in five days. An ulcer was also observed on her right lower limb with a foul odor". She received further home care from a multidisciplinary team. However, records indicate that she received only medical and nursing care, having refused follow-up by other professionals, including a nutritionist. Due to the infectious nature of the ulcer (Figure 1A), treatment was started with cephalexin (500 mg every 6 hours), diclofenac (every 8 hours), and daily dressings.

In March 2018, the leading doctor on the subject was sent to the location at the request of the Deputy Secretary of Health, after reading the medical records following observation of the procedure to dress the infected wound, "from the proximal end of the leg to the foot", and noting aspects of "marked skin weakness and pallor" (Figure 1B). It was identified that, although the patient had started treatment while still in the phase diagnosed as indeterminate leprosy, her refusal to continue treatment over the years had allowed the disease to progress to a severe stage, characterized by an extensive skin ulcer on the right lower limb, with a necrotic, friable, and bleeding appearance.

In his own words, he said: "I was young and I didn't accept the disease, I refused treatment and asked my father to make a room with a bathroom and leave only a door to put food in, which he did". Given the clinical picture presented, characterized by worsening lesions and general deterioration of health, it was necessary to refer him immediately to a specialized center for comprehensive care and multidisciplinary attention, considering his previous medical history and the complexity of his condition.

During the consultation, the patient shared the following statement: "I was young and didn't accept the disease, refused treatment, and asked my father to make a room with a bathroom and leave only one door to put food through, which he did".

Given the severity of her clinical condition, the patient was referred to a specialized centre for comprehensive care. A conclusive diagnosis of well-



Figure 1a and b: Clinical photographs documenting an infected ulcer in a patient diagnosed with Hansen's disease. (A) Photograph taken on the last day of social isolation and (B) registered two months post-isolation, during ongoing treatment, both published with the patient's legal guardian's authorization.

differentiated squamous cell carcinoma was made, with non-assessable surgical margins. Amputation of the affected limb was performed as a therapeutic attempt to control the infection. However, due to complications and systemic deterioration, the patient died shortly thereafter.

Testimonies from relatives and acquaintances reinforced the long-standing impact of stigma on the patient's life. We obtained reports from people close to the patient that *"whenever we went to visit her, we could only see her through a window and only the upper part of her body"*, a behaviour rooted in deep shame and fear of rejection. During the visit, a family member (sister) of the patient shared the following statement: *"M.L.O.S. was young and very pretty when she asked her father to make her a room with a bathroom and to give her food through the window because she was ashamed and didn't want to leave"*. A professional from a leprosy referral centre added, *"She probably isolated herself because of prejudiced attitudes on the part of people in general"*.

Timeline

- 1975 (Age 20): The diagnosis of indeterminate leprosy and treatment with dapsona was initiated with regular follow-up until 1978.
- 1978–1988: No medical records or documented follow-up during this period.
- 1988 (Age 33): Re-evaluated during a home visit, she was diagnosed with VHD. Physical signs included ulceration on the right leg and slight hypotrophy in both hands. No therapeutic intervention recorded.
- 1995 (Age 40): A new home visit noted "no clinical symptoms and negative bacilloscopy test". No further care or treatment plan documented.
- 1995–2018: Medical records show no entries, and the patient remained in prolonged social isolation.
- 2018 (Age 63): The community reported the case to health authorities, and a multidisciplinary team visited the patient, who was found in severe physical decline and extreme social isolation. Clinical signs included an infected ulcer on the right lower limb, food refusal, and five days without bowel movement. Initiated treatment with Cephalexin, Diclofenac, and daily dressings.
- March 2018: Physician evaluation reported paleness and weakness, and an ulcer showed necrosis, friability, and bleeding in the injured limb.
- Post-March 2018: Referral to a specialized centre, diagnosed with well-differentiated squamous cell carcinoma. Amputation of the affected limb was performed.
- Shortly after surgery: The patient died due to systemic deterioration and multiple complications.

DISCUSSION

By the recommendations of the literature on case reports⁷, this study provides an opportunity to discuss the stigma surrounding leprosy, its profound impact on human life, and strategies for controlling the disease. It is noteworthy, and deeply concerning, that a disease known

since antiquity still causes not only physical disfigurement but also persistent social prejudice and psychosomatic harm, as illustrated in this case.

Stigma, understood as the discrepancy between an individual's actual social identity and the social identity attributed to them by others, is a public health problem of significant global relevance. In the context of leprosy, stigma has deep historical roots linked to beliefs, sociocultural values, and misconceptions about the disease. It is essentially a process of discrimination that negatively impacts the lives of affected individuals, manifesting itself in the family, school, work, and even health care settings. This stigmatization contributes to the development of feelings of inferiority, both individually and collectively, leading to adverse biopsychosocial effects, such as social exclusion and psychological distress. These factors compromise early diagnosis, hinder adherence to treatment, and, consequently, are critical determinants in the patient's clinical outcome⁸. In this case, stigma appears to have been one of the main determinants of the patient's clinical trajectory. After diagnosis, she isolated herself socially and consistently resisted therapeutic interventions, contributing to complications that could have been avoided with early and continuous adherence to medical treatment.

Although no explicit discriminatory legislation currently targets people with leprosy in Brazil, legal provisions exist to prohibit the use of discriminatory language and to protect the civil rights of affected individuals. The Brazilian Ministry of Health has implemented public health initiatives to address this issue, including professional training in the diagnosis, treatment, and management of leprosy reactions, as well as promoting social inclusion and reducing stigma. Furthermore, scientific and operational materials have been made freely accessible through official media⁹.

Another important governmental achievement in terms of strengthening the leprosy surveillance and care system was the implementation of the "National Strategy to Combat Leprosy 2019–2022" program⁴, developed in line with the "Global Leprosy Strategy 2016–2020: Accelerating Towards a Leprosy-free World"¹⁰. The Brazilian strategy aims to reduce the disease burden by achieving goals such as a 30% reduction in the number of children with grade 2 disabilities and lowering the national rate of new cases with grade 2 disabilities from 10 to 8.83 per million. The strategy also emphasizes the importance of reporting mechanisms for discriminatory practices in all federal states, reinforcing the need for integrated public policies to promote social inclusion and combat stigma⁴.

The most recent data indicate that the highest prevalence of this disease is concentrated in population groups where conditions such as poverty, malnutrition, and poor housing create an environment conducive to its spread^{11–13}, especially in underdeveloped or developing countries such as India, Brazil, and Indonesia^{14,15}. In Brazil, the North, Northeast, and Central-West regions rank first in the Americas with the highest number of new cases reported and second globally, behind only India^{16–18}. The Global Update on Leprosy reported 182,815 new cases of the disease worldwide, with 13.6% (24,773 cases)

reported in 27 countries in the Americas, with Brazil leading the ranking with 92% (22,773 cases) of the cases reported in this region¹⁸.

Given the chronology of this case, a minimally adequate infrastructure for diagnosis and treatment was already in place, and prescribed therapies could have been effective. However, psychosocial determinants – including stigma and discrimination – significantly worsened the patient’s clinical outcome. These factors, compounded by weak systems of record-keeping, surveillance, communication, and education, highlight the need for comprehensive, multidisciplinary public health approaches.

Recent literature on leprosy in Brazil underscores the importance of these structural and systemic factors. Epidemiological data show that most leprosy patients are urban residents between 28 and 49 years old¹⁹, aligning with the patient’s profile in this case. Additionally, evidence supports the need for coordinated service delivery, effective case management, and active health surveillance led by Primary Health Care teams¹⁹. This is a public health issue that is well illustrated in this case study, where it is possible to identify both the strengths and weaknesses of the care provided to patients by the health system, as well as possible more appropriate strategies for monitoring patients with diagnosed diseases.

Despite advances in clinical understanding of leprosy and the availability of effective multidrug therapy as recommended by the WHO, the major challenges in practice often involve late diagnosis and treatment delays. The main challenges in medical practice related to leprosy refer to the management of cases with late diagnosis or the resumption of treatment after prolonged interruption, often associated with irreversible neurological sequelae and important social repercussions, such as discrimination and stigmatization of affected individuals²⁰. In the present case, although adequate diagnosis and therapeutic planning were provided, treatment was restarted too late to alter the outcome.

The literature also distinguishes between non-adherence and treatment abandonment, both complex and multifactorial phenomena that are often underestimated. Studies show that primary care patients discontinue treatment due to a combination of intrinsic factors (e.g., fear, denial, depression) and extrinsic factors (e.g., unfavorable socioeconomic conditions, misinformation, lack of social support)²¹. In this case, such factors were evident, including poor socioeconomic conditions, limited disease knowledge, familial distancing, and internalized stigma.

Therefore, leprosy must be understood not only from a clinical perspective but also within the broader social and environmental contexts in which affected individuals live. These non-medical dimensions frequently dictate the success or failure of therapeutic outcomes. Although Brazil has adopted WHO-recommended treatment protocols and developed national policies to support people with leprosy, the country remains among the top 22 with the highest disease burden, ranking second in the number of new annual cases^{4,20}.

This situation underscores the profound impact of

biopsychosocial factors – both intrinsic and extrinsic – on disease management and outcomes. It also emphasizes the importance of multifaceted strategies that prioritize health promotion, disease prevention, and recovery. Promoting human dignity, reducing stigma, and encouraging full social inclusion are essential to enhancing both pharmacological and non-pharmacological outcomes, as supported by previous studies^{1,4,6,8,19–21}. As some authors argue, clinical case reports can be powerful tools for raising awareness about neglected diseases²². Research on leprosy is one of the most important in the world, particularly in countries such as Brazil. In addition to informing clinical care, it helps reduce stigma and discrimination by promoting visibility of patients’ experiences. It can also indirectly discourage behaviors such as self-isolation and self-stigmatization, which are often linked to low self-esteem and delayed diagnosis. According to the WHO, such psychosocial barriers remain central obstacles to early-stage detection and successful treatment¹⁸.

Under optimal conditions – early diagnosis and continuous, adequate treatment – leprosy can be cured with a high success rate. However, sociocultural challenges frequently prevent this outcome. As observed in the present case, care was resumed at an advanced stage of leprosy progression, which limited the therapeutic possibilities for recovery and ultimately contributed to the patient’s death. This case report reinforces the urgency of a comprehensive and in-depth debate on the multiple challenges involved in the clinical management of leprosy, including the biopsychosocial repercussions of discriminatory, stigmatizing, and prejudiced behaviors, even in the face of a pathological condition that can be resolved when diagnosed and treated early. The documentation of this patient’s clinical and personal history is a scientific and ethical act, preserving her memory so that, through her experience, it can become a tool for raising awareness among society and, above all, among health professionals. Finally, although we recognize operational limitations during the preparation of this report, the main methodological restriction identified is related to chronologically irregular and incomplete clinical records in the patient’s medical records.

CONCLUSION

The patient in this report experienced the progression of leprosy under unfavorable conditions, with insufficient treatment and strong social stigma. The disease evolved alongside an internalized psychosocial process, affecting self-esteem and generating shame, guilt, and social isolation. The case highlights that the management of leprosy must extend beyond pharmacological treatment, requiring comprehensive care that involves the active participation of health professionals and a psychosocial support network. These emotions resulted in distress, unhappiness, and self-punishment, reinforcing the need for strategies that enhance therapeutic outcomes and improve the quality of life for affected individuals.

Statements

Authors’ Contributions: Conceptualization: FAA, JAB, and LCA; Data curation: FAA; Formal analysis:

FAA; Funding acquisition: No external funding; Investigation: FAA and LCA; Methodology: FAA, IMPB, and LCA; Project administration: FAA, JAB and LCA; Resources: FAA, IMPB, and LCA; Software: Not applicable; Supervision: LCA; Validation: JAB, IMPB, and LCA; Visualization: FAA, LCA, and WPC; Writing – original draft preparation: FAA, IMPB, JAB, WPC, and LCA; Writing – review and editing: FAA, IMPB, JAB, WPC, and LCA. All authors have read and agreed to the published version of the manuscript.

Ethical Approval and Consent

This research adhered to the ethical guidelines outlined in Brazilian legislation regarding research involving the direct participation of human subjects. The research project was approved by the Research Ethics Committee of the University Centre of the Faculdade de Medicina do ABC (FMABC), Protocol CAAE No. 48612521.9.0000.0082. Consent was obtained from the participant involved in the study through the respective ICF for the publication of this case report and accompanying images, following the provisions of Brazilian Resolution CNS No. 466, dated December 12, 2012.

Conflict of Interest

The authors declare that this study was conducted without any commercial or financial relationships that could be perceived as potential conflicts of interest.

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Supplementary Material

S1. Case Report Guidelines (CARE) – <https://doi.org/10.17605/osf.io/9xpfr>

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Resumo

Introdução: este relato de caso destaca o impacto único e grave do estigma social no curso clínico da hanseníase. Ele apresenta a história de um paciente de 63 anos de idade, diagnosticado com hanseníase indeterminada, que permaneceu em isolamento social por mais de três décadas, evoluindo para óbito em decorrência de múltiplas complicações clínicas. O caso ilustra como a estigmatização crônica pode agravar substancialmente a carga biopsicossocial de uma condição potencialmente controlável mediante diagnóstico precoce e tratamento adequado.

Relato de caso: as principais características clínicas incluíam deterioração física e psicológica progressiva, agravada pelo autoisolamento e pela falta de apoio social. Apesar da disponibilidade de tratamento, a paciente teve um fracasso terapêutico atribuído principalmente ao diagnóstico tardio, à negligência social e à ausência de acompanhamento coordenado.

Método: este relatório retrospectivo e descritivo foi baseado em dados extraídos de registros médicos e analisados qualitativamente.

Resultados: os resultados evidenciam que barreiras operacionais e socioculturais, como o prontuário incompleto da paciente, atitudes estigmatizantes e o envolvimento limitado no processo de autocuidado, contribuíram para a deterioração do quadro clínico e para a redução da qualidade de vida da paciente.

Discussão: o caso destaca a importância de uma abordagem de atendimento abrangente no tratamento da hanseníase, indo além do tratamento farmacológico. O diagnóstico precoce deve ser acompanhado de apoio psicossocial e estratégias para combater o estigma e promover a inclusão. Um dos principais achados deste caso é que o sucesso terapêutico na hanseníase está intrinsecamente relacionado aos determinantes sociais de saúde; na ausência de estratégias eficazes para o enfrentamento do estigma e de um acompanhamento longitudinal e integrado, mesmo condições clinicamente tratáveis podem evoluir para desfechos adversos.

Conclusão: o fator limitante deste relatório foi a escassa documentação cronológica nos registros médicos. Além da farmacoterapia, o envolvimento ativo da rede social do paciente é essencial para mitigar o estigma, preservar a autoestima, promover a adesão ao tratamento e apoiar a inclusão social.

Palavras-chave: Doenças Tropicais Negligenciadas, *Mycobacterium leprae*; exclusão social, estigma.

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