HANSENOLOGIA INTERNATIONALIS
hanseníase e outras doenças infecciosas
eISSN 1982-5161

https://doi.org/10.47878/hi.2023.v48.39333

ORIGINAL ARTICLE

Patients' perception of the search for a leprosy diagnosis and care in healthcare networks

Percepção dos pacientes sobre a busca pelo diagnóstico da hanseníase e o atendimento nas Redes de Atenção à Saúde

Percepción de los pacientes sobre la búsqueda de diagnóstico y atención de la lepra en las Redes de Atención Sanitaria

Juliana do Nascimento Sousa[1], *Rafael Everton Assunção Ribeiro da Costa*[2], *Samira Rêgo Martins de Deus Leal*[3], *Arethuza de Melo Brito Carvalho*[4], *Sandra Marina Gonçalves Bezerra*[5]

HOW TO CITE THIS ARTICLE:
Sousa JN, Costa REAR, Leal SRMD, Carvalho AMB, Bezerra SMG. Patients' perception of the search for a leprosy diagnosis and care in healthcare networks. Hansen. Int. 2023;48:1-20. doi: https://doi.org/10.47878/hi.2023.v48.39333.

CONTACT INFORMATION:
Rafael Everton Assunção Ribeiro da Costa
State University of Piauí
E-mail: rafaelearcosta@gmail.com.

RECEIVED IN: 06/27/2023

ACCEPTED IN: 11/10/2023

PUBLISHED IN: 11/28/2023

[1] Graduated in Nursing – State University of Piauí Residency in Primary Care/Family Health at the State University of Piauí, Parnaíba, Piauí, Brazil.
[2] Medical Student at the State University of Piauí, Teresina, Piauí, Brazil.
[3] PhD in Pharmacology from the Federal University of Ceará. Adjunct Professor I of the Department of Nursing at the State University of Piauí, Teresina, Piauí, Brazil.
[4] PhD in Public Health from the Oswaldo Cruz Foundation. Assistant Professor of the Department of Nursing at the State University of Piauí, Teresina, Piauí, Brazil.
[5] PhD in Nursing from the Federal University of Piauí. Assistant Professor in the Department of Nursing at the State University of Piauí, Teresina, Piauí, Brazil.

ABSTRACT

The study aimed to evaluate the perception of patients regarding the care they received in healthcare networks, from the onset of symptoms to the diagnosis of leprosy. This qualitative study involved 15 leprosy patients who were treated at a reference center in the state of Piauí. Data was collected between August and September 2022, using a semi-structured interview guide with three sections: 1) sociodemographic and economic profile; 2) clinical information; and 3) semi-structured questions about the therapeutic itinerary taken for diagnosis and treatment. The study included leprosy patients aged 18 years or above undergoing treatment. Exclusions were made for patients who did not answer essential study questions or went off-topic. The study found that the majority of patients were female, married, with an average age of 58, completed primary education, earned less than one minimum wage, self-identified as mixed-race (*parda*), and lived in Teresina, with the multibacillary form of the disease. After conducting content analysis, three thematic categories were identified: 1) difficulty in self-recognizing the clinical manifestations of leprosy; 2) the therapeutic itinerary of the leprosy patients in the healthcare network; and 3) the perception of leprosy patients regarding the care provided by healthcare professionals. The patients' perception led us to conclude that the search for diagnosis and healthcare was a long and conflicting process until they reached primary care.

Keywords: *Leprosy. Diagnosis. Health care. Multidrug therapy.*

RESUMO

O objetivo do estudo foi avaliar a percepção dos pacientes quanto ao atendimento nas Redes de Atenção à Saúde, desde o surgimento dos sintomas até o diagnóstico de hanseníase. Trata-se de um estudo qualitativo com 15 pacientes com hanseníase atendidos em um centro de referência no estado do Piauí. A coleta de dados foi realizada entre agosto e setembro de 2022, com o uso de um roteiro de entrevista semiestruturado de três blocos: 1) perfil sociodemográfico e econômico; 2) dados clínicos; e 3) questões semidirigidas relacionadas ao itinerário terapêutico para o diagnóstico e tratamento. Foram incluídos pacientes com hanseníase em tratamento e idade superior a 18 anos. Excluiu-se aqueles que não responderam questionamentos essenciais para os objetivos do estudo ou tangenciaram o tema nesse sentido. Predominaram pacientes mulheres, casadas, com média de idade de 58 anos, ensino fundamental completo, que recebiam menos de um salário-mínimo, autodeclaradas como pardas, residentes em Teresina e com a forma multibacilar da doença. Após a análise de conteúdo, emergiram três categorias temáticas: 1) dificuldades no autorreconhecimento das manifestações clínicas da hanseníase; 2) itinerário terapêutico do usuário com hanseníase na rede de atenção à saúde; e 3) percepção dos pacientes com hanseníase sobre o atendimento dos profissionais de saúde. A percepção dos pacientes permite concluir que a busca pelo diagnóstico e o atendimento em saúde foi um processo longo e conflituoso até que estes chegassem a ser atendidos na Atenção Primária.

Palavras-chave: *Hanseníase. Diagnóstico. Atenção à saúde. Poliquimioterapia.*

RESUMEN

El objetivo del estudio fue evaluar la percepción de los pacientes sobre la atención que reciben en las redes de redes de atención sanitaria, desde el inicio de los síntomas hasta el diagnóstico de lepra. Se trató de un estudio cualitativo con 15 pacientes de lepra atendidos en un centro de referencia del estado de Piauí. Los datos se recogieron entre agosto y septiembre de 2022, mediante un guión de entrevista semiestruturada con tres modulos: 1) perfil sociodemográfico y económico; 2) datos clínicos; y 3) preguntas semidirigidas relacionadas con el itinerario terapéutico de diagnóstico y tratamiento. Se incluyeron pacientes con lepra en tratamiento y mayores de 18 años. Se excluyeron aquellos que no respondieron a preguntas esenciales para los objetivos del estudio, o que se salieron del tema en este sentido. Hubo predominio de pacientes del sexo femenino, casadas, con edad media de 58 años, enseñanza primaria completa, com ingresos inferiores a un salario mínimo, autodeclaradas pardas, residentes en Teresina y con la forma multibacilar de la enfermedad. Después de análisar el contenido, surgieron tres categorías temáticas: 1) dificultades en el auto-reconocimiento de las manifestaciones clínicas de la lepra; 2) el itinerario terapéutico de los pacientes con lepra en la red de atención sanitaria; y 3) la percepción de los pacientes con lepra sobre la atención prestada por los profesionales de la salud. Las percepciones de los pacientes nos llevan a concluir que la búsqueda de diagnóstico y atención sanitaria fue un proceso largo y conflictivo hasta que fueron atendidos en atención primaria.

Palabras clave: *Lepra. Diagnóstico. Atención a la Salud. Poliquimioterapia.*

INTRODUCTION

Leprosy is considered a neglected, chronic infectious disease caused by exposure to the bacterium *Mycobacterium leprae*. It has been described since 600 BC and continues to face stigma today due to the physical disabilities that may arise, as it affects the peripheral nerves, especially Schwann cells. Furthermore, the prevalence of this condition is associated with factors such as low educational levels, limited access to quality healthcare, inadequate funding for preventive measures, and unstable housing conditions[1,2]. Physical deficiencies, including changes to the body's visual and internal organs, occur because the bacillus is highly reactive and affects the superficial and peripheral nerves of the skin. In addition, other complications may arise, including neurological complications or type I, II, or III leprosy reactions. Therefore, it has been observed that patients with leprosy have a poor prognosis[2-4].

The diagnosis of this condition relies mainly on a clinic evaluation in which the healthcare provider evaluates signs and symptoms that involve both the skin and nerves. This process includes a dermatoneurological examination, which tests for thermal, painful, and tactile sensitivity. It is important to note that the presence of supplementary tests, such as smear microscopy of intradermal scrapings, skin histopathology, histamine testing, and sweat test may also be necessary[2]. Despite the introduction and standardization of medications, Brazil still exhibits considerable heterogeneity in leprosy distribution. In 2020, the prevalence coefficients were 3.06/10,000 in the Central West, 1.97/10,000 in the North, 1.68/10,000 in the Northeast, 0.39/10,0 in the Southeast, and 0.26/10,000 in the South[5]. Additionally, it is noteworthy that the Northeast region of Brazil is a focal point for leprosy endemicity. This is supported by the increasing mortality rates observed from 2001 to 2017[6].

Simultaneously, the state of Piauí ranks fifth in the Northeast in terms of the number of leprosy cases. The majority of cases involve individuals from inland cities, indicating a trend of internalization. Between 2011 and 2015, the incidence of leprosy cases in Piauí was within the standards proposed by the World Health Organization (WHO)[7].

Most individuals affected by leprosy experience low socioeconomic conditions. They may lack awareness of the signs and symptoms of the disease, be uncertain about which health facility to approach and rely on the Unified Health System (SUS) for access to healthcare and treatment. Moreover, accessing early diagnosis and treatment is difficult due to organizational issues, restricted access to public health services, and a lack of preparedness among professionals[8,9].

To improve patient prognosis and prevent deficiencies, deformities, and psychological problems, early diagnosis, timely treatment, and psychological follow-up are imperative[10].

To achieve this objective, it is crucial to improve the planning of health promotion initiatives, strengthen epidemiological surveillance, and provide more comprehensive care to individuals[6].

The study aimed to evaluate patients' perceptions of care within Health Care Networks (HCN), spanning from the onset of symptoms to the diagnosis of leprosy.

METHODS

Nature of the study

This study utilizes an exploratory and descriptive design with a qualitative approach.

The research employs an interpretive and naturalistic approach to the world, exploring new realms of imagination and creativity, while still maintaining some detachment from strict methodological rigor.

In the application of this investigative approach, phenomena are examined within a more natural context to comprehend and interpret them based on the individual meanings assigned by each person[11,12].

Therefore, qualitative methodology is ideal for understanding the experiences of participants exposed to diverse situations and contexts.

Study location

The study was conducted at the Secondary Care Center, in Teresina, Brazil, which serves as a reference for the care, treatment, and rehabilitation of individuals with leprosy. It also serves as a field for both practice and research. The team is multidisciplinary and includes a dermatologist, nurse, psychologist, physiotherapist, occupational therapist, biomedical technician, orthotic and insole technician, pharmacist, social worker, as well as an administrative and support team.

It is worth noting that, in addition to treatment, patients are offered various activities. These groups include a self-care group for individuals affected by leprosy and mutual help groups involving family members, neighbors, universities, and the community. The purpose of these groups is to address and reduce prejudice.

Study participants

The study involved 15 leprosy patients who received treatment at the center. The selection of interviewees was determined based on theoretical saturation, as this is a study with a non-probabilistic sample.

The patients were aged 18 and above and diagnosed with either the multibacillary (MB) or paucibacillary (PB) form of leprosy and currently undergoing treatment.

The study excluded patients who were unable to provide accurate responses to essential questions, such as the duration of the diagnostic process and their journey within the healthcare system leading to diagnosis and treatment initiation.

Data production

Data were collected between August and September 2022, through an approximately 15-minute interview recorded on an electronic device. Each participant was assigned an identification number and the researcher responsible for records.

The data collection instrument was a semi-structured interview script created by the authors themselves, divided into three parts: 1) identification of sociodemographic conditions – nine questions; 2) clinical data of pathology – three questions; and 3) semi-structured questions regarding the therapeutic itinerary – nine questions (Figure 1).

Figure 1 – Study data collection instrument.

INTERVIEW SCRIPT

Participant:	Data collection date:

FORM

SOCIOECONOMIC AND DEMOGRAPHIC CHARACTERISTICS

01. Gender: F ( ) M ( )

02. Age: ______

03. Educational background:
Illiterate ( ) Incomplete elementary education ( ) Complete elementary education ( ) Incomplete high school ( ) Complete high school ( ) Incomplete higher education ( ) Complete higher education ( ) Specialization ( ) Master's degree/ Doctorate ( )

04. Income:
Less than one minimum wage ( ) One minimum wage ( ) Two minimum wages ( ) Three or more minimum wages ( )

05. Residence: ( ) Teresina ( ) Another city, which one?

____

If you live in Teresina, please inform the area where you reside: Urban (A) Rural (B)

06. Profession/Occupation:

____

07. Do you work outside the home? Yes ( ) No ( )

If yes, in which activity?

____

08. Marital status:

Single ( ) Married ( ) Divorced ( ) Widowed ( ) Cohabitant ( ) Other ( )

09. Color/ethnicity:

White (A) Yellow (B) Black (C) Mixed Race (D) Indigenous (E)

CLINICAL DATA

1. Type of leprosy:
Paucibacillary ( ) Multibacillary ( )

2. Treatment Time:

3. Medications used:

QUESTIONS ABOUT THERAPEUTIC ITINERARY

BLOCK 1 – SIGNS AND SYMPTOMS

	Tell me a little about how you started to suspect you had leprosy
	Did these symptoms bother you and/or interfere with your daily activities?
	Have you ever lived with someone who has leprosy?

BLOCK 2 – DIAGNOSIS AND TREATMENT

	When you suspected you had leprosy, did you seek help at a health facility? Which one?
	Tell me about your journey until you were able to get the diagnosis.
	How was the diagnosis?
	When diagnosed, what were your feelings?
	Tell me what your treatment was like
	Would you like to give any suggestions regarding how they are managing leprosy patients?

Source: Elaborated by the authors.

Patients were approached during their physical therapy sessions or upon their return by a physician or nurse. In a reception room, they were informed about the objectives of the study, asked about their interest in participating in the research and, shortly thereafter they signed the Informed Consent Form (ICF) to initiate the research.

Participants who agreed to participate signed the ICF; to ensure confidentiality, interviews were conducted in a private room and participants were assigned pseudonyms such as P1, P2, P3, etc.

A total of 25 people were interviewed. While listening to the audio recordings and transcribing them, it became clear that theoretical saturation was reached with 15 interviewees' responses.

In addition, the other 10 statements were related to the topics but did not answer essential questions about the time to diagnosis and the journey within the HCN to obtain diagnosis and treatment. Therefore, the number of participants decreased due to exclusions.

Data organization and analysis

After the data collection phase, the interviews were transcribed in their entirety to carry out analysis and to ensure their confidential storage, respecting all ethical issues during the data analysis process.

The analysis of the collected data was based on content analysis, which, according to Bardin[13], is understood as a set of research techniques aimed at understanding the meaning or meanings within a document, and it allows the description and analysis of the collected content, structured in three stages: pre-analysis, which involves the transcription of statements, reading and document selection; exploration, which involves the segmentation of the text into units and the creation of thematic categories; and processing of the results, which involves interpretation and comparison with existing literature to describe the message content, categorize the data, and draw definitive conclusions[13].

Ethical and legal aspects

This research complied with Resolution No. 466/2012, of December 12, 2012, of the National Health Council (NHC), which establishes that all research that directly or indirectly involves human subjects must be evaluated by a Research Ethics Committee (REC)[14], and with Resolution No. 510/2016, of April 7, 2016, of the NHC whose ethical guidelines are specific to qualitative research in the human and social sciences[15].

It is worth highlighting that all ethical issues were respected and the project was accepted and approved by the Committee of the Co-Participating Institution and the REC of the State University of Piauí (REC-UESPI), with Opinion No. 5.574.90 and CAAE 61275722.9.0000.5209.

RESULTS AND DISCUSSION

Sociodemographic and clinical profile

Figure 2 shows the sociodemographic and clinical profiles of the 15 participants included in the study.

Figure 2 – Sociodemographic and clinical profile of participants included in the study.

Code-names	Gender	Age	Marital status	Education	Income	Profession/ Occupation	Color/ ethnicity
P1	F	47	Married	IHS	One minimum wage	Home carer	Black
P2	F	44	Divorced	IHS	Less than one minimum wage	Home carer	Mixed race
P3	M	65	Single	IEE	One minimum wage	Retired	Mixed race
P4	M	60	Single	IEE	Less than one minimum wage	Home carer	White
P5	F	67	Widow	IEE	One minimum wage	Retired	Mixed race
P6	M	47	Married	IEE	Less than one minimum wage	Home carer	Mixed race
P7	M	53	Single	CEE	Less than one minimum wage	Home carer	Mixed race
P8	F	65	Married	IEE	One minimum wage	Retired	Black
P9	F	70	Widow	CEE	Less than one minimum wage	Home carer	Black
P10	M	64	Married	IEE	Less than one minimum wage	Home carer	lack
P11	F	66	Widow	CHS	One minimum wage	Retired	Mixed race
P12	F	61	Married	CEE	Two minimum wages	Entrepreneur	Mixed race
P13	M	56	Married	CHE	Two minimum wages	Home carer	Black
P14	F	18	Single	IHS	Less than one minimum wage	Intern	Black
P15	M	69	Single	CHS	One minimum wage	Retired	Mixed race

Subtitle: F – Female; M – Male; IEE – Incomplete Elementary Education; CEE – Complete Elementary Education; IHS – Incomplete High School; CHS – Complete High School; CHE – Complete Higher Education.
Source: Elaborated by the authors.

Analysis of thematic categories

After transcribing and analyzing the collected material, the narratives were categorized thematically, examining and organizing the predominant themes into three thematic categories: 1) difficulties in self-recognition of clinical manifestations of leprosy; 2) the therapeutic journey of people with leprosy in the HCN; and 3) leprosy patients' perception of care provided by health professionals.

Thematic Category 1 (Difficulties in self-recognition of clinical manifestations of leprosy)

In the speech of most of the participants, when asked how they began to suspect that they had leprosy, it could be observed that they perceived themselves as ill, but did not know how to define a possible cause, as shown in the following reports of patients P5 and P10:

> *My legs hurt; it hurt so much that at night I would cry and put my legs up anyway; it was this constant burning pain (P5).*
>
> *[...] I spent about 6 months thinking it was something else (P10).*

The statements support existing studies that illustrate the lack of the patient's knowledge about the pathology, including aspects such as transmission, clinical manifestations, diagnosis, and treatment. Despite the dissemination of information about the pathology on posters in primary health care (PHC) facilities, it is evident that this information does not effectively reach all target groups, especially those living in situations of social vulnerability[16,17].

Some early manifestations of the disease can be confused with bone problems, allergies, dermatoses, and even skin cancer. These data are similar to those of a study carried out in the backlands of Paraíba, where participants also associated leprosy with other pathologies[16]. Some of the reports are described below:

> *I didn't know, a spot appeared and I waited for it to disappear because I didn't even know that leprosy existed [...] I thought it was a joint problem (P2).*
>
> *It came out over my eyes like dandruff, something I thought was caused by allergies and it was very itchy [...] it was like a rash (P8).*
>
> *Some blisters appeared on my hands [...] they said I had an allergy (P11).*
>
> *There were some purple spots on my body, and I pinched them and didn't feel them; then it also passed [...] I thought it was cancer (P13).*

It has been observed that they initially perceived a disconnection between health and the disease process and sought their alternatives for treatment, seeking health services only when the progression of the disease had an aesthetic impact and there were limitations in routine activities[18], as observed in some reports:

> *I used warm water compresses [...] I wanted to work (P2).*
>
> *Applying ointment (P11).*
>
> *[...] it bothered me, the stain that appeared on my face (P12).*

Even if they perceived themselves to be ill, the confirmation of the diagnosis further exacerbated the frustration and aroused feelings of fear, incapacity, loss, rejection, isolation, and suffering, as social stigma, in addition to prejudice is still a very present situation in the daily lives of these patients, as evidenced by the statements of P1, P2, P4, P6, P8, and P15:

> *Sad for not knowing about the disease, for not knowing what it will be like from now on and I was already limited, I became even more restricted (P1).*
>
> *Terrible because I wanted to work, and I couldn't (P2).*
>
> *[...] I was very discriminated against by people, including even a friend of mine who slammed the door in my face (P4).*
>
> *My marriage even ended; friends and some things went away with it and my whole psyche was shaken (P6).*
>
> *I isolated myself; I feel like I isolated myself from my neighbors and stuff like that (P8).*
>
> *I cried a lot and suffered (P15).*

Upon confirmation of a leprosy diagnosis, patients often face emotional, social, and financial impacts, as well as prejudice and discrimination from others due to the disease, lack of knowledge about the disease, and fear of exposure. This can make treatment adherence difficult. It is important to address this issue and provide support for patients[17,19].

Although leprosy is an ancient disease that has been discussed at WHO conferences, addressed by the Ministry of Health, and involves non-governmental organizations, there are still numerous goals to be achieved in the ongoing efforts to reduce cases in both adults and children. It is crucial to emphasize that Primary Health Care (PHC) should operate more proactively. This involves not only tracing contacts of confirmed cases but also extending efforts to address the disease during routine consultations. It includes home visits and organizing community meetings, using accessible language, and employing strategies to facilitate early-stage symptom recognition. This minimizes the chances of disabilities[20].

Thematic Category 2 (therapeutic journey of individuals with leprosy in the HCN)

This category describes the patient´s journey within the HCN. Patients faced obstacles when seeking guidance and treatment from professionals at a health unit, they encountered obstacles. In their narratives, it was evident that the majority of patients took a considerable amount of time before seeking help.

Connected to this, the majority of patients promptly sought healthcare and consulted various medical specialties to obtain a diagnosis. These factors together are concerning because they increase the time required to diagnose the disease, which can individuals to disabilities[21].

> *In 2014, I started to feel severe pain. In 2015, I went to several doctors, I went to the orthopedist, neurologist, and all the doctors who referred me; in 2016, I gave up; But, in 2017, I got worse, and, in September of 2017, I started taking treatment (P1).*

> *It took me a long time to seek help, the spots started in May of 2022 and then I went to the dermatologist because I had a spot on my back (P9).*

According to the majority, seeking consultations with various specialists and undergoing various examinations, including those in the private health network, was another factor. However, it should be noted that leprosy diagnosis is primarily clinical, and complementary exams are used solely for differential diagnoses. These practices can lead to erroneous diagnoses, which further delay the initiation of treatment[5,22].

It was also noted that professionals from networks not linked to PHC had difficulty recognizing signs and symptoms and making an accurate diagnosis, or even not being able to make it and referring them to another specialist.

> *I started feeling the lump in 2012 and was diagnosed in 2014, but I only felt the heat and that was here much earlier in 2006 [...] I walked around a lot and the doctors just put ointment on the lump (P3).*

> *The doctor just kept saying it was neuropathy because my feet would swell up, they would turn purple, my toes would turn black, so I´ve been in treatment for over a year [...] then I was at the time of the pandemic, we couldn't even go to the hospital, so I paid for a private consultation and there the doctor saw that I already had some spots on my back, I did the test and it was positive (P5).*

> *[...] I did some blood tests and the doctor said that the numbness was due to high cholesterol [...] When it happened in 2012, some blisters appeared, burst, and spent a long time without healing [...] so I had the biopsy and it didn't show anything. Then the doctor asked me to undress, she saw the spots on my back and said it was leprosy and that's when I started the treatment (P11).*

> *[...] I visited a dermatologist and underwent a biopsy and it turned out to be lupus [...] I paid for the consultation and another expensive test; then the results came, and it was revealed that it was leprosy. It took about 4 years for me to know it was leprosy (P12).*

On the other hand, those who visited a Basic Health Unit (BHU) or were referred and found trained professionals achieved an accurate diagnosis and immediately initiated the treatment, and were sent to the Secondary Care facility (SC) with correct and important information about the case for targeted and effective management. This shows the importance of the link between referral and counter-referral as demonstrated by PHC and SC, as it reduces the waiting time for diagnosis, initiation of treatment, and implementation of rehabilitation activities[23].

However, it is still essential to disclose the actions and services offered to users within each level of the HCN, so that they can enter the service network through the PHC, as this is the preferred gateway to health services.

> *I went to the BHU and from there I was transferred here and started my tests [...] the results were immediate; the doctor gave me the medication and then she referred me to the UBS in my neighborhood and I started treatment there for a year (P7).*

> *I went to the doctor because I already had an appointment when I got there, he discovered that I already had a suspicion because there was a numb patch [...] then the doctor at the hospital said it was leprosy and sent me to the other hospital and I was treated for one year (P10).*

> *After a month, a month and a half, I went to the doctor at the clinic to identify the problem. After the examination, they did the biopsy and the doctor found that it was leprosy, so we started the treatment (P14).*

It is important to note that a correlation was found between the time it took to receive a diagnosis and the socioeconomic status of the patients. The process of obtaining a diagnosis was found to be the most challenging and time-consuming aspect. Patients with better socioeconomic conditions receive a faster diagnosis in the private health network compared to those who rely solely on the public network. Once the diagnosis was confirmed, the longest and most difficult part of the treatment began promptly.

> *At that time of the pandemic, I couldn't even go to hospitals, so I paid for a private consultation (P5).*

> *I had to have a private consultation (P6).*

> *I started doing private consultations (P11).*

Despite starting treatment immediately, multidrug therapy can last from 6 to 9 months for PB forms and 12 to 18 months for MB forms of the disease. The average treatment time in this study was 1 year. Longer treatment durations, increase the likelihood of low adherence and abandonment. According to a study conducted in São Paulo, the rate of abandonment and interruption varied from 1.3% to 23.9% and was mainly caused by adverse reactions. Therefore, is extremely important for the healthcare team to supervise daily and monthly doses[24].

The delay in diagnosis of leprosy is often due to patients postponing seeking health services, coupled with the prejudice and stigma associated with the disease. Furthermore, the lack of training among professionals highlights the need for continued education measures to train and update them on leprosy management. This is crucial for minimizing discrepancies in the care provided by PHC and reducing the occurrence of possible physical disabilities[23].

Thematic Category 3 (perception of leprosy patients regarding the care provided by health professionals)

The health professional should provide quality, ethical, and compassionate care while upholding the principles of equity, universality, and integrality of the Unified Health System (SUS)[25,26].

However, over half of the participants expressed dissatisfaction with the public system when asked about their services, as demonstrated in the following statements:

> *I suffered for 5 years because of this [...] if they had listened to me and given me the biopsy again so they could see that I still had leprosy, I would have gotten well sooner (P3).*
>
> *We don't have that much support through the SUS (P15).*

Prejudice was not limited to the general population; it also occurred in the care provided by professionals trained to guarantee reception and active listening, especially when the patient is in a moment of vulnerability.

> *I have seen places where people arrive with wounds and lumps, and the professionals themselves look at them and walk away. There is a rejection (P8).*
>
> *I think that sometimes the dermatologist takes a while to get to the leprosy side and keeps looking for other things and seems like he doesn't want to talk about the subject (P12).*

The phenomenon mentioned can be attributed to technical issues. A cross-sectional study demonstrated that 78.6% of the analyzed health professionals were unfamiliar with the standardized sequence for clinical examination, and 64.3% lacked awareness of the most affected structures[27]. A bibliographic survey characterized the level of knowledge among health academics as regular and/or unsatisfactory[28].

However, some professionals still provided humanized care, by being sensitive to the patient's entire social context. They initiated referral and counter-referral processes for multidisciplinary follow-up by coordination with the SC.

> *I even got depressed, but it didn't go much further because the psychologist called me to talk (P2).*

> *[...] I am well-attended (P4).*
>
> *[...] As far as I have gone, I have been well-attended (P14).*

There is still a barrier to a better understanding of the peculiarities of each patient, making it essential to carry out training and debates to disseminate information about leprosy and to guarantee humanized and comprehensive care[29].

Hence, it is therefore essential to implement measures to improve the efficiency of referral and counter-referral processes, to reduce operational gaps, and to use technology to manage waiting times and facilitate referrals to specialist centers[23].

These practices are important within the overall HCN arrangement as leprosy patients move from primary health care (PHC) for follow-up to secondary care (SC) and tertiary care, where specialized activities are carried out.

The main limitation of the study is its qualitative nature, as this methodology can be subjective, influenced by the researcher's interpretation, and subject to biases that may affect the accuracy and precision of the information collected.

CONCLUSIONS

According to the perception of the patients interviewed, it can be concluded that the process of finding a diagnosis was long and full of setbacks and conflicts. It was observed that the majority of the patients sought SC centers from private networks, returned to the PHC only after a long wait, incurred financial expenses, and underwent numerous consultations and examinations with different specialties near their residences.

As this is a study conducted in an endemic region of Brazil, it would be expected that health workers, in different specialties would be highly trained to suspect and provide early diagnosis of leprosy compared to those working in non-endemic regions. In this way, they would contribute to interrupting the transmission chain, providing effective early treatment, and reducing social stigma and physical disability. Among medical specialties, dermatologists should have sufficient skills to perform early diagnosis and treatment of the disease. Therefore, the results emphasize the need for greater dissemination of knowledge about leprosy in all its aspects.

ETHICAL APPROVAL AND INFORMED CONSENT: *the study was approved by the Research Ethics Committee (REC) of the State University of Piauí, CAAE: 61275722.9.0000.5209.*

CONFLICTS OF INTEREST: *the authors state that there are no conflicts of interest in this article.*

AUTHOR CONTRIBUTIONS: Sousa JN *and* ***Costa REAR*** *contributed to the conception and design of the study, analysis, and interpretation of the results, writing, and critical review of the manuscript content.* ***Leal SRMD****,* ***Carvalho AMB****, and* ***Bezerra SMG*** *contributed to the analysis and interpretation of data, writing, and critical review of the manuscript content. All authors critically reviewed the manuscript writing.*

REFERENCES

1. Santos MB, Santos ADD, Barreto AS, Souza MDR, Goes MAO, Alves JAB, et al. Clinical and epidemiological indicators and spatial analysis of leprosy cases in patients under 15 years old in an endemic area of Northeast Brazil: an ecological and time series study. BMJ Open. 2019;9(7):e023420. doi: https://doi.org/10.1136/bmjopen-2018-023420.

2. Ministério da Saúde (BR). Protocolo clínico e diretrizes terapêuticas da hanseníase. Brasília: Ministério da Saúde; 2022.

3. White C, Franco-Paredes C. Leprosy in the 21st century. Clin Microbiol Rev. 2015;28(1):80-94. doi: https://doi.org/10.1128/CMR.00079-13.

4. Fischer M. Leprosy – an overview of clinical features, diagnosis, and treatment. J Dtsch Dermatol Ges. 2017;15(8):801-27. doi: https://doi.org/10.1111/ddg.13301.

5. Ministério da Saúde (BR). Boletim epidemiológico de hanseníase. Brasília: Ministério da Saúde; 2022.

6. Ferreira AF, Souza EA, Lima MDS, García GSM, Corona F, Andrade ESN, et al. Mortalidade por hanseníase em contextos de alta endemicidade: análise espaço-temporal integrada no Brasil. Rev Panam Salud Publica. 2019;43:e87. doi: https://doi.org/10.26633/RPSP.2019.87.

7. Monteiro MJSD, Santos GM, Barreto MTS, Silva RVS, Jesus RLR, Silva HJN. Perfil epidemiológico de casos de hanseníase em um estado do nordeste brasileiro. Rev Aten Saúde. 2017;15(54):21-8. doi: https://doi.org/10.13037/ras.vol15n54.4766.

8. Silva JSR, Palmeira IP, Sá AMM, Nogueira LMV, Ferreira AMR. Variáveis clínicas associadas ao grau de incapacidade física na hanseníase. Rev Cuid. 2019;10(1):e618. doi: https://doi.org/10.15649/cuidarte.v10i1.618.

9. Lima EO, Silva MRFD, Marinho MNASB, Alencar OM, Pereira TM, Oliveira LC, et al. Therapeutic itinerary of people with leprosy: paths, struggles, and challenges in the search for care. Rev Bras Enferm. 2021;74(1):e20200532. doi: https://doi.org/10.1590/0034-7167-2020-0532.

10. Santos VS, Matos AM, Oliveira LS, Lemos LM, Gurgel RQ, Reis FP, et al. Clinical variables associated with disability in leprosy cases in northeast Brazil. J Infect Dev Ctries. 2015;9(3):232-8. doi: https://doi.org/10.3855/jidc.5341.

11. Godoy AS. Pesquisa qualitativa: tipos fundamentais. Rev Adm Empres. 1995;35(3):20-9.

12. Denzin NK, Lincoln YS. O planejamento da pesquisa qualitativa: teorias e abordagens. Porto Alegre: Artmed; 2006.

13. Bardin L. Análise de conteúdo. São Paulo: Edições 70; 2011.

14. BRASIL. Ministério da Saúde. Resolução CNS nº 466/2012. Dispõe sobre pesquisa envolvendo seres humanos. *Diário Oficial [da] República Federativa do Brasil*, Poder Executivo, Brasília, DF, 13 jun. 2013. Seção 1.

15. BRASIL. Ministério da Saúde. Resolução nº 510/2016. Dispõe sobre a pesquisa em Ciências Humanas e Sociais. *Diário Oficial [da] República Federativa do Brasil*, Poder Executivo, Brasília, DF, 07 abr. 2016.

16. Teixeira BC, Egypto IAS, Nogueira TBSS, Santos EVL, Egypto LV. Itinerário terapêutico de pacientes com diagnóstico de hanseníase no sertão da Paraíba. RBM [Internet]. 2020 [cited 2023 Apr 10];23(3):19-32. Available from: https://www.revistarebram.com/index.php/revistauniara/article/view/817.

17. Carneiro DF, Silva MMB, Pinheiro M, Palmeira IP, Matos EVM, Ferreira AMR. Therapeutic itineraries in search of diagnosis and treatment of leprosy. Rev Baiana Enferm [Internet]. 2017 [cited 2023 Mar 10];31(2):e17541. Available from: http://www.revenf.bvs.br/scielo.php?script=sci_arttext&pid=S2178-86502017000200314.

18. Lima FC, Alencar OM, Pereira TM, Abreu LDP, Albuquerque MD, Rocha RMGS. Aspectos que dificultam a descentralização das ações de controle da Hanseníase em um Município da Região do Cariri-CE. Cadernos ESP [Internet]. 2018 [cited 2023 Mar 10];12(2):49-56. Available from: https://cadernos.esp.ce.gov.br/index.php/cadernos/article/view/142.

19. Farias RC, Santos BRF, Vasconcelos LA, Moreira LCS, Mourão KQ, Mourão KQ. Hanseníase: educação em saúde frente ao preconceito e estigmas sociais. RSD. 2020;9(8):e114984923. doi: http://dx.doi.org/10.33448/rsd-v9i8.4923.

20. Cunha MHCM, Silvestre MPSA, Silva AR, Rosário DDS, Xavier MB. Fato- res de risco em contatos intradomiciliares de pacientes com hanseníase utilizando variáveis clínicas, sociodemográficas e laboratoriais. Rev Pan-Amaz Saude [Internet].2017 [cited 2023 Mar 10];8(2):23-30. Available from: http://scielo.iec.gov.br/pdf/rpas/v8n2/2176-6223-rpas-8-02-00021.pdf.

21. Aquino CMF, Rocha EPAA, Guerra MCG, Coriolano MWL, Vasconcelos EMR, Alencar EN. Peregrinação (Via Crucis) até o diagnóstico da hanseníase. Revista Enferm UERJ. 2015;23(2):185-90. doi: https://doi.org/10.12957/reuerj.2015.12581.

22. Martins PV, Iriart JAB. Itinerários terapêuticos de pacientes com diagnóstico de hanseníase em Salvador, Bahia. Physis. 2014;24(1):273-89. doi: https://doi.org/10.1590/S0103-73312014000100015.

23. Ministério da Saúde (BR). Diretrizes para vigilância, atenção e eliminação da Hanseníase como problema de saúde pública. Brasília: Ministério da Saúde; 2016.

24. Gouvêa AR, Martins JM, Posclan C, Dias TAA, Pinto JM Neto, Rondina GPF, et al. Interrupção e abandono no tratamento da hanseníase. Braz J Hea Rev. 2020;3(4):10591-603. doi: https://doi.org/10.34119/bjhrv3n4-273.

25. Ministério da Saúde (BR). HumanizaSUS: política nacional de humanização: a humanização como eixo norteador das práticas de atenção e gestão em todas as instâncias do SUS. Brasília: Ministério da Saúde; 2004.

26. Ministério da Saúde (BR). Política nacional de atenção integral à saúde do homem: princípios e diretrizes. Brasília: Ministério da Saúde; 2008.

27. Gemelli JMF, Costa L, Almeida MC, Souza EJ. Conhecimento de profissionais da saúde diante da Hanseníase: um estudo transversal. U&C-ACBS. 2019;10(1):45-50.

28. Teixeira E, Palmeira IP, Ranieri BC, Oliveira LB. Knowledge and attitudes of students towards Hansen's disease: a bibliometric study in national and international literature. Rev Enferm UFPI. 2021;10:e881. doi: https://doi.org/10.26694/reufpi.v10i1.881.

29. Sousa GS, Silva RLF, Xavier MB. Hanseníase e Atenção Primária à Saúde: uma avaliação de estrutura do programa. Saúde Debate. 2017;41(112): 230-42. doi: https://doi.org/10.1590/0103-1104201711219.