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RESEARCH

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Access and accessibility in Primary Health Care: experiences of individuals affected by leprosy

Acesso e acessibilidade na Atenção Primária à Saúde: experiências de pessoas com hanseníase

Acceso y accesibilidad en la Atención Primaria de Salud: experiencias de personas con lepra

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ABSTRACT

Objective: to examine the access and accessibility barriers faced by individuals affected by leprosy in meeting their healthcare needs. **Methods:** this is a descriptive, qualitative study conducted between November 2021 and February 2022 in four Basic Health Units in Belém, Pará. A total of 29 individuals diagnosed with leprosy participated in the study. Data were collected through individual semi-structured interviews. The textual corpus was analyzed using IRAMUTEQ *software*. **Results:** Data processing generated 366 text segments and revealed six lexical classes. Lexical class 5 encompasses aspects related to treatment and the availability of medications at Health Units, the quality of care provided by healthcare professionals, and the absence of adequate health education. The conflict between the activities carried out by the Leprosy Control Program in Health Units and the principles of the Brazilian Unified Health System becomes evident through the challenges surrounding access and accessibility to treatment. **Final considerations and implications for practice:** Overcoming territorial and regional challenges is crucial for the successful implementation of leprosy control measures within primary care. Urgent action is needed to reassess the shift scheduling process. Ongoing professional education, coupled with health education for users, creates a more welcoming environment and better addresses patients' needs.

Keywords: Primary Health Care; Health Education; Social Stigma; Leprosy; Health.

RESUMO

Objetivo: identificar as dificuldades de acesso e acessibilidade de pessoas com hanseníase para atender às suas demandas de saúde. **Método**: estudo descritivo, qualitativo, realizado entre novembro de 2021 e fevereiro de 2022 em quatro Unidades Básicas de Saúde em Belém, Pará. Participaram 29 usuários diagnosticados com hanseníase. Os dados foram produzidos por entrevista individual e semiestruturada. O corpus foi submetido ao *software* IRAMUTEQ. **Resultados**: o processamento dos dados resultou em 366 seguimentos de textos e seis classes lexicais. A classe lexical 5 alude ao tratamento e disponibilidade dos medicamentos oferecidos pelas Unidades de Saúde, o bom trato dos profissionais e a ausência de educação em saúde. O antagonismo entre as atividades desenvolvidas pelo Programa de Controle da Hanseníase nas Unidades de Saúde e os Princípios do Sistema Único de Saúde se evidencia com as dificuldades de acesso e acessibilidade ao tratamento. **Considerações finais e implicações para a prática:** peculiaridades territoriais e regionais precisam ser vencidas para que as ações de controle da hanseníase na atenção primária possam se desenvolver. A revisão da rotina nos turnos de agendamentos é urgente. Educação permanente dos profissionais e educação em saúde aos usuários ampliam o acolhimento e contribuem para o atendimento das demandas dos usuários.

Palavras-chave: Atenção Primária à Saúde; Educação em Saúde; Estigma Social; Hanseníase; Saúde.

RESUMEN

Objetivo: identificar las dificultades de acceso y accesibilidad de las personas con lepra para satisfacer sus demandas de salud. **Métodos:** estudio descriptivo, cualitativo, realizado entre noviembre de 2021 y febrero de 2022 en cuatro Unidades Básicas de Salud de Belém, Pará. Participaron 29 usuarios diagnosticados con lepra. Los datos se obtuvieron a través de entrevistas individuales y semiestructuradas. El corpus fue sometido al *software* IRAMUTEQ. **Resultados:** el procesamiento de datos resultó en 366 segmentos de texto y seis clases léxicas. La clase léxica 5 alude al trato y disponibilidad de medicamentos que ofrecen las Unidades de Salud, el buen trato de los profesionales y la falta de educación sanitaria. El antagonismo entre las actividades desarrolladas por el Programa de Control de la Lepra en Unidades de Salud y los Principios del Sistema Único de Salud se evidencia con las dificultades en el acceso y accesibilidad al tratamiento. **Consideraciones finales e implicaciones para la práctica:** es necesario superar las peculiaridades territoriales y regionales para poder desarrollar acciones de control de la lepra en la atención primaria. La revisión en la rutina de programación de turnos es impostergable. La educación permanente de los profesionales y la educación en salud de los usuarios amplían la acogida y contribuyen a satisfacer las demandas de los usuarios.

Palabras Clave: Atención Primaria de Salud; Educación para la Salud; Estigma Social; Lepra; Salud.

INTRODUCTION

Leprosy is a public health issue in Brazil. In 2022, 174,087 new cases were reported worldwide, with 19,635 occurring in Brazil. The country has one of the highest disease burdens in the Americas, ranking second worldwide in the number of cases, surpassed only by India.[1]

Leprosy is a chronic, infectious disease caused by *Mycobacterium leprae*. It has a millennia-long history, having long been considered incurable and associated with physical, moral, and spiritual impurity. The disease visibly manifests on the body through its dermatological and neurological signs and symptoms. Such factors have contributed to the rejection, discrimination, and social exclusion of those affected, reinforcing stigma and prejudice, and ultimately hindering the timely diagnosis of new cases.[2]

Leprosy is diagnosed clinically and treated with the Multidrug Therapy (MDT) regimen, which is provided by the Brazilian Unified Health System (Portuguese Acronym: SUS). Treatment duration varies from six to 12 months, depending on the specific therapeutic protocol.[3] This information is essential for addressing access and accessibility within Primary Health Care (PHC), which functions as the main point of entry for diagnosing and treating individuals affected by the disease.[3]

Despite its high cure rates, leprosy continues to result in disease-related sequelae for many individuals due to insufficient public awareness of its signs and symptoms, delayed case detection, limited access to the health care network, and inadequately structured services that fail to ensure comprehensive care.[4] In this context, implementing preventive and control measures within health services is crucial to reducing endemic levels and mitigating the overall disease burden.[5]

Primary Health Care (PHC) plays a crucial role in leprosy control, functioning both as the main point of entry into the health system and as the coordinator of care delivery. Nursing consultations are essential in this scenario, as they help strengthen patients' understanding of the disease and support its management through the detection of clinical signs, encouragement of adherence, contact tracing, focus on achieving a cure, and prevention of complications. These actions contribute to improving access, reducing stigma, and ensuring the delivery of comprehensive care.[5]

It is essential to highlight the barriers and obstacles that hinder individuals from seeking and receiving care, as these challenges are central to broader discussions on access and accessibility within healthcare systems.[6] In this study, access is defined as the users' ability to engage with health services in pursuit of solutions to their health concerns. On the other hand, accessibility is an essential component of access, focusing on the availability and attributes of healthcare resources, which can either promote or hinder their use by potential patients.[7]

A study conducted with individuals affected by leprosy in the state of Piauí, Brazil, highlights the challenges encountered in healthcare networks—ranging from the onset of symptoms to diagnosis. These challenges are linked to factors such as the self-diagnosis of leprosy symptoms, frequent diagnostic errors, the provision of inappropriate treatments, and patient dissatisfaction with the quality of care provided by healthcare professionals.[8]

A study conducted across both rural and urban areas of an Indian state revealed a large number of undiagnosed leprosy cases, as well as significant barriers to both accessing treatment and adhering to the region's control program.[9] A survey conducted between January 2021 and December 2022 at a dermatological specialty center in Paraguay identified 123 cases of leprosy, accounting for 1.09% of the total consultations. The researchers highlight that a considerable number of cases continue to be diagnosed each year, underscoring the critical importance of early diagnosis and timely treatment to reduce the disease's prevalence.[10]

In its pursuit of a world free from leprosy, Brazil has aligned with the Global Leprosy Elimination Action Plan through the National Strategic Plan for Leprosy Control, which seeks to reduce the disease burden in the country by 2030.[1] The strategy is based on three key pillars: Reducing the burden of leprosy; addressing and preventing the physical complications of the disease, such as grade 2 disabilities; and combating discrimination and stigma against individuals with leprosy and their families.[1] Thus, the action plan aims to improve comprehensive care for individuals affected by leprosy within Primary Health Care (PHC).

Leprosy has a higher incidence rate among the most impoverished populations, who live in unfavorable socioeconomic conditions, often in urban slums, facing low levels of education, poor sanitation, social inequalities, food insecurity, and malnutrition. These factors contribute to an uneven spatial distribution across regions, highlighting the socio-economic disparities within Brazil.[11]

In the state of Pará, leprosy is endemic due to factors such as poor living conditions, a low Human Development Index (HDI), and the existence of hard-to-reach areas, where isolation is driven by both geographical remoteness and limited provision of services. As a result, there is a significant gap in the population's access to healthcare. Hence, it is critical to intensify epidemiological surveillance in the region.[12]

Therefore, understanding the challenges faced by individuals affected by leprosy in Primary Health Care (PHC) enables healthcare teams to identify the factors that hinder comprehensive care, ultimately aiming to improve both access to and accessibility of health services. In light of this, the following question was raised: What barriers to access and accessibility do individuals affected by leprosy encounter in meeting their healthcare needs? This study aimed to identify the access and accessibility challenges faced by individuals with leprosy in meeting their healthcare demands.

METHOD

This is a descriptive study with a qualitative approach, in which the *Consolidated Criteria for Reporting Qualitative Research* (COREQ)[13] tool served as a framework for reporting the study findings, proving to be relevant to the research development.

The research was conducted in four Basic Health Units (BHUs) located in the Guamá Administrative District (DAGUA), in the municipality of Belém, in the state of Pará. Belém is divided into 71 neighborhoods, which are distributed across eight Administrative Districts (ADs): Mosqueiro (DAMO), Sacramenta (DASAC), Entroncamento (DAENT), Outeiro (DAOUT), Icoaraci (DAICO), Bengui (DABEN), Belém (DABEL) and Guamá (DAGUA). These ADs are responsible for organizing health management across the municipality.[14]

The study included individuals over 18 years of age, enrolled at the BHUs and attending any shift, with an appointment scheduled during the data collection period. The exclusion criteria were: individuals with cognitive impairments or communication difficulties that would prevent participation in the study. Of the 45 individuals enrolled in the Leprosy Control Program (LCP) across the four selected Basic Health Units (BHUs), only 29 (64%) were present at the health units during the data collection period, thus constituting the study sample. No participants were excluded, and recruitment concluded once it was determined that sufficient data had been collected to achieve the research objective.[15,16]

The researchers were students and postgraduate nursing professionals, consisting of three females and two males. One of the male researchers was designated to conduct data collection, given his prior field experience and specialized training in data collection protocols.

Data collection took place between November 2021 and February 2022, through semi-structured individual interviews with an average duration of 30 minutes. The interviews followed a systematic script with closed-ended questions to identify sociodemographic profiles, along with five open-ended questions to capture the study's main focus. These questions explored participants' experiences as registered users of the BHUs, their perspectives on leprosy treatment, and the challenges and factors that facilitated or hindered their care. To ensure the script's effectiveness, a pilot test was conducted with four individuals affected by leprosy who were registered at the aforementioned BHUs. The pilot test participants were not included in the study sample, and no modifications to the script were necessary.

At the end of their nursing consultation, participants were personally invited to take part in the study and received a detailed explanation of the research. Those who agreed to take part signed an Informed Consent Form, allowing their statements to be recorded on electronic media (voice recorder). Interviews took place in a private consultation room at the health unit, ensuring participants' confidentiality, comfort, and privacy. Participants were identified by a code composed of the letter "U" (for user), followed by the sequential interview number and the initial of the corresponding health unit (G for Guamá, T for Terra Firme, J for Jurunas, and C for Cremação).

Profile data were analyzed using simple statistical methods and percentages. The interviews were transcribed in full and processed using IRAMUTEQ[17] *software* (Interface de *R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*), version 0.7 Alfa 2. This free, open-source program developed by Pierre Ratinaud enables graphical interpretation through the processing of textual data.[17]

To perform the analysis, Descending Hierarchical Classification (DHC) was chosen, considering words with chi-square (χ^2) values showing statistical significance at $p \leq 0.01$.[12] It is important to note that this type of analysis categorizes texts based on their respective vocabularies, segmenting the dataset according to the frequency of reduced word forms.[17]

The *software* generated a dendrogram linking lexical classes and produced results based on each of their descriptions, primarily using the vocabulary found in text segments—typically three lines long and automatically defined according to the *corpus* size. This process enabled the subsequent organization of classes into thematic categories, allowing the researchers to interpret the respective findings.[18]

Resolution No. 466/2012 of the National Health Council was applied, and the study was approved by the Research Ethics Committee of the *Universidade do Estado do Pará*, under approval number 5.063.941.

RESULTS

Most participants were male (62.1%); aged between 45 and 59 years (55%); married (59%); had incomplete primary education (79%); worked in informal jobs (44.8%), earned a monthly family income of one to two minimum wages (75.8%), and identified as Evangelicals (78%).

A total of 29 interviews were processed using the *software*, which divided them into 366 text segments, achieving a utilization rate of 81.18%. Based on the DHC, the *software* generated five classes. For the purposes of this article, class 5 was selected, titled "Experiences and Challenges: the perception of patients with leprosy" (Table 1). This class accounted for 22.56% of content retention, comprising 70 text segments. Its semantic content reflects participants' perceptions of the treatment provided by the BHUs—from access to services and interactions with healthcare professionals to the availability of health services such as health education initiatives and medication supply.

The terms "good" and "see" (verb) had the highest χ^2 values, 80.7 and 59.64, respectively. These lexical items suggest a sense of satisfaction with the leprosy care and treatment provided by the Basic Health Units (BHUs).

> *I see the treatment at this unit as very good, as I was always well cared for. They requested various tests across different healthcare areas, and the medicines are provided free of charge, which makes it much easier to continue the treatment* (U15J).
>
> *I see the treatment here at this health unit as wonderful. What I find particularly good is its proximity to my home and the fact that the service operates during the morning shift* (U13G).
>
> *I find it good that the medicine is free. If I had to pay for it, I wouldn't be able to afford it, plus I never had any issues picking up the medication* (U8T).

> *I consider the treatment at this health unit to be good. The service is quick, there has never been a shortage of medicine, and the professionals treat me very well* (U28C).

A conflict arises between the BHUs and the activities of the Leprosy Control Program (LCP), particularly regarding the principles of the Brazilian Unified Health System (Portuguese Acronym: SUS). Reports highlight operational limitations at the health unit, where leprosy care is limited to a single daily shift—either morning or afternoon—while priority is given to tuberculosis treatment in the mornings. This is reflected in the lexical items “afternoon”, with 10 occurrences, and “time”, with 11 occurrences. (Table 1).

> *Appointments don’t take long, but the downside is the time to pick up the medication: two in the afternoon. The sun is very strong at that time. I try to avoid sun exposure to protect myself* (U9G).
>
> *What I think is good about this basic health unit is that it’s close to my home and that appointments are only scheduled in the morning. But medicine pick-up is bad, as it can only be done in the afternoon* (U13C).
>
> *What I think is bad is the time for picking up the medication, as it can only be done in the afternoon. During this time, the sun is too strong. It could be scheduled a bit later or very early in the morning to avoid skin exposure to the sun* (U15J).

Table 1. Descending Hierarchical Classification (DHC) of Class 5, generated by Iramuteq *software*, Belém, Pará, Brazil, (n=31).

Words	F	χ2
Good	30	80.7
See (verb)	21	59.64
Here	21	38.63
Medicine	20	37.66
Well	14	33.7
Always	17	28.09
Unit	31	27.87
Find	7	26.69
Afternoon	10	24.68
Lack (verb)	14	23.13
Bad	11	19.33
Medication	13	18.47
Never	5	18.33
Time	11	17.5
Care	6	16.43
Talk (noun)	7	16.42

Source: IRAMUTEQ *Software* Report, version 0.7 alpha 2.0 (2021)

Participants reported that clofazimine caused skin darkening and dryness, largely due to difficulties in protecting themselves from sun exposure.

> *I can’t be exposed to the sun and must use sunscreen, as I can see that my skin is getting darker* (U2C).
>
> *My skin has darkened, but the nurse informed me that this happened due to the medication. Additionally, the disease affects my work, since I can’t be exposed to the sun, but I can’t afford to use sunscreen as it’s too expensive* (U8T).
>
> *I think it would be very good if the health unit provided a skincare kit, as leprosy dries out the skin, sunscreen is expensive, and not everyone can afford it. This makes it difficult [for me] to pick up the medication in the afternoon* (U9G).

The terms “unit” and “medication” are linked, highlight barriers to access and accessibility in leprosy treatment, as well as the challenges of seeing a specialist in rural areas and on the islands. The nearest health unit for residents in these areas does not provide this type of treatment, lacks qualified doctors to meet patients’ needs, and the BHUs frequently face shortages of supplies and materials.

> *My only means of transportation is a boat, which takes about 35 minutes to get there. The health unit on my island does not offer this type of treatment.* (U28C).
>
> *The bad thing is that I live in a rural area, and the boat takes 4 hours to reach this health unit. On one occasion, there was a medicine shortage, and I had to go to another unit to pick up my medication.* (U18J).
>
> *It takes me 35 minutes to get [to the health unit], and treatment is only offered in the afternoon, which makes it difficult because the river is more turbulent or the tide is low at that time; once, my boat even sank* (U28J).

The terms “bad” and “lack” (verb) reflect the challenges faced by participants, including conflicting information received since diagnosis, fear of medication shortages, concerns about treatment interruption, and insufficient information about potential reactions after starting treatment:

> *There were several conflicting pieces of information here; I had to go to different places to find out what I really had. To get my medication, I had to come to this health unit three days in a row, but each time I was given different information. I don’t think the treatment provided by the SUS is good. I’m afraid there will be a lack of medication* (U27T).
>
> *The bad part was when I started taking the medication—more nodules appeared, my face became swollen and red, and I didn’t know what was going on. I had to return for a*

> *medical consultation, and they prescribed a corticosteroid, which made things better. They could have warned me that this would happen, but no one told me anything* (U22J).
>
> *The bad thing was that it took them a long time to figure out what I had. Then they started the treatment, and I noticed that the spots had increased in size and number, becoming darker, while my skin also darkened. They should provide better information about what could happen during treatment* (U6G).

At the time of diagnosis, patients often experience doubts and uncertainty about the disease and its treatment. Along with the lack of information about potential side effects during treatment, the term "talk" (noun) is identified, highlighting the absence of educational initiatives on leprosy at the BHUs, in contrast to what is provided at the Referral Unit.

> *As for areas that need improvement, it would be helpful if there were educational talks about the disease, similar to what they do in Marituba. Everything I know about the disease, I learned there. They explained everything all about leprosy and how it is transmitted, but here they just give you the medication and send you home. They don't explain anything about the disease* (U2G).
>
> *At the Marituba Health Unit they hold talks about the disease, show pictures, and hand out leaflets. I've never seen anything like it at this unit. I believe this could improve health education, which is crucial for ensuring that people are well-informed* (U7T).
>
> *To improve, they could create posters like the ones I saw at the Leprosy Referral Unit, and also provide talks, share information, offer guidance on scheduling exams, and explain the disease* (U10J).
>
> *It would be much better if they explained things to us here at this healthcare unit; I see that in other units, they often give talks and provide a lot of information to patients. I believe that by doing so, many of our problems would be resolved* (U4C).

DISCUSSION

The sociodemographic profile of leprosy patients from the four BHUs in DAGUA was analyzed. The majority of cases were among married males, aged between 45 and 59, with incomplete primary education and a monthly family income ranging from one to two minimum wages. A study conducted in the state of Piauí, which aimed to characterize the epidemiological indicators of 17,075 new leprosy cases, found a similar trend in the distribution of cases by gender, age group, marital status, and education level.[19]

The factors influencing user satisfaction levels at BHUs in Brazil are closely related to how these units are managed. Key elements include the personal and professional treatment provided by healthcare teams, waiting times, respect for privacy, a kind and welcoming reception, attentive listening; clear guidance on an effective care pathway that ensures resolution and a humanized, compassionate approach to care.[20]

Expanding the use of a compassionate approach as a strategy to strengthen healthcare practices is one of the keyways to improve performance and enhance the system's ability to deliver effective solutions. Welcoming individuals affected by leprosy in PHC makes it possible to address both their specific needs and those of a certain region. Since PHCs serve as the main point of entry to the healthcare system, it is essential to promote a welcoming and compassionate approach to reduce inequalities and ensure comprehensive care.[21,22]

A study conducted in the state of Pernambuco, Brazil, which analyzed healthcare practices for patients with leprosy, emphasized that a welcoming approach is essential, as it helps minimize the risk of gaps in care and delays in diagnosing potential cases. Moreover, it creates opportunities to strengthen bonds between healthcare professionals, service users, and their families, reinforcing the foundations of health promotion efforts within the community.[23]

It is important to highlight that activities within Primary Health Care (PHC) encompass both individual and collective dimensions, including health promotion and protection, disease prevention, diagnosis, treatment, rehabilitation, and the maintenance of overall health. From this perspective, the principles of universality, accessibility, and coordinated care for patients with leprosy serve as the foundation, ensuring continuity of care and strengthening the bonds between patients and healthcare providers.[24]

The absence of an effective welcoming approach and the fragility of relationships within Primary Health Care (PHC) often push users to rely on specialized referral services as their primary point of entry, despite the need to overcome geographical barriers and cover transportation expenses.[25] Providing leprosy treatment within PHC is essential, and the proximity of basic health units to residents enhances access, reduces overcrowding at other levels of care, and ensures continuous support for individuals requiring ongoing treatment for chronic conditions.[26]

Healthcare services dedicated to the treatment and control of leprosy should prioritize easy access for patients by offering continuous care and regularly scheduled follow-up appointments, as Primary Health Care (PHC) serves as the main point of entry into the healthcare network.[27] One of the challenges in controlling the disease is the limited availability of patient care, with restricted hours that hinder the continuity of treatment. This issue contradicts the principles of the Brazilian Unified Health System (SUS) and the guidelines of the National Strategic Plan for Leprosy Control, which aim to implement tailored control measures based on the epidemiological characteristics of leprosy in each region and address the specific operational challenges of each locality.[28]

A review study on access to care in Primary Health Care (PHC) identified bureaucratization as a major barrier to care. This is evident in the limited service hours, which pose challenges for users whose work schedules conflict with those of the health units. Furthermore, the tradition of providing care exclusively through face-to-face interactions has resulted in a rigid and inflexible approach that fails to meet the population's needs, thereby hindering access and limiting the delivery of healthcare.[21]

Expanding service hours to include evenings and weekends could lead to improvements in care. However, for this process to be implemented, financial investment is required to recruit human resources and establish new health units.[29] These modifications would not only expand access for patients with leprosy but also enhance their welcoming process, ensuring greater autonomy, the protection of their rights, and the promotion of shared responsibility in health care provision.[30]

There is limited research focusing on the extension of service hours in Basic Health Units (BHUs). However, a study conducted in João Pessoa, Paraíba, on the impact of extending health unit hours into the evening shift, found a notable increase in service demand, especially among the male population. These results suggest that offering alternative hours is an effective strategy to improve access to care, especially for workers who cannot attend health units during standard business hours.[31]

Leprosy treatment consists of a combination of medications that may lead to various side effects, one of which is skin darkening. Although reversible, this side effect becomes a physical and stigmatizing mark that can lead to feelings of dissatisfaction among patients undergoing treatment.[3,32] A study conducted in Colombia with 17 individuals affected by leprosy found that hyperpigmentation caused by clofazimine led to distress, as it sparked fears of exposure, discrimination, and social stigma.[33] Another study reported that out of 305 people with leprosy, 49% experienced mental suffering, 27% faced social isolation, and 52% dealt with significant stigma.[34] Stigma symbols are described as characteristics that convey negative social perceptions.[35] Skin hyperpigmentation, along with other deformities resulting from leprosy, contributes to reinforcing the stigma surrounding the disease.

Furthermore, most participants (79.3%) experience financial constraints, earning less than the monthly minimum wage. As with many public health service users, numerous individuals with leprosy struggle to afford protective products for their skin, face, and hands such as sunscreen and moisturizers, which are essential to prevent the darkening and dryness caused by treatment.[33]

In addition to financial constraints, geographical conditions also influence access to healthcare services. In the North region, a significant portion of intra- and intermunicipal travel takes place by river or road, both of which can be difficult to navigate in certain areas. Users face several challenges in accessing PHC services, including long distances, prolonged travel times, inadequate and expensive transportation to riverside or rural communities, all of which are further exacerbated by the region's seasonal conditions.[36]

In the state of Pará, 50% of municipalities are home to populations living along riverbanks, whose livelihoods rely on fishing, resource extraction, and agriculture.[36] Their way of life, combined with the geographical remoteness from urban centers, exposes them to various vulnerabilities resulting from the lack of effective public policies, inadequate sanitation, limited access to electricity, and insufficient healthcare services—factors that hinder both their engagement with and the continuity of care within PHC.[37]

A study conducted in the state of Acre, aimed at characterizing the organization of PHC for populations living in remote and hard-to-reach areas, also identified several barriers related to transportation. These barriers include the high cost of transportation, the stress caused by traveling long distances to reach the referral health unit, and the uncertainty of receiving care on days without a scheduled appointment. These findings emphasize the significant impact of geographic factors on access to healthcare services.[38]

In other countries, such as Australia—despite cultural, historical, political, and social differences—rural populations have also experienced negative impacts caused by geographic variation. This underscores the role of geography as a barrier to healthcare access for these populations.[39]

An analysis of the geographic distribution of Primary Health Care services shows that Family Health Strategies are predominantly concentrated in metropolitan areas.[40] This heterogeneous distribution reinforces social inequalities by limiting access to healthcare services for specific populations, including Indigenous peoples, Afro-Brazilian communities (*quilombola*), Romani populations, and those living in rural, forest, and riverside areas.

A systematic review of PHC attributes revealed significant disparities in access to and utilization of healthcare services across various countries, often linked to the type of service offered. Expanding healthcare coverage is essential to reduce these disparities, as it can help mitigate access inequalities caused by social inequities.[41]

In addition to geographic barriers, social stigma, and disease-related discrimination, other factors also contribute to delays in leprosy diagnosis. These factors are interconnected with both healthcare services and individual behaviors. Studies indicate that key individual factors linked to delayed diagnosis include gender, age, failure to seek care upon noticing initial symptoms, and fear of receiving the diagnosis.[42,43] On the healthcare service side, delays are often associated with the lack of immediate care during the first visit, excessive referrals to other specialties, and the need for multiple appointments to confirm the diagnosis.[8,43] Collectively, these factors are particularly concerning, as they not only delay diagnosis but also significantly increase the risk of developing disabilities.

When examining the time interval between the onset of symptoms and the final diagnosis, a study conducted in China to explore the spatial and temporal characteristics of leprosy from 2010 to 2020 found diagnostic delays ranging from two to four years, despite China being one of the countries with the highest burden of the disease globally.[44] In contrast, a study conducted in India found that the time to diagnosis from the onset of symptoms was only three months.[45] The difference in diagnostic timelines can be attributed to the level of training of healthcare professionals who manage suspected cases, confirmed cases, and close contacts of individuals affected by leprosy, as they play a crucial role in the effective implementation of disease control measures.

Leprosy treatment with U-MDT can trigger acute inflammatory symptoms known as leprosy reactions or reaction episodes, which result from the body's immune response to the bacillus. Although the exact cause remains unknown, these reactions can be identified early and treated, preventing permanent damage to individuals.[3]

A portion of individuals affected by leprosy struggle to differentiate between the symptoms of the disease and leprosy reactions. This affects how patients respond to their treatment, fostering doubts and reinforcing the stigmatizing nature of the disease. Therefore, professional training is crucial to help patients understand potential reactions, clarify their underlying causes, and emphasize the importance of self-care in preventing disabilities and managing possible side effects.[1,3]

The results of this study indicate that while the care provided by professionals is generally good, a key aspect of the welcoming process—providing comprehensive information about treatment and care, including health education—is often perceived as lacking by users. Health education is an essential activity that strengthens the bond between the patient and the professional. The lack of guidance on leprosy management underscores the need for effective health education practices within Primary Health Care. Health education targeted at the population, along with ongoing training for professionals at all levels of care, enhances early detection of leprosy, reduces diagnostic waiting times, and accelerates the overall diagnosis process.[21]

Providing care that addresses the educational, behavioral, psychological, and social aspects of individuals affected by leprosy, as well as the needs of their families and society at large, is crucial for ensuring effective treatment and promoting the reintegration and inclusion of these individuals into society.[46] Through continuous training and professional development, nurses, as integral members of the multidisciplinary team, can be better equipped to diagnose and manage leprosy. This enables them to establish training programs and set goals for the healthcare team while fostering trust-based relationships with patients.[46]

This study reinforces the findings of an analysis conducted over a decade ago, emphasizing the limitations in accessibility and regionalization within the healthcare network, as well as the persistent regional disparities.[10] Furthermore, it underscores the intrinsic connections between nursing (as both the science and art of care), health, politics, and society.

FINAL CONSIDERATIONS AND IMPLICATIONS FOR PRACTICE

Receiving care through the Brazilian Unified Health System (Portuguese Acronym: SUS), accessing medications, and being well cared for by healthcare professionals are key factors that foster a welcoming environment and ensure patients' right to health is respected. However, physical impairments, the stigma caused by the disease, and difficulties in accessing and navigating treatment represent significant barriers. Territorial and regional challenges must be addressed to ensure the effective implementation of leprosy control measures within PHC. An urgent review of the scheduling process is needed, with the introduction of flexible service hours for consultations and medication distribution. This approach should be complemented by ongoing professional training and health education for users, creating opportunities for dialogue, information sharing, and raising awareness about the disease, its treatment, and all related care. This will ensure that users' needs are duly addressed and that they increasingly feel welcomed and supported within the PHC system.

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DATA AVAILABILITY RESEARCH

The contents underlying the research text are included in the article.

CONFLICT OF INTEREST

None conflict of interest.

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