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ORIGINAL ARTICLE

THE COVID-19 PANDEMIC AND THE FOLLOW-UP OF PEOPLE AFFECTED BY LEPROSY IN HEALTH SERVICES

HIGHLIGHTS

1. COVID-19 has caused difficulties in monitoring leprosy patients.
2. Patients don't fully understand the repercussions of leprosy.
3. Patients are apprehensive about the repercussions of leprosy.

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ABSTRACT

Objective: To analyze the follow-up of people affected by leprosy in health services during the COVID-19 pandemic. **Method:** This is an exploratory, descriptive study with a qualitative approach, carried out in Basic Health Units and the Leprosy Reference Service in Campina Grande-Paraíba - Brazil. Data collection between October 2021 and February 2022. The study population consisted of users undergoing treatment and being monitored for leprosy reactions. The data was analyzed using Bardin's Content Analysis. **Results:** Three categories emerged: users' lack of knowledge about leprosy and its control, their feelings about the disease and treatment, and weakened leprosy control in Primary Health Care. **Conclusion:** We observed fragility in the follow-up of users affected by leprosy, related to the lack of medication and professionals, as well as the user's perception of the disease.

KEYWORDS: Leprosy; COVID-19; Health Services; Pandemics; Patient.

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INTRODUCTION

Given the historical process of leprosy, access to the Brazilian health system for people affected by the disease is still considered difficult due to the long road to diagnostic confirmation and timely treatment[1]. The pandemic caused by the coronavirus, SARS-CoV-2(Severe Acute Respiratory Syndrome Coronavirus 2), in Brazil has caused barriers to control numerous health problems that need continuous monitoring and comprehensive attention in health services.

Among the main public health problems is leprosy, whose etiological agent is *Mycobacterium leprae*, which mainly affects the skin and peripheral nerves, with the capacity to cause neural and dermatological lesions, which gives it a high incapacitating power, responsible for the stigma and discrimination against people affected by the disease[2].

In 2020, 127,396 new disease cases were reported to the World Health Organization (WHO) worldwide. Of these, 19,195 (15.1%) occurred in the Americas region, and 17,979 were reported in Brazil, corresponding to 93.6% of the number of new cases in the Americas. Brazil, India, and Indonesia reported over 10,000 new cases, corresponding to 74% of the new cases detected in 2020. In this context, Brazil ranks second among the countries with the highest number of cases globally, behind only India[3].

Based on the epidemiological indicators and the disease's social impact, Brazilian public health management, following the WHO's recommendations for eliminating the disease, has, over the years, intensified the creation of proposals and strategies for strengthening and integrating Leprosy Control Actions (LCAs) in health services.

It should be noted that despite WHO recommendations and efforts to produce strategic plans, Brazilian states and municipalities still have worrying epidemiological and operational indicators. Progress in early diagnosis and timely treatment is necessary, especially in Primary Health Care (PHC), considered the main gateway to the Unified Health System (SUS)[4].

Studies carried out in Brazil show that LCAs need to advance in the context of PHC[5-7], given problems such as late diagnosis, increased diagnosis in children under 15 years of age, initial diagnoses with an affected degree of disability, interruption, abandonment of treatment and follow-up of leprosy in secondary care units.

Considering that leprosy is a disease that requires early diagnosis, that care for people undergoing treatment must be continuous, and that the COVID-19 pandemic has brought changes to the lives of people, professionals, and health services, it is essential to know how users have been monitored, since based on the advances and weaknesses identified, new care proposals can be discussed among users, professionals, and health managers, to guarantee comprehensive care and control of the disease in the population.

Given this, and to guide the construction of this study, the need arose to understand how people affected by leprosy were monitored during the COVID-19 pandemic. To contemplate this understanding, this study aimed to analyze the follow-up of people affected by leprosy in health services during the COVID-19 pandemic.

METHOD

This is an exploratory-descriptive study with a qualitative approach based on the health promotion and health surveillance policy related to leprosy control actions and the COVID-19 pandemic, developed in Basic Health Units (BHU) and the Leprosy Reference Service of Campina Grande/PB between December 2021 and February 2022.

The care network in the city of Campina Grande is structured by. It comprises levels of health care: Primary Health Care, Secondary Health Care, and Tertiary Health Care (Brazil, 2010), divided into seven Health Districts (HD).

The municipality currently has 119 Family Health Teams (FHT), representing 77.23% of population coverage. The Secondary and Tertiary levels of health refer to specialized outpatient and inpatient care. They are the backbone of PHC, supporting the diagnosis and treatment of diseases and conditions specific to certain population groups[8].

Initially, contact was made with the coordinators of the Leprosy Control Program (LCP) to identify the BHUs with users undergoing leprosy treatment. After identifying the BHU, a simple random sampling was carried out, defining the Health Units by HD with leprosy cases in treatment. Of the seven HDs, only HD IV had no users on the active register, i.e., in treatment. As a result, the survey was only carried out in six HDs. A BHU was drawn from each HD. Of these, five had a family health team, and one BHU had three teams, two of which participated.

In addition to the BHU, the only reference center in the municipality that treats leprosy complications was selected. It should be noted that the BHU in the rural area was not included, as they had no records of leprosy cases.

The population consisted of users in active treatment for the disease who had completed treatment and cases being monitored for leprosy reactions. Given the total number of teams working in PHC and considering the inclusion and exclusion criteria, the sample consisted of 11 users: seven from PHC and four from secondary care.

Regarding inclusion criteria, we considered users with a diagnosis of leprosy classified as Paucibacillary (PB) and Multibacillary (MB), as well as those who have completed treatment and are being monitored for reactional episodes. Those under 18 were excluded, as were users with health problems who could not participate in the interview and users who were being monitored at the Leprosy Reference Service but lived in another municipality.

Two instruments were developed to enable data collection: a questionnaire to characterize the study participants and an interview script to learn about the challenges users faced in monitoring leprosy during the COVID-19 pandemic.

The survey instrument was administered at the BHU and the Reference Center in a reserved place, according to the availability and interest of the study participant, using a dual input digital recorder.

The data related to the characterization of the study participants were analyzed descriptively. The data from the interviews were analyzed using the Content Analysis (CA) proposed by Bardin9, whose analysis technique has three stages: pre-analysis, exploration of the material and treatment of the results obtained, and inference and interpretation.

When transcribing the interviews, we used the naturalistic transcription method, which corresponds to a detailed transcription of what is said and advocates preserving the different elements of the interview beyond the verbal content[10].

The Alcides Carneiro University Hospital Research Ethics Committee of the Federal University of Campina Grande approved the study: 4.629.355. To preserve each participant's identity, the letter U (User) was used, followed by the number corresponding to the order of the interviews.

RESULTS

Of the total number of participants in the survey, six (54.6%) were female. In terms of age group, the highest number of cases of people affected by leprosy was found in the 60 and over age group, five (45.5%), followed by the 30 to 39 age group and the under 29 age group, both with two (18.2%).

The study participants' levels of education and schooling were as follows: two had completed high school (18.2%), four had completed elementary school (36.4%), three had not completed elementary school (27.2%), and two were not literate (18.2%).

Considering the forms of leprosy, six (54.6%) of the study participants were diagnosed with the dimorphic form, one (9%) with the indeterminate form, and four (36.4%) were undergoing reactive treatment.

The analysis of the interviews revealed a greater and more significant number of Record Units (URs) within certain contexts and themes, which is precisely what determined the units of meaning. Three (3) categories were defined: users' lack of knowledge about leprosy and its control actions, users' feelings about the disease and leprosy treatment, and Weakened leprosy control in Primary Health Care.

Category 1 - Users' lack of knowledge about leprosy and its control actions

Category 1 brings together statements about the lack of knowledge of people affected by leprosy about clinical aspects, correct treatment, complications of the disease, and the cure, as we can see in the statements below:

[...] Sometimes I don't understand anything; some say it cures, others say it never cures. (U3).

[...] They say we get well from leprosy, but we don't; we always have sequelae (U9)

[...] I used to take half of one because it was missing, right? Then I'd take it, and instead of taking one pill, I'd split it up, I'd start in the middle and take a band, and the next day, I'd take another so I wouldn't miss it; that's how it went (U4).

Category 2 - Users' feelings about the disease and leprosy treatment

This category was built from the participants' statements about the feelings that emerged after being diagnosed with leprosy, whether about the prejudice, stigma, and fear caused by the historical context of the disease or the treatment of the disease itself:

[...] Whether they like it or not, when people look at a person, they already have that look: what's wrong with him? Will I get it? Am I going to get infected? It was quite difficult

because of that, but I got my head up and I know that there is treatment and that I'll be cured. (U7).

Category 3: Leprosy control weakened in Primary Health Care during the COVID-19 pandemic

Category 3 addresses situations that have hindered the continuity of leprosy treatment in PHC during the COVID-19 pandemic, as shown in the reports below:

[...] here at the clinic they don't do the treatment, I just go to get the medical records and every month I go to the other doctor.

[...] I stopped for two months because the medication was missing, and then it came back to normal; when I went to the clinic, they said that the treatment would start from scratch. (U5)

DISCUSSION

The analysis of this study's results culminated in creating three distinct categories for discussing the qualitative data, making it possible to distinguish between the different problems encountered in the interviews.

Category 1, "Users' lack of knowledge about leprosy and its control actions," shows that people affected by the disease lack knowledge about clinical aspects, correct treatment, complications, and cure.

Corroborating the results of this article, a study[12] carried out in 2021 highlighted that low levels of education and schooling are directly linked to LCAs since this problem leads to fragile living conditions, difficulty in renting and transportation, a deficit in self-care and a lack of knowledge to understand the health/disease process, which would result in a decreased chance of late treatment.

Given the knowledge deficit identified in the statements in this category, it should be emphasized that access to information is essential for promoting comprehensive health care. To provide it properly, it is important to empower the user, strengthen their role in care, and have them as an ally in the care process[13].

In the context of the SUS, information related to health and disease can be provided individually and collectively through health education, which aims to provide knowledge and reflections between professionals and users for adopting new health habits and behaviors[14].

A study carried out in 2020 highlights that health education contributes to the formation of a critical sense of one's health problems and how to deal with them. It makes people reflect on their health and disease situation and seek solutions together with professionals, family, and community[15].

Despite the numerous strategies implemented regarding health promotion, research in Brazil emphasizes health education as a basic and priority tool for promoting health and preventing illness in individuals, families, and the community[16-17].

A 2021 study, based on a health education action promoted at a BHU on the outskirts of Fortaleza, Ceará, in a municipality in Paraíba, about the population's knowledge, found a lack of knowledge about the transmissibility, signs, and symptoms of leprosy and highlighted the need for health education for early diagnosis and treatment[18].

A study based on an experience report from the "Roda Hans/Carreta da Saúde -Hanseníase" project in Paulo Afonso, Bahia, showed that there is still a great deal of misinformation about the signs and symptoms of leprosy, as well as a great deal of stigmatization about the disease, both on the part of health professionals and the population. The same project found that, once health education measures were implemented, there was a satisfactory increase in knowledge, favoring prevention, early diagnosis, and correct treatment by users and health professionals[19].

A study carried out in a hyperendemic city in the northwest of São Paulo showed that among 234 medical records of leprosy patients evaluated between 2013 and 2017, 35 (15%) of users interrupted and abandoned treatment. Given the consequences of interrupting and abandoning treatment, health services must implement measures to mitigate the reasons for interruption or abandonment, thus contributing to adherence to treatment and breaking the epidemiological chain of transmission of the disease[20].

Leprosy abandonment and ineffective treatment have collective and individual consequences, such as continued transmission of the disease, sequelae and physical disabilities, and the risk of developing bacilliferous forms that are resistant to the drugs used in treatment[20].

Bearing in mind that leprosy leaves physical, mental, and social marks and requires long-term care, it is up to health professionals to value health education and provide specific information on controlling the disease, taking into account the socio-cultural conditions of people, families, and the population, so that everyone understands what the disease is and the importance of correct treatment[21].

Considering the adjustments made by the Ministry of Health and the Brazilian Leprosy Society in Brazil to contain the spread of COVID-19, some strategies have been established to control leprosy in health services. Among the guidelines is the maintenance of multidrug therapy (MDT), whose service and delivery of the blisters at the PHC followed the planning carried out by the health team, respecting the safety standards and the vulnerable situation of each user undergoing treatment. As for the referral services, they ensured that scheduled users were followed up even during the public health emergency[3,26].

Some successful experiments were carried out in Brazilian municipalities after the critical period of the COVID-19 pandemic to reduce leprosy's hidden prevalence, understood as the number of cases circulating in the community but not detected by health services.

Category 2, "Users' feelings about the disease and leprosy treatment", reveals the feelings of people affected by leprosy, whether about prejudice, stigma and fear caused by the historical context of the disease or the treatment of the disease itself.

Over the years, prejudice, discrimination, and lack of information have become ingrained in the social construction of leprosy, and these factors make it extremely difficult to cope with the disease. On these aspects, a study carried out in 2020 showed a historical analysis of the prevention of physical disability due to leprosy in Brazil and highlights that this disease has a major impact on various areas of people's lives, whether in social relationships, the workplace, or even the family. The negative impacts on people's lives are caused by the historical context of the disease, which remains present in the social imagination as a mutilating disease that has no cure, resulting in rejection, discrimination, and social exclusion[21].

The analysis of the speeches shows that leprosy causes feelings of sadness, fear, and exclusion since users emphasize that being affected by the disease makes them feel different and neglected. So, their perception of being ill is surrounded by negative feelings, the presence of emotions such as sadness and fear, which can contribute to low esteem and depressive processes.

Corroborating the study's results, a survey carried out in 2021, based on a literature review, found feelings of fear, inferiority, and sadness that coexist with discrimination and lack of information about leprosy. These feelings, experienced daily, make people withdrawn, shy, and unmotivated and sometimes alienate them from family, close friends, and work, reinforcing suffering and psychological illness[22].

It's worth noting that because of the physical, emotional, and psychological effects of the disease, users and families affected by the disease seek support in a variety of ways, including their spiritual beliefs. A study carried out in 2023 looked at the quality of life of people with leprosy at the Hospital Colônia de Carpina, in Piauí, and found that patients' religiosity and spirituality served as tools to overcome and resist the adversities they experienced. In this way, we can see the significant effects that beliefs can have on people's health[23].

During the COVID-19 pandemic, researchers from Brazil and around the world have highlighted in their studies the negative impacts that have emerged in the lives of thousands of people and families due to coping with the pandemic. There has been an increase in depression and anxiety due to the fear of falling ill as a result of infection with the new coronavirus and the fear of complications due to pre-existing illnesses, which require even more care and attention from health professionals[24].

Faced with the complexity of leprosy, we need to take a critical and reflective view since treatment goes beyond a therapeutic regimen to obtain a cure. It should be noted that prejudice and social exclusion are still ingrained in society, which has devastating consequences for the physical and mental health of people affected by leprosy.

Category 3, "Weakened leprosy control in Primary Health Care during the COVID-19 pandemic", addresses situations that have hindered the continuity of leprosy treatment in PHC during the COVID-19 pandemic.

In their speeches, the study participants mentioned some difficulties faced by people affected by leprosy in continuing treatment in PHC during the COVID-19 pandemic. These difficulties include the temporary lack of medication and the absence of a health professional.

In the Brazilian health system, PHC is the first level of health care, and its objective is to develop comprehensive care that positively impacts communities' health. It is considered the center of communication with the entire Health Care Network[3].

Considering that PHC must fulfill its functions of solving the population's health problems, organizing the flows and counterflows of users in the Health Care Network (RAS), and being responsible for the health of users and the population during the COVID-19 pandemic, the MS and the Brazilian Leprosy Society[3,25], at the beginning of the pandemic issued technical notes guiding and recommending how health teams should carry out leprosy control actions. The main recommendations include supervised dosage and treatment of leprosy reactions.

Regarding the lack of doctors in PHC, a review carried out in 2022 sought to analyze the longitudinality of care in the face of the turnover of professionals in the Family Health Strategy. It showed a turnover of this professional in health units in all regions of Brazil. This situation compromises the relationship between the teams and the population, hindering the achievement of the expected results in PHC, since at this level of care, the focus should be on the person, the family, and the community, where a close link between them and the health professionals is valued[26].

Proper treatment of users diagnosed with leprosy is considered fundamental to interrupting the chain of transmission of the disease. It is, therefore, strategic in controlling the endemic and eliminating leprosy as a public health problem. Because of its long duration, adherence to the correct treatment is essential to cure leprosy[27].

Even recognizing the various weaknesses faced by PHC in the face of the COVID-19 pandemic, it is necessary to reinforce that the teams working at this level of care play a fundamental role in ensuring that leprosy control actions are carried out effectively.

This study's limitations include the small number of users interviewed and the difficulty in collecting information at the time it was carried out due to the pandemic.

FINAL CONSIDERATIONS

This study has shown that the COVID-19 pandemic has caused some difficulties in caring for and treating people affected by leprosy. The difficulties experienced by people led to interruptions in treatment due to a lack of medication, inadequate treatment due to a lack of guidance, and difficulties in getting a medical assessment at the PHC due to the absence of this professional. This situation contributes to a regression in disease control, an increase in transmission, and a negative impact on PHC.

It was possible to see that people affected by leprosy have a lack of knowledge about the disease itself, and due to the historical context of the disease, they feel discriminated against by society.

With the implementation of social isolation regimes to avoid contagion by the new Coronavirus and other strategies, such as the reorganization of health units to accommodate better those affected by the pandemic, the population has been less adherence to care for other conditions, especially chronic diseases such as Hansen's disease.

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