

# Leprosy and COVID-19: repercussions on the lives of affected people and promotion of interventions

*Hanseníase e COVID-19: repercussões na vida de pessoas afetadas e promoção de intervenções*

*Lepra y COVID-19: repercusiones en la vida de las personas afectadas y promoción de intervenciones*

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## ABSTRACT

**Objective:** to analyze the repercussions of COVID-19 on the lives of people affected by leprosy and to promote interventions to cope with the problems experienced by users. **Method:** qualitative study of the participant research type, carried out from December 2021 to June 2022 in the metropolitan region of Recife in eight reference health services for leprosy. Semi-structured interviews, telemonitoring and interventions were carried out in self-care groups with users affected by leprosy, and workshops with professionals and managers. **Results:** there were financial repercussions, on access to health services and on the socialization of users. Interventions carried out with users promoted better knowledge practices about the pathology, empowerment and self-care. The workshops with managers and professionals facilitated the resumption and implementation of new self-care groups, activities compromised in the pandemic period. **Conclusion:** COVID-19 had repercussions on the financial situation, socialization and access to health services, with a worsening of the situation of social vulnerability and isolation, already present in the context of leprosy.

**Descriptors:** COVID 19; Delivery of Health Care; Leprosy.

## RESUMO

**Objetivo:** analisar as repercussões da COVID-19 na vida das pessoas afetadas pela hanseníase e promover intervenções de enfrentamento aos problemas vivenciados pelos usuários. **Método:** estudo qualitativo do tipo pesquisa participante, realizado de dezembro de 2021 a junho de 2022 na região metropolitana de Recife em oito serviços de saúde de referência para hanseníase. Realizaram-se entrevistas semiestruturadas, telemonitoramento e intervenções nos grupos de autocuidado com usuários acometidos pela hanseníase, e oficinas com profissionais e gestores. **Resultados:** observaram-se repercussões financeiras, no acesso aos serviços de saúde e na socialização dos usuários. As intervenções realizadas com usuários promoveram melhores práticas de conhecimento sobre a patologia, empoderamento e autocuidado. As oficinas com gestores e profissionais propiciaram a retomada e implementação de novos grupos de autocuidado, atividades comprometidas na pandemia. **Conclusão:** a COVID-19 trouxe repercussões na situação financeira, socialização e acesso a serviços de saúde, com piora da situação de vulnerabilidade social e isolamento, já presentes no contexto da hanseníase.

**Descritores:** COVID-19; Assistência à Saúde; Hanseníase.

## RESUMEN

**Objetivo:** analizar las repercusiones del COVID-19 en la vida de las personas afectadas por la lepra y promover intervenciones para el enfrentamiento de los problemas vividos por los usuarios. **Método:** estudio cualitativo de tipo investigación participante, realizado de diciembre de 2021 a junio de 2022 en la región metropolitana de Recife en ocho servicios sanitarios de referencia para la lepra. Se realizaron entrevistas semiestructuradas, telemonitoreo e intervenciones en grupos de autocuidado junto a usuarios afectados por lepra y talleres con profesionales y gestores. **Resultados:** hubo repercusiones financieras en el acceso a los servicios de salud y en la socialización de los usuarios. Las intervenciones realizadas con los usuarios promovieron mejores prácticas de conocimiento sobre la patología, empoderamiento y autocuidado. Los talleres con directivos y profesionales facilitaron la reanudación e implementación de nuevos grupos de autocuidado, actividades comprometidas en la pandemia. **Conclusión:** el COVID-19 tuvo repercusiones en la situación económica, socialización y acceso a los servicios de salud, con empeoramiento de la situación de vulnerabilidad social y aislamiento, ya presente en el contexto de la lepra.

**Descriptorios:** COVID 19; Atención a la Salud; Lepra.

## INTRODUCTION

Leprosy is considered an infectious, transmissible and chronic disease caused by the *Mycobacterium leprae* bacillus, which preferentially affects the skin, eyes and peripheral nerves. In 2020, 127,396 new cases of the disease were reported to the World Health Organization (WHO), of which 19,195 (15.1%) occurred in the Americas region, with Brazil representing 93.6% with 17,979 cases. In this context, Brazil ranks second in the list of countries with the highest number of cases of the disease, only behind India<sup>1</sup>.

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In Brazil, in 2021 the state of Pernambuco was in fourth place both in the number of new cases in the general population, with 1,276 cases, and in the detection of new cases in children under 15 years old, with 55 cases<sup>1</sup>. The state still has geographic health inequalities and, in socioeconomic terms, 27.17% of all households live in poverty, being considered a 'hyperendemic' leprosy area. These factors favor increased infection and transmission rates for the disease, hindering the WHO<sup>2</sup> efforts to eradicate leprosy.

It is worth mentioning that Pernambuco is located in northeastern Brazil, a region with high burden of the disease, with more cases observed in places with populations that have different vulnerability dimensions. This corroborates with the maintenance/expansion of the cycle of poverty, risk of illness and development of physical disabilities, aspects that are typical of neglected tropical diseases<sup>3</sup>.

In addition to its high prevalence, leprosy also has a stigmatizing burden that is directly linked to its high disabling power, causing nerve damage that, if not timely treated, can lead to disabilities and deformities. In addition to dermato-neurological involvement, it is also possible to observe the presence of mental health repercussions caused by physical disabilities and sequelae that can be related to social stigma, which acts as a strong factor in compromising the daily activities of people affected by the disease and their integration into social life<sup>4</sup>.

It is worth mentioning that the pandemic of the disease caused by the type 2 coronavirus (COVID-19) exerted a direct impact on the management of several chronic diseases, including leprosy, mainly caused by social distancing, adopted as a primordial measure to control spread of the virus at the beginning of this period, but also due to other factors such as difficulty accessing certain health services and procedures considered elective, in addition to the fear of the population in seeking health units<sup>5</sup>. Maricato<sup>6</sup> points out that an open letter was addressed to the UN reporting on the concern about the impacts of the pandemic on the treatment of patients with leprosy, considering the difficulties accessing the medications and health care required by the pathology in therapeutic follow-up.

It is therefore reinforced that the COVID-19 pandemic generated a series of changes in the political, social and economic scopes, with important negative effects for the most disadvantaged population layers, extrapolating the field of health policies, which substantially affected leprosy patients in different social contexts<sup>6</sup>.

Within the context presented, the objective of this study was to analyze the repercussions of COVID-19 on the lives of people affected by leprosy and to promote interventions to cope with the problems experienced by users.

## METHODS

A participatory research was carried out, of the multiple case study type and with an exploratory and qualitative character<sup>7</sup>. Participatory research is characterized as a modality in which the individuals involved participate actively by identifying and critically analyzing their problems in search of solutions. This active participation of the subjects fundamentally aims at emancipation of the participating people/communities<sup>8</sup>.

Methodologically, the participant research was developed in the following phases<sup>8</sup>: discussion of the research project; definition of the theoretical framework, with the objectives, concepts and methods; delimitation of the region to be studied; organization of the research process (institutions and groups to be associated, distribution of tasks, sharing of decisions; selection and training of researchers or research groups; and, finally, preparation of the operations schedule.

Initially, a meeting was held between the research team, volunteers from the Movement for the Reintegration of People Affected by Hansen's Disease (MORAHN), managers linked to the Leprosy Control Program in Recife and health professionals from reference services in leprosy at the municipality, for presentation and discussion of the project, as well as planning for the approach with users and service professionals in the face of the problems faced due to the pandemic. Together, the study objectives, locus, methodology to be used and subsequent steps for data collection and interventions were defined.

The study locus was the metropolitan region of Recife (Pernambuco, Brazil), in eight health services, namely: six reference units for leprosy with a concentration of cases of the disease in Recife (Pina Polyclinic, Gouveia de Barros Polyclinic, Salomão Kelner Polyclinic, Albert Sabin Polyclinic, Lessa de Andrade Polyclinic and Clementino Fraga Polyclinic); Otávio de Freitas Hospital, a state reference for leprosy in Pernambuco; and the Herbert de Souza Center, a reference in the municipality of Cabo de Santo Agostinho. These last two were chosen because they have a Self-Care Group (*Grupo de Autocuidado*, GAC) for people affected by leprosy in their units.

The study participants were users with leprosy linked to the aforementioned reference units, professionals and health managers. The users were selected at random, during their visits to health services on the appointment days for monitoring leprosy and its complications or at the leprosy GAC meeting. Face-to-face semi-structured interviews were carried out with users and Telemonitoring was also resorted to with those who lived far from the health service or who had some difficulty commuting. The number of participants for this study step was defined by the saturation criterion of the diverse information collected<sup>7</sup>, totaling 29 users.

Data collection took place between December 2021 and June 2022 and was in charge of the team from the Research and Extension Group on Care, Social Practices and Right to Health of Vulnerable Populations (*Grupo de Pesquisa e Extensão sobre Cuidado, Práticas Sociais e Direito à Saúde das Populações Vulneráveis*, GRUPEV) at the University of Pernambuco (UPE). The data collected transcribed and organized to perform Bardin's<sup>9</sup> thematic content analysis, based on emerging categories.

Finally, after the data collection and analysis stage, an action plan was developed, aiming to implement strategies to face the problems experienced by the users, and problems identified in the meeting with managers, health professionals and Morhan. Collective interventions were carried out with users, professionals and health managers, as well as individual approaches to users through Telemonitoring.

The research protocol of the current study was approved by the Research Ethics Committee and all participants signed the Free and Informed Consent Form (FICF). To maintain the subjects' anonymity, the testimonies of the study users are addressed with the "Patient" coding, numbered from one to 29.

## RESULTS

The study results were presented in two topics: Repercussions of the COVID-19 pandemic on the lives of people affected by leprosy (categories: Difficulties faced by people affected by leprosy during the COVID-19 pandemic; Permanence of the leprosy stigma both by users and by the general population); and Interventions aimed at people affected by leprosy, health professionals and managers.

### Repercussions of the COVID-19 pandemic on the lives of people affected by leprosy

In this study stage, 29 people affected by leprosy were interviewed (16 men and 13 women), selected from the six leprosy reference health units in the city of Recife, the Otávio de Freitas Hospital and the Herbert de Souza Center. The interviewees were aged between 21 and 81 years old.

There was predominance of males among the study participants, with 55.2% men and 44.8% women. Regarding the clinical form of leprosy, 79.3% are cases of the multibacillary type and 20.7% of the paucibacillary type. With regard to the social data, there was predominance of earning from one to three minimum wages as family income, representing 62.1%, whereas in terms of schooling there was prevalence of people with complete High School, representing 34.5%.

The following categories emerged after analyzing the interviews: Difficulties faced by people affected by leprosy during the COVID-19 pandemic; and Permanence of the leprosy stigma both by users and by the general population.

#### *Difficulties faced by people affected by leprosy during the COVID-19 pandemic*

The new reality imposed by the pandemic brought with it difficulties that exerted direct impacts on the lives of people affected by leprosy. Among the general difficulties, financial hardships, access to health services and socialization were found.

It was possible to observe that nearly 41% of the interviewees reported financial problems, which directly interfered with the users' social situation:

*Financial difficulties [...] that made the situation worse [...] and [...] the disease that started to arrive, right? and I had to stay at home without being able to go out [...] I'd only go to the hospital and get home and stay home [...]. (Patient 26)*

In addition to financial hardships, another aspect raised by users was related to problems in accessing health services, where nearly 13% reported this difficulty. Many services began to operate for fewer hours during the pandemic or did not work at all, which made it difficult to maintain the health care of users who need continuous monitoring:

*I had a lot of difficulty accessing the health center[...] I had a lot of damage due to leprosy, I can't walk properly, I feel a lot of pain and to get to the health center I need to take the bus, you know? But I can't get on the bus[...] There's still the issue of COVID that I'm very afraid of getting on and the bus is a crowded place, then all this comes together and I can't go to the health center[...] (Patient 01)*

*Everything's more difficult, I only go to the doctor when the day is scheduled[...] but go to the health center, there it's already closed for the day, then three, four days closed and then it opens again[...] then people start to get sick and it all comes back again [...] in the center almost all the employees got sick[...] then it's difficult for me[...] (Patient 26)*

Finally, it was also possible to observe the recurrence of another difficulty: socialization. Approximately 27% of the interviewees reported socialization difficulties arising from the social distancing generated by the COVID-19 pandemic, in which some respondents reported the need to readjust their realities, interfering with their socialization, which was not reported by the others:

*Difficulties keeping in touch with the family [...] just from a distance during the pandemic, personal contact became more difficult [...] (Patient 09)*

*Social difficulty, interacting with people because of the pandemic [...] I didn't have social interaction [...] fear of contamination and I was already going through a leprosy treatment process [...] social contact was more restricted [...] even my son's school became virtual [...] (Patient 08)*

#### **Permanence of the leprosy stigma both by users and by the general population**

During the interviews, the users reported experiences of prejudice during this COVID-19 pandemic period, as well as in previous contexts, bringing to light situations in which it is evident that this prejudice and stigma remain around people with leprosy. The interviewees reported situations that happened to family members and close people:

*There was [...] this woman who was with me and disappeared, she left in fear [...] until today. [...] She left for the inland, not wanting to know more about me, and she never came back. (Patient 18)*

*My daughter-in-law [...] got pregnant and wouldn't let my son come to my house. [...] She glared at him so he wouldn't take my food [...] (Patient 05)*

Discrimination instances can also occur at the most diverse and unexpected environments, which can provoke unusual responses from users with leprosy, as reported below by the patient about an experience in her workplace:

*I arrived at work and was poorly received [...] then I was separated into a room to work alone [...]. It was better that way, I worked more relaxed. (Patient 15)*

*The interviewees also reported situations in which they realized that they suffered discriminatory attitudes by health professionals in some services:*

*I went to the ICU because of the medication [dapsona] [...]. They wanted me to be isolated because of leprosy [...] and taking dapsona. (Patient 04)*

*The doctor at the polyclinic [...] asked me to hide it and say it's a blood allergy [...]. I still do that today. (Patient 03)*

It was possible to show that the reflexes of these prejudiced attitudes were somehow harming the autonomy and social life of these individuals:

*No, because, kind of [...] he had it and didn't tell anyone. [...] Then I didn't have much because of that, right? [...] O had a neighbor there at the time that he had it [...] she had no contact and went to take BCG just because she was our neighbor [...] Then we were afraid to say [...] (Patient 23)*

*[...] He was only afraid of me when he saw me [...] 'No one will come close to you' [...]. I felt that bad thing, the urge to vomit [...] (Patient 24)*

Finally, some users reported that, in a way, the new coexistence and social isolation rules imposed by the pandemic contributed to "minimizing" situations experienced with prejudice, whether due to the use of a face mask or to the very isolation and withdrawal from socializing with other people:

*I believe that the pandemic helped with the lack of prejudice due to the use of masks and social distancing [...] (Patient 11)*

*No [...] those times I didn't have social interaction [...] (Patient 08)*

#### **Interventions aimed at people affected by leprosy, health professionals and managers**

Based on meetings with the management, health professionals and analysis of interviews with users, an action plan was developed that involved carrying out educational activities with users of the GACs and training with health professionals and managers. It is noteworthy that one of the issues raised by health professionals and managers was the suspension of GACs activities.

For users with leprosy, face-to-face interventions were carried out in the GACs in three reference services that had their activities suspended in the first year of the pandemic, but which were resumed during the study. There were eight meetings that promoted self-care practices, empowerment of people affected by the disease and discussions about the rights to health, assistance, social security and stigma reduction.

In addition to that, Telemonitoring was carried out with some patients that had difficulty commuting to the health service or lived far away, where, in addition to guidelines and discussions on the aforementioned topics, explanatory folders were also sent via WhatsApp® about leprosy and self-care practices.

It was possible to identify that, after the discussions, some users were more empowered and stated their desire to participate in meetings of other users' groups, such as MORHAN. Demands from the users were also identified regarding access to dressings, appropriate footwear and self-care supplies such as moisturizers, lubricating eye drops and sunscreens. Part of these demands was forwarded to the competent bodies and others were met by the UPE's GRUPEV research and extension group itself through the purchase of inputs such as sunscreens, foot pads, cooking gloves, lubricating eye drops and appropriate footwear.

The interventions carried out with a focus on health professionals and managers were conducted through three workshops linked to GRUPEV research studies, entitled "Workshop for the implementation and strengthening of support groups for self-care in leprosy", given by the research coordinators, where 25 professionals selected in the initial stage of the research participated. The output of the workshops were plans for implementing new GACs and strengthening existing GACs. The National Coordination Office of the Leprosy Control Program in Brazil also participated remotely in one of the workshops.

During the meetings, the concepts of care, self-care and self-care groups were discussed, with the participants sharing experiences about self-care groups experienced during the pandemic period. The challenges related to leprosy actions since the beginning of the pandemic and the intervention strategies devised were highlighted, as well as due planning for the creation of new self-care groups.

## DISCUSSION

As reported by users, due to the health crisis caused by the pandemic, financial difficulties arose. During the pandemic, there were more severe impacts for 37.3 million people who lived in informality, as they do not have rights such as vacations, maternity and medical leave, minimum wage, 13<sup>th</sup> salary, Guarantee Fund for Length of Service (*Fundo de Garantia por Tempo de Serviço*, FGTS) and unemployment insurance<sup>10</sup>.

Considering that leprosy is a neglected disease closely associated with populations that are in precarious living and health conditions, the importance of financial resources for subsistence and promotion of health care practices and prevention of disease complications is highlighted. In a narrative review, it was verified that most leprosy cases were in people with low income and/or schooling levels, and these variables are also considered risk factors when analyzed for the presence of physical disability<sup>11</sup>.

In relation to access to health services, the users reported obstacles in seeking care, with changes observed in the priority of health services that were extremely focused on COVID-19, which revealed several vulnerabilities in organization of the services to adequately monitor and control pre-existing conditions, such as leprosy. These issues made chronic health conditions such as leprosy less of a priority at the moment, thus opening a gap in the needs of health services for these patients<sup>12</sup>.

Some interviewees reported that they underwent fewer experiences of prejudice due to lack of interaction with other individuals as a result of the social distancing imposed by the pandemic. Many people with leprosy choose precisely to seek this self-isolation in their homes as an alternative to avoid discriminatory actions, thus being able to aggravate the disease by not receiving timely treatment<sup>4,15</sup>. Thus, this pandemic context and its restrictive social measures emerge as enhancers of the already existing isolation in people affected by leprosy.

The social stigma in leprosy is still present, representing a factor that can affect social and family relationships, oftentimes interfering with people's health situation. In addition, with the advent of the pandemic, measures such as social distancing exerted negative impacts on vulnerable populations, threatening psychological well-being due to associated discrimination, loneliness and isolation<sup>12</sup>. A stigmatized person may feel reduced in their individuality by being dehumanized as an individual, affecting their self-respect and autonomy. These various negative feelings can result in social exclusion and denial of human rights<sup>4,13</sup>.

This stigmatization also extends to health professionals who, not adequately prepared, negatively influence the approach to users, reinforcing the negative feelings of exclusion, anguish and shame that those affected already experience and do not assist in their understanding of the disease. This can even occur in basic health units, showing that health professionals have limited knowledge about the disease and difficulties diagnosing it<sup>14</sup>. Therefore, it is indispensable that knowledge about leprosy is widely disseminated and that health professionals are duly prepared and trained to provide humanized and comprehensive care, intervening appropriately and in a timely manner to ensure greater adherence to the treatment and social inclusion<sup>4</sup>.

Faced with the difficulty of coping with and controlling leprosy, especially aggravated by the pandemic, it is pertinent to have actions that encourage improvements in the living conditions of people affected and at risk of leprosy infection and better organization of health services with quality that can promote continuity of the assistance provided to the population<sup>12</sup>. It is noted that, given these various factors, it is essential that adequate and comprehensive care is offered in health services to contain evolution of the disease<sup>11</sup>.

It is pertinent to take into account the impaired quality of life of patients with leprosy sequelae. These sequelae cause physical and psychological limitations that interfere with the subjects' performance of daily activities and autonomy. Increased knowledge about the disease, self-responsibility and enhancement of self-care actions have positive repercussions on the health of people affected by leprosy<sup>16,17</sup>. Therefore, it is indispensable that health education actions and specific self-care groups are encouraged, so that users can develop the necessary skills to face the health conditions resulting from leprosy and promote their own self-care.

It is also worth noting the Telemonitoring tool, which was used as a resource to reach users affected by leprosy, especially those who lived in distant places or who had difficulties commuting. In addition to that, as the pandemic restricted people's movements, Telemonitoring contributed to health care continuity, safeguarding their health and reducing the exposure risks<sup>18</sup>. In addition, it is a low-cost technology with quick access to the patients and which allows for a recurrent interaction of the health team with the users<sup>19</sup>, proving to be extremely relevant for the integration of this tool in the health programs carried out by the Unified Health System (*Sistema Único de Saúde, SUS*).

### Study limitations

The study was limited to the experience in a single Brazilian state, requiring further studies in the national scenario, as there are multiple experiences of service organization, even in the SUS context.

### CONCLUSION

The study pointed out repercussions on the financial situation and socialization of users, with a worsening of their social vulnerability and isolation, situations that were not exclusive, in the context of the pandemic, to people affected by leprosy. It was highlighted that, for some users, the mask and distancing provided fewer situations of discrimination. This finding reminds us of the relevance that stigma still has in the context of the disease, which can be related to situations of self-exclusion.

The interventions carried out with the users in the study exerted a positive impact on the lives of those affected, where assistance directed at the users contributed to improving self-care, promoting empowerment and reducing the stigma.

It is important that managers and implementers of health and social assistance policies take measures in order to minimize the negative effects of the COVID-19 pandemic on the lives of people with leprosy. Health professionals who assist these people should be aware of signs of isolation and mental distress in this population group to provide comprehensive health care, considering the unique issues caused by the stigma of the disease. However, it is also indispensable to emphasize that the entire society should be active regarding the needs of this population segment.

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#### Author's contributions:

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