

# Experiences of social stigma of people living with Hansen's disease in Brazil: silencing, secrets and exclusion

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**Background:** Hansen's disease is a chronic, infectious and transmissible disease that is considered a public health problem in Brazil. Hansen's disease is marked by stigma and prejudice, because it carries with it a strong negative social image, reinforced by policies of social isolation in the community.

**Methods:** A qualitative study was conducted in Ribeirão Preto, an inland city of the state of São Paulo, Brazil. Eleven patients under treatment for the disease were interviewed. The interviews were audio recorded and transcribed in full, then were analyzed through the stages of transcription, transposition and reconstitution, as informed by concepts proposed by Goffman.

**Results:** The results showed that the marks of stigma are still present in the twenty-first century and were presented in two axes: 'Stigma and work for the person affected by Hansen's disease' and 'The experience of stigma in the family'. The participants refer to fears of losing their jobs and of being ridiculed, which stops them talking about the disease. Regarding their families, the participants reported episodes of discrimination, the creation of family secrets and fear of relatives' reactions.

**Conclusions:** All these aspects interfere in the follow-up and treatment of patients and need to be considered and welcomed by health professionals. It is recommended that these aspects are addressed in the initial training and continuing education of health professionals.

**Contexte:** La maladie de Hansen est une maladie chronique, infectieuse et transmissible, considérée comme un problème de santé publique au Brésil. La maladie de Hansen est marquée par la stigmatisation et les préjugés, car elle véhicule une image sociale fortement négative, renforcée par des politiques d'isolement social au sein de la communauté.

**Méthodes:** Étude qualitative menée à Ribeirão Preto, une ville intérieure de l'État de São Paulo, au Brésil. Onze patients traités pour la maladie ont été interrogés. Les entretiens ont été enregistrés et transcrits intégralement, et ont été analysés en suivant les étapes de transcription, de transposition et de reconstitution, selon les concepts proposés par Goffman.

**Résultats:** Les résultats montrent que les marques de la stigmatisation sont toujours présentes au 21<sup>ème</sup> siècle et ont été présentées selon deux axes : 'La stigmatisation et le travail pour la personne affectée par la maladie de Hansen' et 'L'expérience de la stigmatisation dans la famille'. Les participants évoquent la peur de perdre leur emploi, la peur d'être ridiculisés, ce qui les pousse à ne pas parler de la maladie. En ce qui concerne les familles, les participants ont rapporté des épisodes de discrimination, la création de secrets de famille et la peur des réactions des proches.

**Conclusions:** Tous ces aspects interfèrent dans le suivi et le traitement des patients et doivent être pris en compte et accueillis par les professionnels de la santé. Il est recommandé que ces aspects soient abordés dans la formation initiale et la formation continue des professionnels de la santé.

**Antecedentes:** La enfermedad de Hansen es una enfermedad crónica, infecciosa y transmisible, considerada un problema de salud pública en Brasil. La enfermedad de Hansen está marcada por el estigma y el prejuicio, ya que conlleva una fuerte imagen social negativa, reforzada por políticas de aislamiento social en la comunidad.

**Métodos:** Estudio cualitativo realizado en Ribeirão Preto, una ciudad del interior del estado de São Paulo, Brasil. Se entrevistaron a once pacientes en tratamiento para la enfermedad. Las entrevistas fueron grabadas en audio, transcritas en su totalidad y analizadas a través de etapas de transcripción, transposición y reconstitución, según los conceptos propuestos por Goffman.

**Resultados:** Los resultados muestran que las marcas del estigma siguen presentes en el siglo XXI y se presentaron en dos ejes: 'Estigma y trabajo para la persona afectada por la enfermedad de Hansen' y 'La experiencia del estigma en la familia'. Los participantes mencionan el miedo a perder sus trabajos, el temor a ser ridiculizados, lo que les impide comentar sobre la enfermedad. En cuanto a las familias, los participantes reportaron episodios de discriminación, la creación de secretos familiares y el miedo a las reacciones de los familiares.

**Conclusiones:** Todos estos aspectos interfieren en el seguimiento y tratamiento de los pacientes y deben ser considerados y acogidos por los profesionales sanitarios. Se recomienda abordar estos aspectos en la formación inicial y la educación continua de los profesionales sanitarios.

**Keywords:** Hansen's disease, healthcare, leprosy, prejudice, social isolation, social stigma.

## Introduction

Hansen's disease, formerly called leprosy, is a disease that is considered endemic in Brazil, where it is characterized as a public health problem for the country, which occupies second place in the world ranking of cases of the disease. In addition to its magnitude, Hansen's disease has a disabling power, a factor that contributes to the stigma and discrimination of people affected by the disease.<sup>1</sup> In 2020, 127 936 new cases in the world were reported to the WHO and, of these, 17 979 were in Brazil.<sup>1</sup>

It is considered a dermatoneurological pathology due to the involvement of nerves and skin, but above all it is a disease that causes fear, social isolation and loss of self-esteem, affecting mental health. A study carried out in Brazil found a prevalence of 70.4% of common mental disorders among people affected by Hansen's disease with complications. The study states that prejudice, stigma, pain and disabilities secondary to the disease help explain the impacts on the mental health of those who are affected.<sup>2</sup>

Furthermore, Hansen's disease is related to social inequality, affecting people in different social classes unequally. From 1924 to 1962, the Brazilian state was responsible for compulsorily isolating people, reinforcing stereotypes and worsening the psychological trauma experienced by patients and their families.<sup>3</sup>

On 29 March 1995, the term 'Hansen's disease' officially replaced the term 'leprosy' by the law 9.010, aiming to reduce the stigma of the person affected by the disease. According to the law the use of the term Hansen's disease became mandatory in Brazil.<sup>4,5</sup>

Even although changing the name of the disease was an attempt to alleviate the situation, stigma and prejudice are still present.<sup>3</sup>

People living with Hansen's disease experience a variety of uncomfortable situations associated with the 'label' they receive socially at the time of diagnosis. Managing prejudice and other people's views upon you in different aspects of life becomes part of the routine. Studies carried out in Brazil indicate that people living with the disease end up experiencing separation from family, coworkers and friends, harsh expressions of fear of contagion and other forms of prejudice.<sup>6,7</sup>

The literature points out that there is a correlation of negative associations of stigma as a specific attribute of difficulties related to social relationships and circumstances, so that any positive social attribute previously constructed before Hansen's disease is not credible and there is a process of disbelief and prejudice through the disease and consequently towards the person affected by the disease.<sup>8</sup>

These difficulties are associated with the stigma surrounding the disease.<sup>8</sup> The provision of adequate and accessible treatment, the existence of support groups and social movements, can be important strategies for the proper care of people affected by Hansen's disease and their families.<sup>9</sup>

Hansen's disease also carries a significant impact on the stigma of people affected by the disease. This impact is present in the family and community where the meanings of the disease are constructed through fear, rejection, a lack of acceptance and insensitivity. For the family and community there is a feeling of threat from the person affected by the disease in the daily lives of people who do not experience the disease.<sup>9</sup>

In Brazil, the treatment for those affected by Hansen's disease is offered free of charge by the Unified Health System (SUS); it is available at any healthcare facility and, once started, within a few days of treatment the transmission is interrupted.<sup>10</sup> In the country there is also an important movement to raise awareness

about Hansen's disease and combat stigmatization and discrimination, with emphasis on the Movement for the Reintegration of People Affected by Hansen's disease (MORHAN), a non-profit organization founded in 1981, which has promoted a significant debate about the person affected by Hansen's disease and its insertion in society.<sup>11</sup>

This study is justified by the need to understand the experiences of people affected by Hansen's disease through the use of the concept of concealment developed by Goffman. In this way, it will be possible to understand how people affected by Hansen's disease and health professionals manipulate the process of hiding information to avoid stigma and social exclusion. Therefore, promoting the improvement of care in health services in the context of the Brazilian SUS.

Given the context, the aim of this study was to analyze the experience in the management of the information for people affected by Hansen's disease in relation to the social stigma related to the disease.

## Materials and Methods

### Study design

This is a qualitative study that used the concepts of stigma developed by Erving Goffman.<sup>8</sup> The study followed the recommendations established by the Consolidated Criteria for Reporting Qualitative Research (COREQ).<sup>12</sup>

### Theoretical-methodological framework

According to Goffman, a Canadian sociologist, stigmas are created and managed by subjects in social interactions, and also directly influence these interactions. In this way, the concept of stigma is given a relational meaning and the understanding that its constitution takes place socially.<sup>8</sup>

Goffman points out that stigma is characterized by attributes and stereotypes that are used in a derogatory way in a social relationship. The stigmatization process is evidenced by the discrepancy between the 'virtual' social identity, the one projected by the individual and expected by the social collective to which they belong, and the 'real' social identity, the one that actually occurs in the encounter, in mixed relationships (between normal individuals and the stigmatized).<sup>8</sup>

Goffman distinguishes three types of stigmas: individual guilt, abominations of the body and tribal, racial, national and religious stigmas. In Hansen's disease, the physical changes resulting from the disease or its treatment frame the stigma associated with the disease and the issue of the abomination of the body. The deviation from 'normality' observed in the encounter is a central concept in the social construction of stigma. Spots on the skin, deformities in the extremities, hyperpigmentation of the skin resulting from drug treatment, nodulations and other characteristics related to the body constitute the deviation from 'normality' that trigger stigma.<sup>8</sup>

Another important concept elaborated by Goffman is the categories of belonging that stigmatized people can have: the category of discredited people are those with characteristics perceived as distinct from normal people and known by the collective; and the category of discreditable people are those

with characteristics that are also distinct from normal people, but not always perceived by them.<sup>8</sup>

For Goffman,<sup>8</sup> the stigma is characterized by a moment of rupture between what is projected to oneself and to others, destroying the positive characteristics and qualities of the individual and exerting a power of control over their actions and ruining their social identity. This stigma felt by the person affected by Hansen's disease leads to decreased quality of life due to anxiety, stress, depression and suicide attempts.<sup>9</sup> There is a strong connection between the past and the present of Hansen's disease, such that not even the technological advances that prove the possibility of curing the disease and strategies developed by the WHO are sufficient to reduce or eradicate the stigma and prejudice related to the disease.

The concepts related to social stigma elaborated by Goffman were chosen in this study because they help to understand and problematize social relations and the impacts on the lives of people who have attributes that are not accepted by society, such as those caused by Hansen's disease.

### Study setting

The study was carried out in the Brazilian municipality of Ribeirão Preto, an inland city of the state of São Paulo, Brazil, 314 km away from the capital. It is noteworthy that the municipality is endemic for Hansen's disease and, therefore, a priority for actions aimed at controlling the disease.

The city where the research was conducted has a considerable prevalence coefficient of the disease. It is a hub of work and healthcare and therefore receives migrants from various regions of the country where Hansen's disease is significant in epidemiological terms, especially the north and northeast. It has a network of public services linked to the Unified Health System with primary care units, specialized outpatient clinics and hospitals. The diagnosis and treatment of Hansen's disease in the city are performed by the public health network and the health units that attend the local population affected by Hansen's disease were allocated in the study.

### Study participants

The inclusion criteria were men and women aged > 18 y, residents in the city studied who were under Hansen's disease treatment in one of the units responsible for the treatment. The exclusion criterion was people unable to interact with the researcher at the time of collection. The selection of the study participants was carried out by means of intentional convenience sampling and the size of the sample acquired (a total of 11 participants) was sufficient for thematic saturation to occur. Potential participants were invited to participate in the study, being approached at the health service where they were being treated.

### Interviews

Previously, contact was made with the manager and the nurse of the health units, and then the researcher attended on the days of care. In the waiting room, people were invited to participate and,

if they accepted, the interviews were carried out in a private room. All those invited agreed to participate in the study. The interviews were conducted during June and July 2018 and lasted 17–45 min.

## Data production

The technique used for data production was the semistructured interview, based on a guiding script with sociodemographic identification questions and questions about the experience of the person with Hansen's disease. The interviewer had previous preparation through pilot interviews, transcription and critical analysis with the study supervisor.

## Data analysis

The interviews were audio-recorded and transcribed in full, and were organized from three steps: transcription, transposition and reconstitution.<sup>13</sup> Transcription consists of transforming the audio into text format articulated field notes; transposition is the categorization of the data and includes the participants' gestures in the researcher's words and understanding, analysis of what is experienced, of what is manifested, based on the framework that underpins the research; and reconstitution is the argumentative writing.<sup>13</sup>

The analysis was based on the concepts proposed by Goffman,<sup>8</sup> considering work and the family as privileged meeting places for analyzing the experiences of people affected by Hansen's disease and stigmatized by the disease.

## Ethical aspects

Ethical rights and duties were assured, such as anonymity of the participants, clarification about the purpose of the study, protected confidentiality, as well as the right to withdraw from the study at any time. The participants signed the consent form and received a copy of it.

## Results

### Characterization of the study participants

In total, 11 patients participated in the study, five women and six men, aged 42–70 y. Regarding education, four study participants had incomplete elementary school education, two had complete elementary school I, three had incomplete elementary school II, one was illiterate and one had complete higher education. The work roles of the participants are seamstress, nursing attendant, transport driver, farmer, cleaning worker, secretary, upholsterer, pedagogue, bricklayer, farm worker and watchman.

The research participants reported their experiences in relation to the pathology and its impacts. The results are presented in two thematic axes referring to experiences at work and with their families. The choice of thematic axes is based on the understanding that work and family are places of encounters, of significant social interactions for people affected by Hansen's disease, where stigma can be highlighted and also problematized.

The letter 'P' followed by Arabic numbers from 1 to 11 is used to indicate the participants in the study and the letter 'R' to indicate the researcher who conducted the interview.

### Axis 1–Stigma and work for the person affected by Hansen's disease

The study participants reported changes that have occurred, in their work routine and in their relationships with colleagues, as well as fears about losing their jobs because they have Hansen's disease and of being ridiculed by coworkers:

*And not even for the company... because I might tell my boss about this and he might fire me because of this, or I don't know, we don't know how the person's life is, I don't know. I kept it to myself. Everything that they asked, that I worked in the factory, I was like... it is not allergies, it is allergies, everything was allergies (P1).*

*I didn't talk about my work, because unfortunately we have moments that we can't be true, you have to omit something in order to survive or continue the fight, but at no time did I stop worrying about the people who lived with me (P8).*

It can also be observed from P1 and P8 that attributing another meaning to the clinical manifestations of the disease on their bodies and omitting information was a strategy for acceptance in the collective environment in their workplace. The strategy used by the study participant was the intention not to be excluded from this social environment and, more than that, to remain, because for the study participant, the person affected by Hansen's disease could be excluded and, in this case, fired, losing their job, which could be an aggravation in the face of the situation experienced, including issues related to mental health, such as depression and anxiety due to the negative impact.

For study participant P3, the fear of embarrassment in the eyes of their coworkers makes the choice to omit more feasible, as this can lead to other negative and unexpected reactions and, in addition, there is also a fear of losing one's job, which, as mentioned above, could lead to an aggravation of the situation related to economic status and mental health:

*And in your work, how was it, did you tell about the disease? Did you let them know? (R)*

*No, in my work I didn't count no ...ahh from fear of them making fun of me (P3).*

*Hmm I see. And you continue to work normally? (R)*

*Normal (P3).*

The participants also referred to early exit from work through disability retirement. The response of P2 demonstrates that the situation was handled by the workplace itself. There was institutional action in favor of retirement of the study participant:

*And who made this suggestion for you to retire on disability?*  
(R)

*My lawyer and the hospital, the hospital itself* (P2).

*Ahhh the hospital you worked at?* (R)

*Yes! Which is Maternity—[name of workplace]* (P2).

*I got it!* (R)

In the responses from P8, social responsibility is evident, as is the fear of transmitting the disease to coworkers, given the interaction that takes place in these workplace environments. But, at the same time, there is still concern, fear and uncertainty, once again, about the possible negative reactions of work colleagues due to the prejudice related to the disease:

*At the moment my only concern was that I was transmitting it to someone else, because we know that there are medicines, treatments, all that... and besides the transmission, I was worried about people knowing, because there is still a lot of prejudice nowadays* (P8).

There was reference to health professionals in discouraging disclosure at the workplace of the disease:

*And at your work, did you tell them about it?* (R)

*No, the doctor said: 'Don't tell them, otherwise they will be afraid,' but she said: 'You can relax, you are taking medicine, there is no problem.'* (P9)

The responses of study participant P9 show the interference of the health team, specifically the doctor, to silence the diagnosis, encouraging non-disclosure for the patient's own preservation, because if it were shared with coworkers, unexpected and negative situations could occur.

There were also references to non-interference in work activities during the period of the diagnosis and treatment:

*And are you still working?* (R)

*I work normally, I keep working* (P7).

*Even when these reactions started?* (R)

*No, I never stopped working, I continued working normally, for me it didn't disturb me at all, I was more careful not to hurt myself, I felt it more, my skin is more sensitive...you touch a part, I work sometimes with welding, you burn your hand, you feel it, it's more sensitive, your body, you have to be careful not to hurt yourself, in general...normal life* (P7).

It can be seen from the responses of P7 that he was encouraged to carry on with his work activities, not making the disease

an obstacle or a hindrance. Instead, the study participant reformulated his day-to-day life, for example redoubling his attention when carrying out activities that could hurt him, given the change in sensitivity caused by the disease.

It is possible to see in the participants' responses a handling, a manipulation of information about the unwanted attribute. The fact that they have Hansen's disease is not revealed in meetings with people at work or is discouraged from being revealed, as happened in the meetings with the health professionals who attended to the participants. This manipulation of information occurs through interaction and the discrepancy between the 'virtual' social identity expected in the world of work, healthy workers and the 'real' social identity, being affected by Hansen's disease. The subjects manifest their 'discreditable' characteristics when interacting with 'normal' people.

## Axis 2—The experience of stigma in the family

Respondents reported experiencing family secrets about Hansen's disease, fear of their spouse's reactions, experiences of prejudice and feelings of hurt and shame:

*I never told anyone about many things... to my children, I don't let them worry. Because my mother died without knowing that I had this disease, my father... my two brothers also, who I lost recently, not recently, one was in 2000 and the other in 2004* (P2).

The family environment is usually a place where people open up, getting to know each other better. The attitude of not sharing more intimate information, even with family members, may be related to a more reserved personality. However, when the study participant P2 says that her mother, father and two brothers died without her sharing her diagnosis with them and that she does not tell her children because she does not want to worry them, she somehow hints at the magnitude of the stigma associated with the diagnosis, which makes it a secret and also stigmatizing:

*Then I went on, I went on, then my mother started talking to me, talked to my father... it was difficult for my father to pass this on to me, because I think he... I don't know if he is ashamed, what he had... with him it was stronger, my father was even isolated like this... Then my father told... that he had Hansen's disease, he had Hansen's disease, he had all these strong things... when my father had it. But then he told us about it, he didn't want to... you know, he was ashamed, I don't know, because he was the one that was isolated, right, he was kind of isolated. He told... to me. Then he told me that he had all this and so on, but he never told us about it... to me... I don't know why, for what reason, he didn't tell us either. But then he said that at the time I was hospitalized, they took care of me, everything, but that was when I found out, at the beginning I even cried, because I said oh my God, what am I going to tell my husband now? All this married stuff, what will my husband think, I kept thinking about this. Did you understand?* (P1)

For P2, hiding the disease from his family was a strategy to avoid worry, which may also be associated with fear of

unexpected reactions from family members, especially negative ones, given the relevance of the stigma associated with Hansen's disease.

In the response from P1, it can be seen that the father was afraid to share with his family that he had Hansen's disease, justified by the shame of the disease, which is associated with stigma. When they say that it was 'stronger' with him, it highlights the issue of the disease's systemic involvement, which leads to varying degrees of incapacity, as well as the person's isolation from society, which was common in the past. When the daughter is affected by Hansen's disease, the secret is opened up to the family and there is concern for the husband, fearing unexpected negative reactions.

Stories circulate in the family about the period of isolation of people affected by the disease in leper colonies:

*It was Hansen's disease right... my... my mother said that when people had this disease they were excluded, they were taken to another place which was the Casa Branca [White House]... they would get it at dawn, put it in the car and take it away... or they would come dead from there or... or they would stay there .... because there was no treatment, they stayed there. Mom told us, Dad told us, that they had certainly seen someone, right, because in the family there was no one like that... I tell you, I was rewarded [laughter] (P2).*

For study participant P2, it is clear that the stigma associated with the fear of encountering prejudice from one's own family constitutes an element of the social stigma faced by people with Hansen's disease. A point that deserves to be highlighted is that social isolation and, consequently, the fear built in the family creates barriers to feeling welcomed during the treatment process:

*I don't talk to anyone because there is prejudice, even in the family I have faced... sister-in-law, niece. I... my sister-in-law used to ask 'Where were you?' to her daughters... 'I was with my aunt'... 'Where did you eat? Did you sleep with her?' Then I don't even comment anymore, I let it go... it came back again and I, I avoid it (P2).*

*We are afraid, you know... sometimes we are even afraid of prejudice, because I don't have prejudice against anything, nothing at all, and now there are people in our own family who does (P2).*

The study participant P2 also shows how people affected by Hansen's disease were treated in the past, being forcibly removed from their families, from their lives, to be isolated in a place called Casa Branca. The place did not guarantee treatment or that the person would leave alive. What happened was the isolation of 'healthy' people.

In addition, P2 references not talking to family members about the disease because of the prejudice in his own family environment, which causes him to shut up and exclude himself.

There is also a process of covering up the undesirable attribute in the family environment. Although family relationships are socially a welcoming space, where people can be who they really are and assume their real identity, it can be seen that the family

is a place that reproduces the prejudices present in society and the process of stigmatization.

## Discussion

For Goffman,<sup>8</sup> individuals have a 'virtual' social identity, which is represented by a set of socially expected characteristics, and a 'real' social identity, which may or may not diverge from these expectations. The discrepancy between virtual and real identities can give rise to stigma. In this sense, the discrepancy has the effect of distancing the individual from society and from themselves in such a way that they end up being a discredited person in front of an unreceptive world.<sup>8</sup>

In order to understand the phenomenon, the author proposes classifying people into three categories: the 'equals', who are the people that share the stigma; the 'normals', who are those who do not share the stigma; and the 'informed', who are those who have a close friendship, family or professional relationship with those who experience the stigma and, being aware of the characteristics that confer the stigma, treat them as 'normals'.<sup>8</sup>

According to Goffman, when the stigmatizing condition is not immediately identifiable, people can choose not to reveal the condition, introducing the concept of concealment, which consists of the manipulation of hidden information that discredits the self.<sup>8</sup>

The results presented in axis 1 reveal the reasons that support the decision of people affected by Hansen's disease not to inform people in their workplace about the disease. It can be seen that the participants in the study chose to keep their condition quiet in the workplace because the label imposed by the diagnosis could trigger unexpected reactions, embarrassing situations and even dismissal.

In situations where there were specific signs of a discrepancy from the conditions of normality (without the disease), such as the dermatological manifestations of the disease reported by one study participant, the participant chose to lie, saying that it was an allergy, to ensure that the strongly stigmatizing label of a person affected by Hansen's disease was covered up.

In the results presented in axis 1, it can be seen that the advice to keep the diagnosis secret in the workplace often came from the health professionals themselves, who are aware of the stigma associated with the disease and, as well as dealing with diagnosis and treatment, are concerned with preparing people for life with the disease by protecting them from stigma.

Studies evidence that Hansen's disease significantly impacts the mental health of those people affected, with stigma playing an important role in the development of the negative impact, causing significant psychological trauma and mental disorders such as depression and anxiety.<sup>14,15</sup>

There is a discrepancy between the 'virtual' social identity, the one expected by society in relation to the individual who works, who must present an image without marks, without deformities, resistant enough to withstand the physical, psychological and social pressures that work 'naturally' can bring and that we must 'naturally' endure without too many complaints, and which conflicts with the 'real' social identity presented by the person affected by Hansen's disease or health problems that capitalist society stigmatizes.

In axis 1, the results of the study indicate that there is, on the part of health professionals, the orientation not to tell about the Hansen's disease diagnosis to their employers.

These indications were also observed by Goffman in his studies when he discusses that it is interesting to note that this type of information manipulation is often recommended by doctors, especially when they have to be the first people to inform the individual about his or her stigma. Thus, doctors who discover a case of Hansen's disease may suggest that the new secret remains between the doctors, the patient and the next of kin, perhaps proposing this type of discretion to ensure the patient's continued cooperation in their treatment.<sup>8</sup>

The stigma that comes from health professionals themselves regarding users affected by Hansen's disease can be related to the meanings and senses elaborated by them in their experiences in the care of people affected by Hansen's disease, as well as their contact with the historical, social and religious context that permeates the constitution of this pathology.<sup>16</sup>

The results presented in axis 2 point out that even within the family environment there is the need for secrets about the diagnosis of the disease. It is noteworthy that the results also point to the experience of family exclusion and the partner's fear of the diagnosis of Hansen's disease.

Hansen's disease interferes not only with the lives of patients or former patients, but also with their families, friends and the people they live with.<sup>17</sup> In general, people associate the disease with Hansen's disease, which refers to an incurable disease, with extensive and disfiguring lesions, that affected impure people and separated them from their families, from their acquaintances, isolating them.<sup>18</sup> This denotation means that the disease is associated with terrifying and negative stigmas.<sup>19</sup>

Nasir and collaborators<sup>20</sup> indicate that patients with Hansen's disease and their families tend to maintain a communication channel with health professionals and some family members, closing themselves to other families, friends and outsiders. As pointed out in this study, having Hansen's disease is treated as a secret.

As a care strategy, it is important to involve the family in the care of the person with Hansen's disease; this can be a way to reduce the stigmatization of patients within the family.<sup>21</sup> However, for the involvement of the family to be really effective, it is necessary that the attention given to the user should be less focused on biological aspects.

Living with Hansen's disease can cause fear and segregation.<sup>22</sup> In this study, the results indicate that fear and judgment at work and in the family environment are constitutive elements in the construction of stigma surrounding Hansen's disease, and promote an action of concealment, in which the stigmatized subject seeks to hide the attribute given socially as pejorative, as a strategy to minimize the effects that stigma brings, such as the feeling of shame caused by prejudice. This finding corroborates other studies.<sup>16,23</sup>

Social transformations such as the end of the period of compulsory isolation, the change in the name of the disease, changes in communication and interaction patterns mediated by digital technologies, as well as the expansion of the network of primary healthcare services, could have changed people's relationship with Hansen's disease, but this has not happened.

## Conclusions

The study shows that social stigma is present in the study participants' experiences and can directly interfere in their treatment and follow-up.

Health education strategies about Hansen's disease and an acceptance of differences should involve patients and their families, and it is necessary to establish a therapeutic bond between the patient, family and health professionals, a bond that should also help to combat the stigma about Hansen's disease.

At the time of each meeting between health professionals and users, an attentive look is necessary, which can go beyond the disease. It is necessary to consider the social aspects of the disease, where social stigma is found. Therefore, a careful and comprehensive look at the person affected by Hansen's disease is necessary to mitigate the effects of the disease and also social stigma.

One of the strategies could be health education that allows the breaking of the stigma through knowledge, then supporting those affected and their families towards better acceptance of the disease and social coexistence.

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**Data availability:** The data underlying in this study cannot be shared publicly due to the ethical commitment assumed with the study participants and the Research Ethics Committee. The data will be shared upon reasonable request to the corresponding author.

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