Attributed meanings and self-reported feelings about illness of people living with leprosy

Significados atribuídos e sentimentos autorreferidos sobre adoecimento de pessoas que vivem com hanseníase

Significados atribuidos y sentimientos autoinformados sobre la enfermedad de las personas que viven con lepra

Alex Vilas Boas de Miranda[1], Claudia Suely Barreto Ferreira[2], Cleuma Sueli Santos Suto[3], Jones Sidnei Barbosa de Oliveira[4], Cristiane dos Santos Silva[5], Carle Porcino[6]

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1. Universidade do Estado da Bahia. Senhor do Bonfim, Bahia, Brazil.
https://orcid.org/0000-0002-0311-4383

2. Universidade do Estado da Bahia. Senhor do Bonfim, Bahia, Brazil.
https://orcid.org/0000-0002-9801-9169

3. Universidade do Estado da Bahia. Senhor do Bonfim, Bahia, Brazil.
https://orcid.org/0000-0002-6427-5535

4. Universidade Federal da Bahia. Salvador, Bahia, Brasil.
https://orcid.org/0000-0002-1170-2652

5. Prefeitura Municipal de Jequié. Jequié, Bahia, Brazil.
https://orcid.org/0000-0003-3822-1397

6. Universidade Federal da Bahia. Salvador, Bahia, Brazil.
https://orcid.org/0000-0001-6392-0291

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RESUMO
Objetivo: compreender os significados atribuídos e sentimentos autorreferidos sobre o adoecimento por pesssoas que vivem com hanseníase. **Método:** pesquisa qualitativa, desenvolvida em um município da região norte da Bahia. Realizou-se entrevistas semiestruturadas e observação sistemática, que originou três categorias analíticas, por meio da análise temática categorial de Bardin. **Resultados:** os participantes revelaram sentimentos de medo, inferioridade e tristeza que coexistem com a discriminação e a falta de informação sobre o adoecimento. Estes sentimentos vivenciados cotidianamente os afastaram de familiares e pessoas próximas, reforçando sofrimentos e adoecimento psiquico. **Conclusão:** o enfrentamento diário do preconceito pode interferir no prognóstico da doença, na adesão ao tratamento e qualidade de vida, o que requer uma conduta profissional pautada em acolhimento, escuta qualificada e constante diálogo.
Descritores: Hanseníase; Emoções; Vulnerabilidade social; Profissionais da saúde; Atenção Primária à Saúde.

ABSTRACT
Objective: understand the meanings attributed and self-reported feelings about falling ill by people living with leprosy. **Method**: qualitative research, developed in a municipality in the northern region of Bahia. Semi-structured interviews and systematic observation were carried out, which originated three analytical categories, through Bardin's categorical thematic analysis. **Result**s: the participants revealed feelings of fear, inferiority and sadness that coexist with discrimination and the lack of information about illness. These feelings experienced daily removed them from family and close people, reinforcing suffering and psychic illness. **Conclusion:** the daily confrontation of prejudice can interfere in the prognosis of the disease, in adherence to treatment and quality of life, which requires professional conduct based on welcoming, qualified listening and constant dialogue.
Descriptors: Leprosy; Emotions social vulnerability; Health professionals; Primary Health Care.

RESUMEN
Objetivo: comprender los significados atribuidos y los sentimientos autoinformados sobre enfermarse por las personas que viven con lepra. **Método:** investigación cualitativa, desarrollada en un municipio de la región norte de Bahía. Se realizaron entrevistas semiestructuradas y observación sistemática, que dieron origen a tres categorías analíticas, a través del análisis temático categórico de Bardin. **Resultados:** los participantes revelaron sentimientos de miedo, inferioridad y tristeza que conviven con la discriminación y la falta de información sobre la enfermedad. Estos sentimientos vividos a diario los alejaban de sus familiares y personas cercanas, reforzando el sufrimiento y la enfermedad psíquica. **Conclusión:** el enfrentamiento diario de los prejuicios puede interferir en el pronóstico de la enfermedad, en la adherencia al tratamiento y la calidad de vida, lo que requiere una conducta profesional basada en la acogida, la escucha calificada y el diálogo constante.
Descriptores: Enfermedad de Hansen; Emociones Vulnerabilidad social; Profesionales de la salud; Primeros auxilios.

Introduction

Considered a public health problem, leprosy, known for centuries by leprosy, is a disease identified / diagnosed within the main diseases of world history. Even though she was attacked by leprosy, she was considered a sinner or the fate of living in unhealthy environmental conditions "determined" by the occurrence of infection. Two years ago, leprosy was associated with a social and cultural factor, and its illness was marked by the stigma of the concept of “incurable” aggravation.[1]

Infectious and contagious disease, transmitted by airways, considered to be of low pathogenicity and high infectivity, since a small portion of the affected population will develop the disease. Symptoms appear as white or reddish patches on the skin in the form of plaques and / or nodules, commonly associated with loss of local sensation, which can cause the involvement of peripheral nerves and serious physical disabilities.[2]

The impact caused by a disease can negatively interfere in people's daily lives. In the case of leprosy, due to situations of prejudice, exclusion, discrimination and abandonment, psychosocial problems are enhanced. As they are generated and shared in the fabric of social relationships, the meanings and feelings of people living with leprosy are related to psycho-emotional suffering, doubts, insecurity, lowering of esteem, ignorance, fear and physical deformities that can be caused by the disease.[3]

Although it is commonly found in regions with higher poverty rates, due to inadequate housing, environmental and sanitary conditions, leprosy is identified in all ages and social classes. Regardless of the way in which the person was affected / diagnosed, there is specific treatment, above all, without leaving sequelae and possible permanent physical deformities when treated in a timely and correct manner.[4]

In this sense, Primary Care, through the Surveillance System, is essential in creating alternatives for the elimination of leprosy, with an emphasis on strategic actions to promote health and prevent diseases developed in the Family Health Strategy (FHS). It is part of the actions developed by the ESF to actively search for suspected cases, since the early detection and timely treatment of positive diagnoses does not require sophisticated equipment, which makes the identification of the disease more feasible, even in minimally structured municipalities.[5]

Even with the structuring of a program aimed at neglected diseases such as leprosy, the feeling of fear associated with social exclusion and prejudice is one of the determining factors for the removal of people affected by leprosy from health units. Thus, understanding how people experience and (res) mean the disease, helps health professionals to develop interdisciplinary plans to ease suffering, stigmas, expand social / family reception and provide adherence to treatment without interruption.[6]

We seek to foster the construction of knowledge so that, increasingly, people who (con) live with leprosy or show signs and symptoms of the disease have access to information about the importance of early diagnosis and timely treatment in order to improve the quality of care. life. Thus, this research was based on the following question: what are the meanings attributed and self-reported feelings about the illness?

Therefore, the study aimed to understand the meanings attributed and self-reported feelings about the illness by people living with leprosy.

Method

Exploratory-descriptive study, with qualitative approach.[7] Research developed in a municipality in the interior of the State of Bahia, with an ESF as its locus. In this unit, people living with leprosy are welcomed, diagnosed, promptly treated in accordance with the form of the disease, receive guidance on diagnosis, treatment, follow-up, the importance of alerting intradomicillary contacts and referral for psychosocial support from a multidisciplinary team.

The choice of the referred unit was intentional, due to the academic approach in the development of curricular activities and for providing assistance to people affected by leprosy, based on the construction of bonds, permanent dialogues and monitoring by a multidisciplinary team, aspects that help in improving the user(s) quality of life.

Inclusion criteria were users who were affected by leprosy, over 18 years old, with a positive clinical diagnosis, and who had already started drug treatment. As exclusion criteria, those who were in the diagnostic confirmation process. After applying the criteria, three people participated in the interview.

A semi-structured instrument was used containing closed questions about the sociodemographic characterization regarding gender, age group, time of diagnosis / treatment, marital status, education; while the open ones allowed to apprehend the attributed meanings and feelings about their experience in the intercourse of the diagnosis and treatment of leprosy.

The interviews were conducted between May and June 2018, in a space / room reserved at the ESF, previously scheduled. An informant preferred to be interviewed at home, for that, access to her home was through the support of one of the Community Health Agents (CHA) responsible for the territorial area, who was available to schedule the interview, remember the day of the interview. visit and accompany the responsible researcher.

The interview conducted at the participant's home provided a more calm and safe environment, which favored greater participation and involvement. The interviews were recorded in audio format on an electronic device, after the participants' consent, and lasted approximately one hour.

At the end of each interview, the statements were transcribed and, in possession of the entire transcribed corpus, the material was submitted to the data analysis process. The Content Analysis Technique was used in the Thematic modality, following the steps of successive and fluctuating readings, construction of provisional hypotheses of the content of the text, determination of the units of records based on themes (sense of the word, phrase, paragraph)) and association of record units into theme units.[8]

The registration units were organized in a grid built in Microsoft Word, three columns were divided for each interviewee, in each of them the main thoughts, emphasis and concepts were organized based on the key questions. After this process, through phrases, words and paragraphs connected and recurring in the three speeches, the analytical dimensions for the study were outlined.[9]

According to the analysis of the testimonies collected in the interviews, three thematic units emerged, namely: "Marks visible on the body and (un) visible on the soul: the loneliness of those who face the stigmas of leprosy"; "Experiencing the feelings contributes to continue the daily work routine"; and, "Interfaces in the" role "of the health professional vis-à-vis the person living with leprosy". The thematic units were discussed in the light of the current literature on the topic.

The study was submitted to the Research Ethics Committee (CEP) of the University of the State of Bahia and approved under opinion No. 2,024,502. The ethical principles that guide research involving human beings were respected, as recommended by Resolution no. 466/2012 of the National Health Council. After clarifying the importance, objectives, risks and benefits, the subjects were invited to participate in the research, by acquiescence, reading and signing the Informed Consent Form (ICF).

Para garantia do sigilo, privacidade e anonimato das(os) participantes a coleta de dados ocorreu em ambiente privativo/reservado, mesmo para aquela em que o ambiente domiciliar foi cenário da coleta. Além disso, as(os) participantes foram identificadas por codinomes: PA - participante A; PB - participante B; e PC - participant C.

Results and Discussion

Among the study participants, one self-reported a woman and two self-reported a man; both had complete elementary school education, income of up to two minimum wages and age ranging between 28 and 52 years. The initial diagnosis occurred in less than a year, at which time the spots and / or loss of sensation were identified by the people affected.

The analysis of the thematic units allowed to understand the meanings attributed and the feelings guided by the self-reference of people affected by leprosy, as well as the identification of factors that hinder the treatment and the implementation of measures to interrupt the chain of transmission of the disease.

Visible marks on the body and (un)visible on the “soul”: the loneliness of those who face the stigmas of leprosy

The fear of collective exclusion and the lack of information about the disease, are still the main obstacles faced daily by those living with leprosy, especially in situations where the visit to the health unit is necessary and needs to happen from the beginning diagnosis and throughout the continuity of treatment / follow-up.

This is an important aspect, as it directly affects treatment adherence, clinical follow-up and, consequently, implies lesions / deformities resulting from the slow and progressive action of Mycobacterium leprae.[10-11]

Leprosy is still neglected in Brazil and has repercussions in the field of health, global policy records and health practices such as those that not only prevail in conditions of poverty, but also contribute to the intensification of inequalities.[4] In this sense, the reports of the participants in this study indicate that the person living with leprosy needs effective actions by the public health system with a view to changing the social perception of the disease.

In this respect, invisibility potentiates stigmatization and “carriers” feel as if they are “different” from other people, according to the following speeches:

> *When it's time to leave, you have to wear your pants so nobody can ask, but when it came out on your face? [...] So we have, I don't know, to back off.* (PA)
>
> *I lied saying it was an allergy because some people didn't want to touch it close to me.* (PC)

People affected by leprosy report the perception of negative feelings, which begin after the diagnosis and materializes by the presence of emotions such as sadness and fear, which together can contribute to lowering the esteem, triggering a depressive process and enhance social isolation. The stigma caused by being a "carrier" of a disease with physical and psychological marks may cause the individual to fear judgments, which in this way, resort to the distancing / isolation of living in society, family spaces and even social and health devices.

Among the psychological problems presented by people living with leprosy, depression frequently presents itself as it interferes with the individual's functionality and, consequently, with his adaptation to collective life. In these cases, the removal of family members and close people makes the illness process even more painful.[12-13]

In this context, we found, in the participants’ statements, the occurrence of more serious and disabling forms of the lesions caused by leprosy. Probably due to the possible delay in seeking health services, driven by the lack of knowledge of signs and symptoms; reinforced by fear of diagnosis and social stigma. In addition, it was possible to identify feelings of inferiority and sadness associated with the diagnosis of the disease, as observed in the following reports:

> *The feeling is not very good, no, if we don't get attached to God, we get depressed, I was sad, I didn't want to go to Mass or to any place anymore ... When I go out, I have to put on pants.* (PA)
>
> *When I found out I was so sad. People kept looking, looking at my arms, asking what it was, I answered it was allergy, I lied because it was too ugly, then they just kept looking at my arms ".* (PC)
>
> *I feel really bad ... I feel sad, right, but do what, right?* (PB)

The reported sadness is consistent with the existence of psychological vulnerability on the part of people living with leprosy, not necessarily because it is a potentially disabling disease, but because it causes changes in body image that negatively affect the self-esteem and identity of the patient. subject. Such aspects tend to favor the emergence of questions of a psychic nature, such as: depression, sadness, anxiety and stress.[14]

However, it is believed that simple measures such as: early diagnosis, psychotherapeutic and multiprofessional monitoring, especially in the context of the FHS, in addition to health education aimed at the community, which are effective actions to clarify diseases, ways of contagion and leprosy cure. All of this has direct implications for reducing the stigmatizing conception of the disease and "carriers" of the leprosy bacillus.

Experiencing the feelings contributed to continue the daily work

The construction of this thematic unit took into account the speeches of the (the) participants in relation to the difficulty and need that they had to remain at work. Thus, some reports pointed out the need to expose the body in activities whose clothing did not fully cover the lesions caused by leprosy, in addition, the development of more vigorous and intense activities caused pain. Adverse reactions to medications were also pointed out as limiting the performance and / or continuity of Daily Living Activities (ADL).

For some participants, the level of impairment caused by the disease generated effects in which the daily routine was impaired, such as repercussions on the family's income, due to the temporary or permanent removal from productive activities.

> *I stopped working because I can't sunbathe, nor do I want to leave the house.* (PB)
>
> *I stopped working because I feel pain, my strength has diminished, the sun is not good. My mind and body are tired, I think the drugs hit my head, how can I support my family?*(PA)

The life stage most affected by leprosy is related to the stages of life at a productive age: young adults. In this phase, this population group represents a large part of the "potentially active population". This is one of the aspects that incurs serious occurrences when considering that leprosy causes sequelae and physical disabilities that limits the exercise of activities, even the simplest ones, like ADLs.[15-16]

Leprosy proliferates more easily among the most vulnerable socioeconomic strata of the population, affecting the age group of 41 to 50 years. It is known that the referred age group is considered to be productive, with high development of work activities, mainly due to the inversion of the age pyramid with regard to population aging and, consequently, increased productivity from 40 years old.[17] Thus, reaching people in this age group causes not only their social / cultural exclusion, but also impacts on economic activities with a considerable drop in family income and consequences on quality of life.[18]

The confirmation of the highest degree of disability, which probably occurs due to the delay in starting treatment and / or not adhering to it, was identified in the speeches of the participants and made it evident that health professionals need to act actively in the communities in which they operate. Effective involvement can provide greater dissemination of information and knowledge about the main signs and symptoms of the disease, as well as access and treatment.

Interfaces in the "role" of the health professional vis-à-vis the person living with leprosy

The importance that health professionals, especially nurses, have in the face of diagnosis, treatment, monitoring and attention to the global needs of the person with leprosy is well known. However, in this study, with regard to the way they perceive the care provided by health professionals, the statements of those (s) who live with the disease proved to be driven by feelings of exclusion insofar as they seek assistance in health care units. In this regard, they seem to be distancing themselves from professionals who do not want them around, as can be seen in the excerpts below:

> *At the health center, some people / professionals do not touch me, I think because they know about the disease.* (PC)
>
> *The people look ... It is not good ... even at the healthcare unit the "people" (health professionals) treat us differently.* (PB)

The role of the FHS is relevant when offering health services in an equitable and quality manner so that there is a high quality of life and health for the population enrolled. In this scenario, the role of the nurse as a member of the health team stands out, who must provide their services in an ethical and qualified manner, effectively intervening in the health / disease process of people.[19]

It is worth mentioning the importance of the FHS in the diagnosis and cure of leprosy, however, there is a technical-scientific weakness in most health teams in the face of suspected leprosy cases. This insecurity collaborates strongly in reducing the demand for diagnosis, in addition to contributing to the evasion process of those (s) who are already under treatment, due to the low confidence and credibility passed by professionals to the population.[20]

We evidenced, in the speech of an interviewee, how the lack of qualification and professional unpreparing develops as a consequence the provision of unsatisfactory service for the population, whose resolution is also questionable, since it does not address the real needs of the user:

> *Since 2013 I had these spots, but the doctors only said it was allergy, I took medication for a while and nothing improved, then this year it got worse, there were many more spots and uglier ones.* (PC)

From the experience of this participant, it can be inferred that the delay in the clinical diagnosis seems to have contributed to delay the start of treatment. Although the identification of the signs and symptoms of leprosy cannot be the responsibility of a single professional, on the contrary, the other professionals working in the FHS must remain attentive and solicitous for the permanent discussion of clinical cases within the scope of ESF.

The commitment with the compulsory notification of the disease by the ESF / USF team is relevant, since it can provide (re) distribution of resources and / or investments and actions in areas / regions with a higher incidence of leprosy. However, unpreparedness and little investment in professional qualification contributes to the underreporting of new cases, and consequently an underestimated number of infected people.[21]

For the leprosy control, collective involvement and investments in professional (re) qualification are necessary, as it is a disease with a relatively high stigmatizing social burden, which requires effective action by professionals and the community to adopt a posture of inclusion, acceptance and understanding of people affected by this disease.

Conclusion

The study concluded that feelings such as fear, sadness and depression permeate the participants' discourse, showing prejudice, stigma and discrimination experienced by people with leprosy. Revealing that not only society, but also health professionals who work in Primary Care incite such feelings and enhance the process of illness. Thus, they consequently interfere with the prognosis of the disease.

Aspects such as the change in physical appearance and the shame of saying that the disease has contributed to the abandonment of work and directly affect their mental health. The distancing from family and close people due to feelings of inferiority and sadness, resulting from the diagnosis and treatment are enhanced. In this sense, the conduct of the health professional must be guided by welcoming, qualified listening and constant dialogue.

Thus, there is a need for studies aimed at the perception of health professionals, family members and managers in order to know the factors that have prevented actions / attitudes and specific planning of comprehensive care provided to people living with leprosy.

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Correspondent Author
Jones Sidnei Barbosa de Oliveira
Universidade Federal da Bahia
400 Mucio Uchoa Cavalcante Av. ZIP 50730670.
Engenho do Meio. Recife, Pernambuco, Brazil.
jonessidneyy@gmail.com