

# CUIDADO É FUNDAMENTAL

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## CONCEPTIONS ABOUT LEPROSY FOR RIVERSIDE DWELLERS: EVIDENCE FOR NURSING CARE

*Concepções sobre a hanseníase por ribeirinhos: indícios para o cuidado de enfermagem**Concepciones de la lepra de los ribereños: evidencias para la atención de enfermería***Luana Cavalcante Cardoso Caetano<sup>1</sup>** **Bruna Sabino Santos<sup>2</sup>** **Iací Proença Palmeira<sup>3</sup>** **Angela Maria Rodrigues Ferreira<sup>4</sup>** **Larissa Lima Figueira Freire<sup>5</sup>** 

### RESUMO

**OBJETIVO:** identificar as concepções de ribeirinhos da Amazônia paraense sobre a hanseníase. **Métodos:** estudo qualitativo e descritivo, realizado com 42 pessoas de uma comunidade ribeirinha do norte do Brasil, por meio de entrevista individual, semiestruturada. Aos dados aplicou-se análise temática de conteúdo. **Resultados:** prevalecem as concepções negativas sobre a hanseníase, amparadas no preconceito, sustentadas em uma visão mágico-religiosa e histórica de pecado, impurezas e castigos associados ao histórico da lepra, que envolve os processos saúde/doença e vida/morte, em que não ter hanseníase significa vida e tê-la se associa à morte. **Considerações finais:** evidenciaram-se saberes cristalizados do senso comum, baseados na religiosidade e no contexto histórico e sociocultural que explicam as múltiplas visões sobre essa doença milenar, e mostram que sua compreensão recebe mais influência de sua raiz histórica milenar e bíblica do que de sua história médica e social.

**DESCRITORES:** Conhecimento; Hanseníase; População Rural; Cuidados de Enfermagem; Enfermagem.

<sup>1,2,3,4,5</sup> Universidade do Estado do Pará, Pará, Belém, Brazil.

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**CORRESPONDING AUTHOR:** Luana Cavalcante Cardoso Caetano

**E-mail:** luanacaetano\_16@hotmail.com

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## ABSTRACT

**OBJECTIVE:** to identify the conceptions of riverbank dwellers in the Pará Amazon about leprosy. **Methods:** A qualitative and descriptive study was carried out with 42 people from a riverside community in the north of Brazil, using individual, semi-structured interviews. Thematic content analysis was applied to the data. **Results:** negative conceptions of leprosy prevail, based on prejudice, sustained by a magical-religious and historical view of sin, impurity and punishment associated with the history of leprosy, which involves the processes of health/disease and life/death, in which not having leprosy means life and having it is associated with death. **Final considerations:** crystallized common sense knowledge, based on religiosity and the historical and sociocultural context, which explains the multiple views on this ancient disease, and shows that its understanding is more influenced by its ancient and biblical historical roots than by its medical and social history.

**DESCRIPTORS:** Knowledge; Leprosy; Rural Population; Nursing Care; Nursing.

## RESUMEN

**OBJETIVO:** identificar las concepciones de los ribereños de la Amazonia Paranaense sobre la lepra. **Método:** estudio cualitativo y descriptivo realizado con 42 personas de una comunidad ribereña del norte de Brasil, mediante entrevistas individuales semiestructuradas. Se aplicó el análisis temático de contenido a los datos. **Resultados:** prevalecen concepciones negativas sobre la lepra, basadas en prejuicios, sustentadas en una visión mágico-religiosa e histórica de pecado, impureza y castigo asociada a la historia de la lepra, que involucra los procesos de salud/enfermedad y vida/muerte, en los que no tener lepra significa vida y tenerla se asocia a la muerte. **Consideraciones finales:** se ha demostrado que el conocimiento de sentido común cristalizado, basado en la religiosidad y en el contexto histórico y sociocultural, explica las múltiples opiniones sobre esta antigua enfermedad y demuestra que su comprensión está más influida por sus raíces históricas antiguas y bíblicas que por su historia médica y social.

**DESCRIPTORES:** Conocimientos; Lepra; Población rural; Cuidados de enfermería; Enfermería.

## INTRODUCTION

Leprosy is an infectious disease, and its high infectious power is a public health problem. According to the World Health Organization (WHO), Brazil is currently the second country in the world with the highest number of leprosy cases, and the second country with the highest number of new cases, behind only India. In the northern region, Pará is considered a hyper-endemic state for leprosy. In 2023, 1,349 new cases were reported, 92 of which occurred in minors, and in 2022, Pará was the state in the northern region with the most worrying situation regarding the disease.<sup>1-2</sup>

The endemicity of leprosy reveals weakened health actions and services in terms of interrupting the chain of transmission, making it a challenge, especially in terms of promoting health equity for populations considered vulnerable, with cultural particularities and life dynamics, influenced by the unique biogeography of the Amazon region. This atypical way of living and dealing with the health-disease process and the ways of taking care of oneself are reflected in the health actions recommended for the control of some diseases, especially stigmatized ones.

The Global Leprosy Strategy 2021-2030 proposed by the WHO served as the basis in Brazil for drawing up the

Guidelines for Surveillance, Care and Elimination of Leprosy, and for the creation of the National Strategy for Coping with Leprosy 2024-2030, which brought changes in the approach to coping with the disease, now instead of aiming to eliminate leprosy as a public health problem, the national strategy seeks to focus efforts on preventing transmission. However, the objectives remain the same as those of the previous strategy (2019-2022): reducing the burden of the disease, improving and qualifying comprehensive care for those affected in primary care, specialized services, outpatient and/or inpatient care, as well as guiding the work of managers, technicians and health professionals in management, planning, evaluation of reception, diagnosis, treatment, prevention of disabilities and service organization.<sup>1-3</sup>

These public policies aim to take action to combat the stigma and prejudice that have run through the centuries, because for a long time the terror associated with physical and socio-cultural marks remained imputed to the sick to denigrate the biopsychosocial and cultural being that they represented. In May 1962, by decree of Law 968, the compulsory isolation model was abolished and in 1995 Law 9010 of March 29 was created, which proposed changing the term leprosy to Hansen's disease in all official health

documentation, as an attempt to ease the stigma and prejudice surrounding this disease.<sup>4-1</sup>

However, memories of the disease are still present today, referring to the time of leprosy instead of Hansen's disease, when the disease had no cure and the patient was compulsorily excluded from social life and forced to live confined in hospitals/colonies, building up the symbolic construction of that disease that still has repercussions today in the imagery of Hansen's disease.<sup>5-1</sup>

Nurses have a fundamental role to play in deconstructing these stigmas, as they are the primary care professionals responsible for managing the disease, from detection and monitoring treatment to cure. To this end, it is essential to acquire a range of knowledge that allows us to understand the patient's view of the marks affixed to their physical body by the disease, which affects cultural issues in the private and social experience of each person living with leprosy and its problems.<sup>6</sup> In this sense, accessing the conceptions of riverside dwellers about leprosy can help professionals understand their attitudes and care practices towards the disease.

The aim of this study was therefore to identify the conceptions of river dwellers from the Amazon region of Pará about leprosy.

## METHOD

This was a qualitative study carried out in a riverside community in a municipality in the state of Pará. The participants were 29 women and 13 men who met the inclusion criteria: age 14 and over; living in the community for more than six months; belonging to the catchment area and being registered with the community's Family Health Strategy (ESF); being in any health condition: those who had never had the disease, leprosy patients (on drug treatment), as well as those who had completed treatment and been discharged cured. As for the exclusion criteria, there were no records of people unable to answer the questions.

A semi-structured interview was used as the data collection technique, using a script with two parts: one with closed questions to capture sociodemographic data and the other with open questions to capture the conceptions of the riverside dwellers about leprosy: When I say leprosy, what does it make you think of? when I say "So-and-so has leprosy", what image comes to mind?

Ethical principles were respected, and the project was approved by the Research Ethics Committee under opinion no. 3.087.982 (CEP: 66.063-010). The participants signed the Informed Consent Form (ICF) and their identities were

preserved through the use of alphanumeric codes, consisting of the letter R (ribeirinho) followed by the sequential number of the interview.

The data was collected between April and October 2019. The interviews were individual, recorded with consent, lasted approximately 30 minutes and took place in the participants' homes. They were then transcribed, and the sociodemographic data was subjected to simple and percentage statistics, and the interviews were subjected to thematic content analysis.<sup>7</sup>

## RESULTS

Among the 42 participants, 18 (42.8%) were aged between 16 and 30; 29 (69%) were female; 31 (73.8%) had a stable marital situation. As for schooling, 24 (57.1%) had incomplete primary education. The most followed religion was evangelicalism with 25 (59.5%) participants. The majority, 40 (95.2%), reported working informally.

Three thematic categories emerged from the content analysis: C1-Physical and functional repercussions; C2- Two names, same disease; C3- Religious and/or mystical repercussions.

### C1- Physical and functional repercussions

In this category, we sought to identify the physical and functional repercussions of the disease for the riverside dwellers. Among the participants, 36 (85.7%) highlighted physical deformities as the main aspect of the disease:

*I think leprosy is a very dangerous disease. I'm scared because it can leave you crippled and lead to death. So how do we work? It's difficult."* (R26)

*I've heard that it (leprosy) eats away at your fingers and if you don't take care of it, you'll lose more parts of your body.* (R2)

*I think that losing a body part is very painful, very sad, just imagining that I could lose my fingers is very painful.* (R22)

### C2- Two names, same disease

This is a dense category, which runs through the speeches and carries the social weight of the former "leprosy", referring to the stigma and prejudice arising from the change in body image. 36 (85.7%) of the participants linked leprosy to the former leprosy.

*Leprosy is the same disease, leprosy. I think it's just changed its name, but this disease causes the flesh to fall apart and wounds to appear. I've seen people with it."* (R6)

*From what I understand, leprosy is the same as the leprosy of the past, which removed the organs, ate the finger, wounded [...]. (R41)*

*Leprosy is similar to that leprosy, because there are also sores on the skin and a clear liquid comes out. I think leprosy is more serious and you have to be more careful, because it seems to be contagious, if I'm not mistaken. (R5)*

### C3- Religious and/or mystical repercussions

Religious explanations for the disease are still very strong in the imagination of this population, since "leprosy", as mentioned in biblical texts, was part of the testimony of 15 participants (35.7%).

*Leprosy is an evil thing, a curse that has come to attack a person's life. I think it was a test from God. God sent his servant this disease and he lost several things, including parts of his body, friends and children [...]. (R14)*

*I know that the Bible talks about leprosy, the plagues that will come upon the world, there's even a passage in the Bible that talks about a person who had leprosy, everyone left him and he lived there. (R24)*

*In the Ten Commandments (soap opera) it was said that when people acquired leprosy, they were kept in a cave away from the people for a period of quarantine. Those who believed in God received a cure, those who didn't died. (R21)*

## DISCUSSION

Leprosy is a serious disease that arouses negative feelings and conflicting thoughts, as the illness evokes a debilitated image of the body due to biopsychosocial disabilities.

One of the repercussions is death. Death is a socio-historical-cultural construct resulting from the person's environment and involves existential, subjective and spiritual dimensions about the meaning of life and finitude.<sup>8</sup> Leprosy can lead to systemic complications, which can affect the neurological system at different levels and lead to physical incapacity, but there is a consensus in the literature about its low lethality rate, based on the assertion that the patient dies with leprosy and not from leprosy.<sup>9</sup> However, this relationship with death continues to be the subject of reflection and people's negative attitudes towards the disease.

The social imaginary that punishes people with leprosy involves two processes: health/disease and life/death (not having leprosy/life and having leprosy/death). In the Middle Ages, control measures were aimed at those affected, excluding

them from the community. These practices were preceded by civil and religious rituals, in which the sick person was officially declared dead, with possible resurrection, according to divine will.<sup>10</sup> Thus, it appears that living with leprosy was a death sentence.

The historical course of leprosy, together with the riverside culture, which is built on the relationship/communication with natural elements, which become symbols of individual and community subjectivity, encompassing beliefs, myths, legends, values and customs, are determining factors in the attitudes and knowledge that these individuals acquire through the learning process related to the environment in which they live.<sup>11</sup>

Leprosy is cited for the loss of body parts, the result of a stigmatized social image linked to the history of "leprosy". Because it is a dermatoneurological disease, if diagnosed late it can have serious consequences. The impairment of the peripheral nervous system leads to a progressive decrease in sensitivity, which can cause a loss of tactile function, resulting in disabilities and deformities such as perforating ulcers, bone necrosis, neuropathic bone lesions and mutilation.<sup>12-13</sup>

At the time of "leprosy", because there was no treatment, it was common for the patient to be left with deformities, generating fear of contagion in people. Leprosy is considered to be humanity's oldest disease, and for this reason it has been part of the dramaturgy of human suffering since antiquity.<sup>13</sup> Thus, the prejudice and stigma surrounding leprosy are based on a historical construction of sin, impurity and punishment, directly associated with the image of people living with the disease.<sup>14</sup>

Added to this, the disfiguring and disabling sequelae of the disease resulted in multidimensional disorders. This contributed to the patient's social and family isolation.<sup>15</sup>

Thus, the stigma and prejudice arising from the change in body image carries with it the social weight of the old "leprosy" and this idea is still present, considering that this link is still there, as found in this study. The historical value of the leprosy stigma in terms of social isolation was reduced with the implementation of multidrug therapy and the approval of law 9.010/95, but this was not enough to eliminate prejudice.<sup>16</sup> The difficulty in changing the nomenclature is due to the fact that the view of "leprosy" as a place of exclusion is still very strong in communities with low access to information, as is the case with the population in this study.<sup>17</sup>

Riverine communities are characterized by little social organization and low political influence.<sup>18</sup> In addition to being quite distant from large urban centers, riverine communities are often forcibly included in general public policies without the specificities of their way of life being taken into account.



As a result, they face major economic, educational and health problems.<sup>19</sup>

This diverges from what the National Primary Care Policy proposes, since it says that primary care actions should involve all health processes, from promotion to rehabilitation and health surveillance, considering each population with its determinants, needs and peculiarities.<sup>20</sup> Thus, it is clear that the riverside population has limited access to information, reflecting directly on their conceptions of leprosy, and as a result outdated conceptions about the disease emerge, linking it to “leprosy”.

The inseparability of leprosy from Hansen’s disease goes far beyond a change of name. In ancient times, leprosy was seen as a punishment/curse, which justified the individual’s illness. This connotation has repercussions for the present day, as “leprosy”, as mentioned in the biblical texts, was part of some of the participants’ testimonies.

In this context, it should be noted that Amazonian religious culture has been strongly influenced mainly by Catholicism and indigenous traditions. For the riverside population, faith in God has an unquestionable dimension; it accompanies them at all times of their lives, whether in health, illness, danger, financial difficulties, among others, and the churches in these communities play an important role, including in social organization.<sup>21</sup>

Christian culture is one of the essences that make up the identity of the riverside populations.<sup>22</sup> This justifies the great influence of biblical texts on the riverside dwellers’ way of thinking about “leprosy”, considering that Judeo-Christian religiosity predominates among them, relating leprosy to the sacred scriptures.

Historically, religion has had a direct influence on the life of society, on its way of thinking and acting, and from this comes the influence of knowledge and attitudes about leprosy, especially with regard to biblical references to “leprosy”.<sup>23</sup>

The Judeo-Christian Bible is the most widely read and sold book in the world, with significant importance for Brazilians, and Christianity is the religion with the largest number of followers. However, the information it contains is often misinterpreted due to the various translations throughout history, which can lead to the spread of incorrect concepts. This also applies to leprosy, which at the time this sacred text was written was called leprosy. The Bible mentions this disease through parables which, for centuries, were used to blame individuals, associating it with divine punishment and giving it a connotation of sin.<sup>14</sup>

In this way, the Bible establishes the memory of “leprosy”, which is why it can be considered a founding text, because by

describing in its scriptures how to identify a leper and how to deal with him, it reinforces the effects of the meaning of being a leper that are reinscribed from memory and reconfigured in different temporalities.<sup>17</sup> In addition to this context, the lack of information also reinforces the maintenance of prejudice, since the leprosy/leprosy association links the disease to its historical process of contagion, without treatment and without cure, in which isolation was the only course of action.<sup>14</sup>

The results show that there is a need for health education work that takes into account the riverside dwellers’ knowledge about leprosy and adds new knowledge to existing knowledge, making them allies in disseminating information about the disease and thus helping to deconstruct stigma and prejudice in relation to leprosy.

The Family Health Strategy (ESF), as the developer of health actions in the community, is responsible for the closest monitoring of its target population. When it comes to the populations of the Campos and the Forest, it requires nurses to recognize the local cultural specificity, with the aim of providing care geared towards the reality of the community and thus being able to share ideas and knowledge for more effective health education, for which it is necessary to use language that is accessible to all members.<sup>24</sup>

Due to the geographical isolation imposed by the rivers, when they become ill, the river dwellers establish their own ways of taking care of their health, using their cultural heritage to find answers to their health problems. It is necessary for the health team, including nurses, to understand and respect the knowledge of this population in relation to leprosy.

## FINAL CONSIDERATIONS

In the conceptions of the riverside dwellers, the image of leprosy is still associated with “leprosy” and, as a result, the stigma that produces prejudice and social exclusion remains. The social repercussions of deformities bring with them magical-religious reflections on the disease, resulting in negative feelings such as fear of contamination and death. Such conceptions can potentially compromise the care recommended for people affected by leprosy.

The limitations of this study were due to the atypical environment occupied by the riverside population, as it has restrictions in terms of mobility and access, thus restricting the obtaining of scientific results in the Amazon scenario. Therefore, this study is limited to investigating the concept of leprosy in a single riverside community in the interior of Pará.

However, the results of this study can encourage reflection on the subject and be applied to communities with similar

characteristics. Expansion to other contexts will allow the data to be studied in greater depth, enabling more robust analyses, especially with regard to the distribution by age group and gender of the participants.

In this sense, this study could serve as a basis for future research on the subject, highlighting the need for research tools, as well as preventive and educational approaches to overcome barriers to access and information for these communities.

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