

My Color Is Not Like This, This Is the Color of the Medicine: Body Image of Individuals Under 15 Years Old Who Had Leprosy in Petrolina, PE and Juazeiro, BA

Michelle Christini Araújo Vieira¹  Maria da Glória Lima Cruz Teixeira²  Kamyla Vieira Ribeiro³ 
Kalliny Mirella Gonçalves Barbosa⁴  Thaysa Maria Vieira Justino⁵  Bruna Vidal⁶  Emily Fernandes Pereira⁶ 

¹Universidade Federal do Vale do São Francisco – UNIVASF. Petrolina/PE, Brasil.

²Universidade Federal da Bahia – UFBA. Salvador/BA, Brasil.

³Centro Universitário Facisa – UNIFACISA. Campina Grande/PB, Brasil.

⁴Universidade Estadual de Feira de Santana – UEFS. Novo Horizonte/BA, Brasil.

⁵Secretaria Estadual de Saúde de Pernambuco – SES-PE. Recife/PE, Brasil.

⁶Universidade Federal do Vale do São Francisco – UNIVASF. Petrolina/PE, Brasil.

E-mail: michelle.christini@univasf.edu.br

Abstract

This article aimed to understand the repercussions of leprosy on body image in individuals under 15 years old affected by leprosy. Fourteen children and adolescents under 15 years old who were registered in the Leprosy Control Program of Petrolina-PE and Juazeiro-BA and who had been discharged as cured participated in the study. A semi-structured interview technique was used, covering guiding questions about the experiences of the child and adolescent with the disease, addressing family, social aspects, and perceptions arising from the experience. The data obtained were analyzed using symbolic interactionism and Erving Goffman's sociology, also taking into consideration more contemporary readings on performativity. Based on the narratives produced, the aspects of body image of children and adolescents with leprosy were highlighted and organized into thematic axes: body image, effects of leprosy, racialization of the disease, and its consequences. It is evident that the predominant element of the research is anchored in the diseased and marked body images present in all interviews. Thus, for participants afflicted by leprosy, the body is perceived as "ugly," "sick," and "rejected," and such body image is associated with a negative impact on their self-image.

Keywords: Leprosy. Body Image. Social Stigma. Minors under 15 years old. Public Health.

INTRODUCTION

Leprosy is recognized as a serious social and public health problem, with the infection affecting the skin and nerves of individuals, potentially resulting in severe deformities and physical disabilities, as well as changes in skin color caused by treatment, which

contributes to social exclusion and the perpetuation of the disease stigma. The damage caused by leprosy has implications on physical, emotional, and sociocultural levels, which often interferes with the relationship of individuals affected by the disease with their

body image^{1,2}.

This fact is related to the overemphasis on beauty, evaluating bodies based on their interaction with the environment and overshadowing the subjectivity of individuals in pursuit of the socially constructed ideal body. This is because the definition of body image goes beyond the concepts of the terms "image" and "body," intertwining with each individual's unique qualities and characteristics that are constantly disregarded by the beauty industry. Through media, this industry stimulates the conflict between the actual body and the idealized body. It promotes the standardization of bodies by appealing to consumerism to conform to norms and beauty standards deemed desirable³.

In this perspective, body image relates to how an individual perceives and feels about their body. This perception is influenced by physical, emotional, and mental dimensions, as highlighted by Schilder (1977)⁴. Schilder reintroduces a concept of body image that operates with three structures: physiological, which involves anatomical and physiological aspects; libidinal, reflecting emotional experiences within human relationships; and sociological, built upon personal relationships and the acquisition of cultural and social values^{3,5}.

From this perspective, it is possible to comprehend the implications caused by body image distortion, especially in the context of a body afflicted by leprosy. The stigma associated with leprosy combines stereotyping and separation, manifesting as social exclusion, rejection, and problems in individual or group social interactions. In the realm of health, Erving Goffman⁶ categorized stigmatized individuals as "different from the norm," often associated with weakness, immorality, or danger, thereby linking them to undesirable characteristics or stereotypes.

Considering the social repercussions on individuals' bodies and images, it is noteworthy that the stigma surrounding leprosy is embedded in a historical context intertwined with notions of divine guilt and punishment. This stigma is further intensified by the "embodiment of stigma" through visible patches and deformities arising from the disease. These alterations stem from the mixed clinical nature of leprosy-associated neuropathy, which affects both sensory and motor-autonomic nerve fibers. This condition is justified by the affinity of *M. leprae* for peripheral nerves, leading to the gradual and silent progression of the disease, resulting in diminished sensitivity (thermal, painful, and tactile), loss of sweating, changes in natural skin lubrication, and/or decreased strength. If not detected and treated early, the patient can develop physical deformities and permanent disabilities^{7,8}.

The clinical manifestations and how the bodily appearance of a person with leprosy is altered are determining factors for the stigmatization of the disease. Beyond the acceptance process, some situations further intensify the changes in the body of individuals with leprosy. This is even evident during treatment, where clofazimine, one of the medications in the Multidrug Therapy (MDT), can cause skin hyperpigmentation, altering the patient's natural skin color and creating yet another visible mark that highlights the stigmatizing nature of the disease⁹.

Regarding the epidemiology of the disease, in Brazil, the new case detection rate was 1.99 per 10,000 population in 2020¹⁰. This is a sensitive indicator for assessing the epidemiological situation, reflecting the endemic pattern within a specific region¹¹. According to Freitas¹², the expansion of the disease among individuals under fifteen years old in-

tensifies transmission. Examining household contacts and increasing the cure rate is crucial, enabling early detection and timely treatment to halt the disease's progression.

Thus, the importance of investigating body image in individuals under 15 and the implications of this ancient disease becomes evident. This is associated with understanding the health of this minority population com-

prehensively to comprehend the specificities and repercussions of leprosy on body image, assuming compromised self-esteem as a starting point. Considering the scarcity of qualitative studies on individuals under 15 years old affected by leprosy, this article aims to provide some insights to comprehend better the impacts of this disease on the body image of young individuals affected by leprosy.

METHODS

A qualitative research approach was employed, drawing on the theoretical framework of Erving Goffman's¹³ sociology and his symbolic interactionism, aiming to understand how individuals interpret objects and their interactions with others and how this behavior is translated and interpreted in specific situations. Notions such as "frontstage," "performance," and "stigma" were utilized to comprehend the process of health and illness. Frontstage is linked to an individual's unconscious and expressive performance, while performance encompasses all activities that impact others. Stigma, on the other hand, is characterized by the divergence between an individual's actual attributes and the negative perception imposed by society¹³.

This article is part of the Doctoral thesis in Public Health titled "*Leprosy among Youth in Brazil: From Epidemiological Overview to Daily Repercussions*", defended at the Institute of Collective Health at the Federal University of Bahia (ISC/UFBA).

Fourteen young individuals of both sexes participated in this research, meeting the

following inclusion criteria: under 15 years old, being registered in the leprosy control program of the municipalities of Petrolina, PE and Juazeiro, BA, and having been discharged after a successful cure. The participants' ages ranged from 08 to 14 years, with eight being female. All of them were attending school, primarily in elementary education. Regarding the operational classification of leprosy, which determines the treatment regimen with Multi-drug Therapy (MDT) based on the number of skin lesions, quantity of affected nerves, and Degree of Physical Impairment (DPI), four participants had the Paucibacillary (PB) form, having up to five skin lesions with altered sensitivity. In comparison, ten participants had the Multibacillary (MB) form, with more than five lesions and altered sensitivity¹⁴.

Table 1 describes these participants by age (at the onset of the illness and during the interview), operational form of leprosy, and sex. The young individuals were identified by fictional names representing flowers from the Caatinga ecosystem, associated with their active form, as outlined below.

Table 1 – Presentation of participants by fictional name, operational form, sex, age at onset of illness, and age at the interview. Petrolina-PE and Juazeiro-BA, 2016-2017.

| Fictitious name | Operational form developed | Gender | Age at onset of illness | Age at interview |
|--------------------------------|----------------------------|--------|-------------------------|------------------|
| <i>Catingueira</i> Pauci | Paucibacillary | Female | 09 years | 11 years |
| <i>Cebola-brava</i> Pauci | Paucibacillary | Male | 10 years | 16 years |
| <i>Cipó-urtiga</i> Multi | Multibacillary | Male | 10 years | 15 years |
| <i>Coroa-de-frade</i> Multi | Multibacillary | Male | 09 years | 10 years |
| <i>Flor de Mandacaru</i> Multi | Multibacillary | Female | 11 years | 13 years |
| <i>Jitirana-azul</i> Multi | Multibacillary | Female | 11 years | 19 years |
| <i>Malva</i> Pauci | Paucibacillary | Female | 13 years | 16 years |
| <i>Maracujá-do-mato</i> Multi | Multibacillary | Female | 08 years | 11 years |
| <i>Melosa-roxa</i> Pauci | Paucibacillary | Female | 12 years | 15 years |
| <i>Mulungu</i> Multi | Multibacillary | Male | 12 years | 16 years |
| <i>Paineira-rosa</i> Multi | Multibacillary | Female | 10 years | 13 years |
| <i>Pau D'arco-roxo</i> Multi | Multibacillary | Male | 14 years | 17 years |
| <i>Quipá</i> Multi | Multibacillary | Female | 13 years | 15 years |
| <i>Velame</i> Multi | Multibacillary | Male | 11 years | 13 years |

Source: Direct data from the research.

The recruitment was carried out through the Infectious Disease Services of the municipalities, contacting the families regarding their interest in participating in the research. At the time of the interview, the participants were cured. They consented to participate in the study by signing the Informed Assent Form - IAF and having the legal representative's authorization through the Informed Consent Form - ICF, as provided for in Resolution CNS no. 510/2016. The interview took place in a location and at a time convenient for the guardians of the minors. Most of them were conducted at the participants' homes, except one that took place in a university space. The interview occurred with the participants' permission and lasted an average of one hour and thirty minutes.

Data collection took place between 07/22/2016 and 01/15/2017, using a semi-

-structured interview technique, a method characterized by the use of guiding questions in a flexible manner, allowing the interviewer to use subjectivity to ask questions not outlined in the script¹⁵. The interview aimed to produce narratives about the body image that young individuals had during and after being affected by leprosy: What did it mean to you to receive a leprosy diagnosis? Did leprosy cause any changes in your body? What changed in your life after you found out you had leprosy?

It is worth noting that all interviews were recorded with the participant's consent. The interpretation of the results followed the approach discussed by Squire¹⁶, which delves into research involving narratives. The author discusses ways to gather and analyze narratives of personal experiences, concei-

ved as a chain with a succession of social, cultural, and historical meanings that are not universal. This indicates that this set of signs operates with particularity rather than generality and cannot be reduced to theories.

Therefore, working with narratives served as a facilitator to understand how body image is constructed by young individuals affected by leprosy and the strategies used as a defense mechanism to cope with possible adverse repercussions arising from the experience. In the analysis process, an effort was made to organize the narratives based on thematic categories that emerged during the reading of each interview. In this article, the following themes or analytical "axes" will

be focused on: I - body image: *a beautiful body is one without leprosy*, an ugly body is one with leprosy; II - fear of the effects of leprosy; III - racialization of the disease and its implications.

In addition to seeking possible "interconnections" between the stories surrounding leprosy, the narratives were also important in highlighting peculiarities, "ruptures," and "inconsistencies" within these stories¹⁶.

This research was approved by the Committee on Ethics and Deontology in Studies and Research of the Federal University of Vale do São Francisco-CEDEP/Univasf, CAAE 52801216.0000.5196, and opinion number 1.448.193.

RESULTS

The research revealed that, for the interviewees, a body with leprosy is perceived as "sick" and "ugly," unlike a body without leprosy. This body image had a negative impact on self-image and altered the individual's "real social identity" before, during, and after the illness.

Regarding the question, "What did the diagnosis of leprosy mean to you?" *Mulungu Multi* responded:

"When they told me I had leprosy, I didn't think much. I was just anxious to get to the end of the treatment and get rid of it, to have the mark on my face go away quickly because it was ugly, and the marks on my face were what bothered me the most. It left a significant mark, and I looked really bad with that dark thing marked on my face" (Mulungu Multi).

In addition to the perceived ugliness associated with the body affected by leprosy, the participants also felt impacted by changes in skin color. When asked, "What did the

leprosy diagnosis mean to you?" *Cipó-urtiga Multi*, thirteen years old during his illness, pointed out that what bothered them the most was the altered and pronounced color of their skin resulting from clofazimine, which is an aminophanzone dye and exerts a slow bactericidal effect on *Mycobacterium leprae*. Clofazimine is one of the drugs used to treat both the PB and MB forms of leprosy.

"The worst thing that happened was changing the color of my skin because when I think of leprosy, I think of skin color change, headache, spots, and itching. But the change in color bothered me a lot, and I really want to have my normal color back because it bothers me a lot. My color was almost the same as my sister's, a little darker" (Cipó-urtiga Multi).

Mulungu Multi was twelve years old, and his body had been marked significantly, with marks on his legs, back, and chest. However, the spot that developed on his face drastically altered their self-esteem. In interactions

with this young person, this was a frequent concern. Whenever other topics were brought up, the conversation often circled back to the mark on his face and the eagerness to have his image restored. Thus, in response to the guiding question, "Did leprosy cause any changes in your body?" the participant shared:

"When I go out in the sun, I get darker, and this scar looks even uglier; I just hope they disappear, and if they don't go away, we'll just deal with it, even though the one on the face bothers me a lot because it's ugly, and we were used to being fair-skinned, with these things on the face, people start teasing. [...] The swelling and these marks were the things that changed the most for me, and there are still marks on my back, plus the ones on my legs that don't bother me like the one on my face does; the face bothers me" (Mulungu Multi).

Quipá Multi and Flor de Mandacaru Multi were twelve and eleven years old during their illness, respectively. They both presented with spots, ulnar nerve involvement, and developed an "ulnar claw." Ulnar nerve lesion results in loss of sensation and is known as ulnar nerve paralysis. The condition can affect the ability to perform fine movements, such as gripping, causing the hand to resemble a claw.

"This thing on my hand won't come back. My normal fingers that I wanted, they won't come back. [...] I didn't want to feel ashamed, but I couldn't help it; it's just that I see myself differently from other people. That's what bothers me the most" (Quipá Multi).

"People would question, sometimes when the teacher began to write on the board, and because of how it affected my hand, sometimes it would start to hurt, I felt pain... that's when it began" (Flor de Mandacaru Multi).

The narratives revealed a fear associated with the changes that the disease caused in the physical body, whose marks endured. From the account of Cebola-brava Pauci, perceptions of ableism in the face of potential

disabilities resulting from the disease and apprehension regarding the possibility of reinfection become evident. Regarding the guiding question, "What changed in your life after finding out you had leprosy?" the participant responded:

"After the wound, a lot changed. I've had this wound on my leg since I was ten years old. I think it's really ugly, and it bothers me a lot. I'm afraid it might come back again... I'm afraid of losing my leg... I didn't like this spot because it's all 'weird' still. And it seems like it's changing color. It used to be white, then turned black, now it's black... I'm not ashamed of the spot. I wear shorts, normally. My problem is just the fear of it coming back. It doesn't bother me, but if it were on my arm, I'd be ashamed because it would be a big noticeable spot..." (Cebola-brava Pauci).

Furthermore, participants' accounts highlighted instances of social discrimination due to the darkening of the skin caused by Clofazimine. In response to the question, "What changed in your life after finding out you had leprosy?" participants shared their experiences:

*"I still go out in the sun, no problem; I just get dark. The color changes, gets dark, really dark, and I find it very bad to change color. Others started calling me black, and that bothers me; it's not good. **My color is not like this; this is the color of the medicine**" (Cipó-urtiga Multi).*

"There was a day when I looked at my body and thought, 'Oh my God, I'm so dark.'... I had to be careful in the sun because I got really dark. We didn't imagine I'd get this dark. The doctor said I would, but I got so dark that I didn't want to go to school. I was really dark, and people at school would say, 'Wow, you're getting tan, really tan,' and 'Look how dark you are.' I'd say, 'Oh, I don't know, maybe it's the sun from my house to school,' and they'd reply, 'but your house is nearby, you don't even get sun.'... 'Flor de Mandacaru, you're so dark.' That bothered me because I realized that, like those who have prejudice

against people with darker skin, it worried me a lot. I thought, 'Wow, they suffer', and now I'm suffering too. I was really worried, 'Oh my God, what if I get even darker than this'" (Flor de Mandacaru Multi).

Mulungu Multi had no option to hide his condition; his mark was on his face. In his narrative, he referred to the disease as "this

disease", expressing his strong discomfort with being called "black".

"I used to be really fair-skinned, and that bothered me because I was used to being called 'fair-skinned.' Now they came up with other nicknames like Zé and black guy. I went from being 'fair-skinned' to 'black guy.' I put up with it, I could take it" (Mulungu Multi).

DISCUSSION

Body image: a beautiful body is a body without leprosy, an ugly body is a body with leprosy.

For contemporary youth, the body is not just "a body." They use their body as a symbol, "facades," wearing their "masks" for recognition and acceptance by others, enabling communicative interaction. This body carries a repertoire of "disguise charades" capable of transforming them into "multiple and fictitious selves." In this game of "disguise charades," a stranger tries to impress the other with positive credits, even though being a "character" in Goffman's sociology, the "discredited" one^{6,17,18}.

Society categorizes their peers with minimal expected attributes, and stigma arises when the standard "normal" stereotype becomes incongruent with what is imagined for a specific individual. This normative expectation emerges through the framing of the other⁶. Thinking about individuals under 15 with leprosy means thinking about the "discredited," where the characteristics that set them apart from "normality" are already known or immediately evident. In the case of the "discreditable," the stigma characteristic is neither known by peers nor immediately perceptible. This is the clear differentiation between those with PB and MB forms of leprosy. A young person with the PB form is "discreditable" to themselves, bearing the weight of the illness and managing to conceal leprosy. This is in contrast to those with

the MB form, whose condition is revealed by "bodily signs" being "discredited" by their peers.

In a world where media strongly influences the spread of beauty ideals, the notion of the perfect body, and where personal image navigates social networks marked by the culture of self and the overemphasis on appearance, what contradicts the notion of beauty is generally rejected^{19,20}. Youth, along with women, are often identified as the groups most commonly dissatisfied with their body image²¹. According to Goffman⁶, the "real social identity" is the category of attributes the individual indeed possesses.

The medicinal treatment for leprosy involves a combination of drugs: clofazimine (CFZ), rifampicin (RFM), and dapsone (DDS). Individuals undergoing therapeutic regimens must be informed about the possibility of skin discoloration, changing from red to dark brown, alteration in the color of the conjunctiva, tears, sweat, saliva, urine, and feces caused by the medication. The most common skin-related effects associated with CFZ are hyperpigmentation and ichthyosis. RFM can lead to hepatotoxicity, thrombocytopenia, hemolytic anemia, and pseudogripal syndrome. Adverse reactions in laboratory tests may show the presence of anemia associated with DDS use. Additionally, it's noted that due to the emergence of adverse drug reactions, treatment adherence can be affected^{22,23}.

The body image of people with leprosy is also affected by the disabilities and deformities that have arisen due to inadequate disease management or delayed diagnosis. Thus, these deformities and disabilities bring about life changes, and actions to prevent such issues must not solely be based on the "physical dimension of the body" and a technical approach. Despite leprosy being considered an adult disease, where disabilities or deformities typically result from delayed diagnosis, young individuals also experience the same issue of having their bodies affected by the disease²⁴.

From a perspective of anatomic-functional normality, the body represents the image of "equality". The perception of body image and beauty influences the construction of a person's identity. Historically, the standardization of beauty or the "labeling" of what is beautiful is shaped by social, economic, historical, and local contexts. Thus, among adolescents, media and societal pressures influence beauty standards and become sources of concern, given that adolescence is characterized as a phase of identity formation. Dissatisfaction with body image arises from the discrepancy between the real and idealized body image, and the imposition of beauty parameters reproduces scenarios of exclusion¹⁹.

In this regard, the body can be perceived in two ways: the body we "have" (object-body), which can be measured, weighed, "known by pathologists after our death," and the body we "are" (subject-body), which we know through self-perception²⁵. This is the "made," "performed" body, in continuous interaction throughout daily practices, including with objects and materials, such as clofazimine. Mol and Law²⁵ emphasize that although the lived body is not fragmented, it is also not a coherent whole. The belief that we have a "coherent body" or that we are a "totality" conceals much work. For these authors, the body is thus an area of tension, a "complex configuration". However, these

tensions cannot be avoided in our daily lives; they can only be managed.

Therefore, a body-with-leprosy is seen through the practices of the interlocutors. Thus, it is conceived as a product or effect of many interactions: between the young individual, clofazimine, biological reactions, school, technical procedures, professionals, family, leprosy, discourses, etc. This is a network of relationships between the individual and the "objects of practice." What emerges is a material body immersed in symbolic webs of a lived, intertwined, and tense "reality".

Fears of the Effects of Leprosy on the Body

In the present day, influenced by the culture of beauty consumption, the internalist and introspective model of self-description and construction is overlaid by the formation of bio-identity, where the creation of ideal models of individuals is based on the appearance of the body²⁶. When associated with diseases that alter the human figure, the perpetuation of the beauty ideal leads to repercussions that interfere with daily life. In the case of leprosy, such issues are strongly marked by fear and ideas related to contagion and prejudice²⁷.

The fear and anxiety arising from leprosy can only be understood and explained by focusing on the "body and the senses associated with it," as it affects two essential dimensions: aesthetic appearance and productivity. A person's self-image with leprosy influences interpersonal relationships due to the feeling of estrangement related to one's own body, causing isolation, shame, and difficulty in accepting the new body image within society^{28,29}.

The concealment of the marked body results from the fear of social exclusion, as it is within this physical structure that the "bodily signs" of stigma are revealed, and this disruption of body image hinders the adherence to

self-care, as well as the socialization of individuals with leprosy, thereby amplifying the stigma of the disease³⁰.

Racialization of the disease and its ramifications

Based on the discussions about stigma proposed by the literature, these young individuals can be categorized into two stigmas: 1) abominations of the body and 2) tribes of race, nation, and religion⁶. The stigmas of abominations of the body manifest through the marks left by the disease. This is a process from others toward the young person. The stigmas of race, nation, and religion, specifically here of race, are a process from others toward the young person and also from the young person toward themselves. They perceive themselves as belonging to another race due to the darkening of their skin, leading them to the prejudice that is produced, which they may eventually experience for belonging to this group. There is a racialization of the disease when the side effect of clofazimine causes the skin to discolor and darken, and young individuals also find themselves experiencing racial discrimination from their peers.

Therefore, to understand this "young body afflicted by leprosy", it is crucial to understand this "network" in which the affliction is produced. In this sense, the phenomenon of leprosy occurs or emerges in the daily lives of these young individuals, including a heterogeneity of events and actions. Following the same direction as Mol and Law²⁵, to "know" leprosy, it is important to understand it as a product of these practices, including the appearance of the first numb patch on the skin, errors and delays in diagnosis, family interactions after the discovery of the affliction and their tensions and fears, visits to the clinic for clinical examination that involves a thorough assessment of the entire body to count the patches for clinical and

operational classification of the disease, interaction with inadequately qualified professionals trying to understand the nuances of the youth's world, laboratory tests that involve scraping the ears and elbows with the squeeze of forceps and a cutting scalpel, and test results, which may or may not show the presence of *Mycobacterium leprae*, and even if not detected, will still be a positive case of leprosy, as this test is intended to aid in determining whether the case is PB or MB.

All of this will confirm that the person has a stigmatizing disease by completing a notification/investigation form that categorizes them into demographic and clinical boxes and turns them into an epidemiological number. For PB cases, the treatment lasts six months, and for MB leprosy, the duration is twelve months. In both types, the individual must visit the health facility monthly to take a supervised dose of medication in the presence of a healthcare professional.

During the treatment, the patient will receive a blister pack of medication to take at home for twenty-seven days, will resort to strategies to conceal the marks of the disease through clothing, maintain family secrecy, fear of disabilities, fear of not being cured, fear of discrimination and exclusion. And only after all of this can they be considered cured. However, this is not an easy task because lying or omitting a condition, having a modified routine, adhering to medication use, and bearing a marked and exposed body – all this brings about changes that affect the individual's life in various aspects.

In the process of constructing this study, there was a recognition of the limitation in knowledge about the issues and coping strategies of young people living with leprosy due to the scarcity of scientific publications addressing this topic. This limitation prevented the theoretical grounding of the findings and comparison of results. Nevertheless, the presented results are essential for highlighting how this disease negatively impacts

daily life and the defense strategies used by young individuals and their families to navigate the phase of affliction.

Thus, it is possible to perceive that the present study raises the possibility of developing research on the daily lives of young pe-

ople afflicted with leprosy, the strategies of families in this coping process, such as family perceptions of affliction, gender issues, and leprosy, analysis and adaptation of pharmaceutical presentation of medication for young individuals, among other relevant issues.

CONCLUSION

While preparing this article, it was challenging to find works with the same theme to support the findings on the topic theoretically. Thus, some terms were used to represent the theme; this "young body with leprosy" is perceived and "performed" by individuals in their daily interactions. For this purpose, responses commonly repeated by biomedical experts are disregarded. From the analyses presented in the article, a vast and unexplored field for research was observed, with some paths that can enable an understanding of how a stigmatizing disease affects the lives of young individuals.

It is important to understand that the body afflicted by leprosy takes on multiple forms through the intersection and heterogeneous actions, i.e., those originating from the general population and its "common sense" from the young individuals themselves, mediated by their fears, anxieties, values, and knowledge; and from healthcare professionals, often conflicting with the patient's perceptions. It is within this scenario that relationships inter-

twine and create tension.

For these young individuals, their bodies with leprosy are seen as "ugly," "sick," and "rejected," and this body image has a negative impact on their self-image, with positive notions about the affliction not being captured. It is also essential to highlight the repercussions of changes caused during the onset of leprosy, whether induced by the disease or medications. These alterations pose challenges for the afflicted individuals in terms of interacting with their families and various social groups.

Therefore, it's crucial to understand perceptions of the health/illness process, democratize information, provide appropriate technologies, and understand the socio-cultural imagery related to leprosy, the imagery of the body itself, and the daily practices of different actors. Indeed, knowledge of these practices will be important and necessary for rethinking and creating new strategies for healthcare and educational actions for young individuals who live or have lived with leprosy.

Author Statement CREdiT

Conceptualization: Vieira, MCA; Teixeira, MGLC; Ribeiro, KV; Justino, TMV; Vidal, B; Pereira, EF. Methodology: Vieira, MCA; Teixeira, MGLC; Ribeiro, KV; Justino, TMV; Vidal, B; Pereira, EF. Validation: Vieira, MCA; Teixeira, MGLC; Ribeiro, KV; Justino, TMV; Vidal, B; Pereira, EF. Formal analysis: Vieira, MCA; Teixeira, MGLC; Ribeiro, KV; Justino, TMV; Vidal, B; Pereira, EF. Research: Vieira, MCA; Teixeira, MGLC. Resources: Vieira, MCA; Teixeira, MGLC. Elaboration of the original draft: Vieira, MCA; Teixeira, MGLC. Writing and proofreading: Vieira, MCA; Teixeira, MGLC; Ribeiro, KV; Justino, TMV; Vidal, B; Pereira, EF. Supervision: Teixeira, MGLC. Project management: Vieira, MCA; Teixeira, MGLC.

All authors read and agreed with the published version of the manuscript.

REFERENCES

1. Souza AO, Martins MD. Aspectos afetivos e comportamentais do portador de hanseníase frente ao estigma e preconceito. *Rev. de Inic. Cient. da Univer. Vale do Rio Verde*. 2018;8(1). [citado em 9 de abril de 2022]. Disponível em: <http://periodicos.unincor.br/index.php/iniciacaocientifica/article/view/2984>.
2. Sardana K, Khurana A. Leprosy stigma & the relevance of emergent therapeutic options. *The Indian J Med Res.* 2020 Jan;151(1):1-5. doi: 10.4103/ijmr.IJMR_2625_19. [citado em 20 de abril de 2022]. Disponível em: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7055175/pdf/IJMR-151-1.pdf>.
3. Russo R. Imagem corporal: construção através da cultura do belo. *Mov. & Percep.*, 5(6), p. 80-90, 2005. [citado em 1 de junho de 2022]. Disponível: <http://ferramentas.unipinhal.edu.br/movimentoepercepcao/viewarticle.php?id=39>.
4. Schilder, P. (1977). *A imagem do corpo*. Buenos Aires: Paidós.
5. Secchi K, Camargo BV, Bertoldo RB. Percepção da imagem corporal e representações sociais do corpo. *Psic: Teor e Pesq [Internet]*. 2009;25(2):229-36. doi: <https://doi.org/10.1590/S0102-37722009000200011>. [citado em 1 de junho de 2022]. Disponível em: <https://www.scielo.br/j/ptp/a/XJTvDh7DNdbMfwLLPZrXpbF/?format=pdf&lang=pt>.
6. Erving G. *Estigma: notas sobre a manipulação da identidade deteriorada*. 4ª ed. Editora Guanabara. 1988. [citado em 4 de junho de 2022]. Disponível em: https://www.mprj.mp.br/documents/20184/151138/goffman,erving.estigma_notassobreamanipulacaodaidentidadedeteriorada.pdf.
7. Uchôa R, Brito K, Santana E, Soares V, Silva M. Perfil clínico e incapacidades físicas em pacientes com hanseníase. *Rev. de Enferm. UFPE online [Internet]*. 2017 Mar 2; 11(3): 1464-1472. doi: 10.5205/reuol.10263-91568-1-RV.1103sup201719. [citado em 22 de maio de 2022]. Disponível em: <https://periodicos.ufpe.br/revistas/revistaenfermagem/article/view/13990>.
8. Santos AR, Ignotti E. Prevenção de incapacidade física por hanseníase no Brasil: Análise histórica. *Cien Saude Colet*. 2019. [citado em 4 de agosto de 2022]. Disponível em: <http://cienciaesaudecoletiva.com.br/artigos/prevencao-de-incapacidade-fisica-por-hanseniase-no-brasil-analise-historica/17077?id=17077>.
9. Silva WCS, Costa NL, Argentino S, Oliveira NP, Rodrigues DS. A estigmatização da Hanseníase: Vivências dos pacientes tratados em uma unidade básica de saúde. *Braz. J. Develop. [Internet]*. 2020;6(3):15824-33. [citado em 1 de junho de 2022]. Disponível em: <https://ojs.brazilianjournals.com.br/ojs/index.php/BRJD/article/view/8208>.
10. Brasil. Ministério da Saúde. Secretaria de Vigilância em Saúde. *Boletim Epidemiológico: hanseníase*. 2022. [citado em 6 de agosto de 2022]. Disponível em: https://www.gov.br/saude/pt-br/centrais-de-conteudo/publicacoes/boletins/epidemiologicos/especiais/2022/boletim-epidemiologico-de-hanseniase-_25-01-2022.pdf.
11. Boigny RN. Falhas operacionais no controle da hanseníase em redes de convívio domiciliar com sobreposição de casos em áreas endêmicas no Brasil. *Epidemiol. e Serv. Saúde*. 2020;29(4). doi: <https://doi.org/10.5123/S1679-49742020000400004>. [citado em 22 de maio de 2022]. Disponível em: <https://www.scielo.br/j/ress/a/YjWgZXwYLwxMdkwXdQhfS8r/?lang=pt>.
12. Freitas BH, Xavier DR, Cortela DD, Ferreira SM. Hanseníase em menores de quinze anos em municípios prioritários, Mato Grosso, Brasil. *Rev. Bras.de Epidemiol.[Internet]*. 2018;21. doi: <https://doi.org/10.1590/1980-549720180016>. [citado em 1 de junho de 2022]. Disponível em: <https://www.scielo.br/j/rbepid/a/pzBkX8BKMCdBLtWdp5JQckQ/?lang=pt>.
13. Erving G. *A representação do eu na vida cotidiana*. 16ª ed. Editora Vozes. 2009.
14. Brasil. Ministério da Saúde. Secretaria de Vigilância em Saúde. Departamento de Articulação Estratégica de Vigilância em Saúde. *Guia de Vigilância em Saúde [recurso eletrônico]*. Brasília: Ministério da Saúde; 2021. 1.126 p. : il. [citado em 20 de junho de 2022]. Disponível em: https://bvsmis.saude.gov.br/bvs/publicacoes/guia_vigilancia_saude_3ed.pdf.
15. Santos, AF; Jesus, GG; Battisti, IK. Entrevista semi-estruturada: considerações sobre esse instrumento na produção de dados em pesquisas com abordagem qualitativa. *Salão do Conhecimento*, 7 (7), 2021. [citado em 20 de junho de 2022]. Disponível em: <https://www.publicacoeseventos.unijui.edu.br/index.php/salaocohecimento/article/view/20805>.
16. Squire C. O que é narrativa? *Civitas*, Porto Alegre, 14(2) p. 272-284, maio-ago 2014.
17. Pais JM. Busca de si: expressividades e identidades juvenis. In: Almeida MIM & Eugenio F. (Orgs.), *Culturas Jovens: novos mapas do afeto*. p.07-21. Rio de Janeiro: Zahar Editor. 2006.
18. Koury MGP. Sobre Erving Goffman e a análise do fracasso em *The Presentation of Self in Everyday Life*. *Dilemas, Rev Estud Conflito Controle Soc*. 2019; 12(3):525-540. [citado em 1 de junho de 2022]. Disponível em: <https://revistas.ufrj.br/index.php/dilemas/article/view/24692>.
19. Leite LC, Souza VDP, Oliveira LR, Munk M. As vivências do PIBID: o que é bonito pra você? Com a Palavra, o Professor [Internet]. 2019. 4(9):15-35. doi: <https://doi.org/10.23864/cpp.v4i9.378>. [citado em 22 de maio de 2022]. Disponível em: <http://revista.geem.mat.br/index.php/CPP/article/view/378>.
20. Santos MS, Gonçalves VO. Uso das redes sociais, imagem corporal e influência da mídia em acadêmicos dos cursos de educação física. *Rev. Itinerarius Reflectionis [Internet]*. 2020;16(3):01-18. [citado em 22 de maio de 2022]. Disponível em: <https://www.revistas.ufg.br/rir/article/view/58815>.
21. Gonçalves FTD, Menegon VGS, Oliveira MMS, Silva RR, Carneiro MS, Lemos AVL, Guimarães LDA, Araújo ZAM, Conceição PWR, Silveira CAS. Imagem corporal feminina e os efeitos sobre a saúde mental: uma revisão bibliográfica sobre a intersecção entre gênero, raça e classe. *REAS [Internet]*. 2020;(39):e 2194. doi:<https://doi.org/10.25248/reas.e2194.2020>. [citado em 1 de junho de 2022]. Disponível em: <https://acervomais.com.br/index.php/saude/article/view/2194>.
22. Filho TA, Souza VA, Souza MM, Marques AE, Sousa FDA. Efeitos adversos à poliquimioterapia em pacientes com hanseníase atendidos nas unidades básicas de saúde na cidade de cajazeiras - pb. *Educ. Ci. e Saúde [Internet]*. 2020;7(1). doi:<https://doi.org/10.20438/ecs.v7i1.254>. [citado em 25 de junho de 2022]. Disponível em:<http://periodicos.ces.ufcg.edu.br/periodicos/index.php/99cienciaeducacaosaude25/article/view/254>.

23. Pires CA, Dos Santos MA, Biasi BH, Moreira AG, Coimbra AC, Ferreira MC, Nascimento MS, De Brito JB, Carneiro FR. Análise da ocorrência de reações adversas à poliquimioterapia no tratamento para hanseníase. REAS [Internet]. 2021;13(2). doi: <https://doi.org/10.25248/reas.e6233.2021>. [citado em 22 de maio de 2022]. Disponível em: <https://acervomais.com.br/index.php/saude/article/view/6233>.
24. Oliveira JDCP, Marinus MWLC, Monteiro EMLM. Práticas de atenção à saúde de crianças e adolescentes com hanseníase: discursos de profissionais. Rev Gaúcha Enferm. 2020;41:e20190412. doi: <https://doi.org/10.1590/1983-1447.2020.20190412>. [citado em 1 de junho de 2022]. Disponível em: <https://repositorio.ufpe.br/handle/123456789/34120>.
25. Annemarie MOL; John, LAW. Embodied Action, Enacted Bodies: The Example of Hypoglycaemia. Body and Society. 2004;10(2-3); p. 43-62.
26. Ortega F. Das utopias sociais às utopias corporais: identidades somáticas e marcas corporais. In: Almeida MIM & Eugenio F. (Orgs.), Culturas Jovens: novos mapas do afeto. p. 42-58. Rio de Janeiro: Zahar Editor. 2006. [citado em 1 de junho de 2022]. Disponível em: http://old.scielo.br/scielo.php?script=sci_nlinks&ref=000150&pid=S1413-8123201200040002700019&lng=en.
27. Marinho FD, Avellar LZ, Souza LG, Nardi SM, Coutinho GC. Hanseníase: sentidos e facetas do convívio para adolescentes com a doença e seus familiares. Cad. Bras. de Ter. Ocup. [Internet]. 2018;26(4):837-48. doi: <https://doi.org/10.4322/2526-8910.ctoao1251>. [citado em 22 de maio de 2022]. Disponível em: <https://www.scielo.br/j/cadbto/a/kcybmhVgl7FBhtmG6C7j4Qz/?format=pdf&lang=pt>.
28. Nascimento E, Coelho V, Souza C, Pereira M, Freitas M, Rocha A, Paula A. Auto-percepção da aparência física, das relações conjugais e da atividade sexual de indivíduos com Hanseníase. Rev. de psicologia [Internet]. 2019; 13(48): 113-129. [citado em 1 de junho de 2022]. Disponível em: <https://idonline.emnuvens.com.br/id/article/view/2145>.
29. Gonçalves M, Prado MA, Silva SS, Santos KD, Araujo PN, Fortuna CM. Work and Leprosy: women in their pains, struggles and toils. Rev. Bras. de Enferm. [Internet]. 2018 [citado em 2 junho de 2022];71(suppl 1):660-7. doi: <https://doi.org/10.1590/0034-7167-2017-0598>. Disponível em: <https://www.scielo.br/j/reben/a/h8yhG4LQ3csDnVMRFZcHm7g/?lang=en>.
30. Coppi MA, Ueker KG, Teston SF. Aceitação social, autoimagem e bem-estar subjetivo de adolescentes. SIEPE [Internet]. 2018 [citado 1 de junho de 2022]. Disponível em: <https://portalperiodicos.unoesc.edu.br/siepe/article/view/17699>.

Received: 22 september 2022.

Accepted: 05 July 2023.

Published: 19 september 2023.