

Effects on the daily lives of children and teenagers who lived with leprosy

Repercussões no cotidiano de crianças e adolescentes que viveram com hanseníase

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DOI: 10.1590/0103-11042022E6111

ABSTRACT The study aims to understand the effects of the disease on the daily lives of children and teenagers affected by leprosy. This was a qualitative research based on the theoretical framework of ‘The Sociology of Erving Goffman’. We interviewed 14 participants individually, nine children and five teenagers, who underwent treatment for leprosy and were cured. A semi-structured interview was used, covering sociodemographic information and guiding questions about the participants’ experiences with the disease, family, social aspects, and perceptions derived from the experiences. The data were analyzed by the sociology of Erving Goffman. The narratives emphasized the effects on daily life related to leprosy discovery, interaction networks, such as family and health professionals, health care, overcoming strategies and expectations. It was verified that the predominant element of the research is anchored in the fear of being discovered and discredited, in the perspective of having their identity of health resignified, by the illness, and by the evidence in view of the participant’s experience due to prejudice, anonymity, and secret. This symbolically suggests that the participants experienced a certain construction of negative social life around leprosy. The illness directly interferes with their daily life and development, especially in the participant’s social relationships.

KEYWORDS Leprosy. Child. Adolescent. Activities of daily living. Social stigma.

RESUMO O estudo apresenta como objetivo compreender as repercussões da doença na vida cotidiana de crianças e adolescentes acometidos pela hanseníase. Trata-se de uma pesquisa qualitativa com base no referencial teórico ‘A Sociologia de Erving Goffman’. Foram entrevistados, individualmente, 14 participantes, sendo 9 crianças e 5 adolescentes tratados e curados da hanseníase. Utilizou-se entrevista semiestruturada, abrangendo informações sociodemográficas e questões norteadoras sobre a vivência dos participantes com a doença, aspectos familiares, sociais e percepções advindas da experiência. Os dados foram analisados pela sociologia de Erving Goffman. As narrativas enfatizam as repercussões do cotidiano relacionados com a história da descoberta da hanseníase, as redes de interação como família e profissionais de saúde, dos cuidados com a própria saúde, de estratégias de superação e expectativas. Verificou-se que o elemento predominante da pesquisa se ancora no temor de ser descoberto e desacreditado, na perspectiva de ter sua identidade de saúde resignificada, pelo adoecimento e perante a vivência dos participantes com o preconceito, sigilo e segredo. Conclui-se, de modo simbólico, que os participantes vivenciaram uma construção de vida social negativa em torno da hanseníase. O adoecimento interfere de modo direto no cotidiano e desenvolvimento dos participantes, repercutindo principalmente nas relações sociais.

PALAVRAS-CHAVE Hanseníase. Criança. Adolescente. Atividades cotidianas. Estigma social.

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Introduction

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae* and is a serious public health problem due to its high prevalence in the North, Midwest and Northeast regions of Brazil. It can cause permanent physical disabilities and deformities that severely limit the performance of daily activities¹.

In addition to physical problems, affected people experience social exclusion and stigmatization. The latter is an ancient problem associated with guilt and divine punishment. Stigmatization persists for several years after the disease has been cured and is considered one of the main obstacles to diagnosis, treatment, and care by health teams in several countries².

The diagnosis of leprosy is essentially clinical and epidemiologic and is made in Basic Health Units by dermatoneurologic examination to investigate lesions in areas of altered sensitivity or peripheral nerve involvement. At diagnosis, a strategic classification is made into multibacillary if the person has more than five lesions and paucibacillary if they have up to five lesions; a clinical classification of the disease is also made: indeterminate, tuberculoid, borderline, and Virchowian¹. These classifications are recognized by the Ministry of Health as one of the main difficulties in the interpretation and application of sensitivity tests for the diagnosis of the disease in children under 15 years of age. However, a complementary protocol for leprosy case investigation has been established for this age group, a PCID < 15¹.

Since 2000, leprosy has been eliminated as a public health problem in many countries, with a prevalence of < 1 case per 10,000 inhabitants. However, the problem persists in developing countries. While 13 countries reported between 1,000 and 10,000 new cases in 2019, India, Brazil, and Indonesia recorded more than 10,000 new cases, making Brazil the second most detected country in the world³.

In Brazil, the rate of newly detected leprosy cases in the general population in 2020 was

6.51 per 100,000 inhabitants. In the Midwest, it was 18.06; in the North, 14.52; in the Northeast, 10.21; in the Southeast, 2.04; and in the South, 1.41. All regions showed a decrease in this rate between 2001 and 2020. Among the states, Mato Grosso, with a rate of 53.54, and Tocantins, with 46.53, are considered hyperendemic. Maranhão is classified as very high with 21.99, five states as high, 16 as medium, and only 3 as low. The location of this study, the state of Pernambuco, is classified as medium with a rate of 13.47, and the municipality of Petrolina is considered hyperendemic with 44.59⁴.

The high prevalence of leprosy in children under 15 years of age in the Northern, Northeastern, and Midwestern regions indicates that joint community and state efforts are needed to achieve the Department of Health's goal of reducing the disease in the population of this age group⁵.

The daily life of adults affected by leprosy is a topic much discussed in the literature, which generally highlights the difficulties faced by patients: impairment of emotional and sexual life, fear of the unknown, isolation, reduced ability to work, psychological problems, and low self-esteem due to prejudice against the disease, which are all problems leading to restriction of social life⁶.

With regard to children and adolescents, the discussion is quite limited, as there are few studies that address daily life aspects and generally point to problems related to school dropout, devaluation of self-image, changes in self-esteem, effects of taking medications, fear of change, prejudice, and self-prejudice⁷. Based on this discussion, the importance of developing studies on this special population is clear.

It's noteworthy that disease at this stage of life is a sensitive indicator of the epidemiological situation of leprosy, because the sources of infection are usually the adult family members, which means that they do not receive a diagnosis early or timely treatment. In this way, children come into close and prolonged contact with patients and become infected at a young age, showing the hyperendemia of the disease^{8,9}.

In this sense, the study proposed to shed light on the daily lives of children and adolescents who've experienced the disease, and their social relationships and tensions associated with living with leprosy, taking into account their experiences and characteristics from diagnosis through the course of the disease to treatment and cure.

With this in mind, this study asks the following guiding question: what is the impact of leprosy on the daily lives of affected children and adolescents? Considering that children and adolescents are more vulnerable than the adult population, this study aims to investigate the impact of leprosy on the daily lives of affected children and adolescents.

Material and methods

This research had a qualitative approach, using the 'Erving Goffman's Sociology' as a theoretical framework, especially with regard to stigma and the representation of the self in daily life, which are important contributions to understanding the process of health and disease¹⁰. In particular, in this study, we used some concepts developed by Goffman in his work on stigma, such as virtual social identity, real social identity, discredited, and discreditable, to interpret the impact on the daily lives of children and adolescents who experience a disease process through leprosy¹¹.

This article is part of the doctoral thesis in public health entitled 'Leprosy among adolescents in Brazil: from epidemiological panorama to impact on daily life' defended at the Instituto de Saúde Coletiva of the Federal University of Bahia (ISC/UFBA).

Nine children and 5 adolescents participated in this study, for a total of 14 participants. The respondents were young people affected by the disease, who were purposely selected and met the following inclusion criteria: cured people of both sexes, residing in the São Francisco Valley region, aged between 11

and 18 years, registered in the Leprosy Control Program. Exclusion criteria were: a disability that prevented participation in the survey and no permission from the legal representative to participate in the study.

Recruitment was conducted through the municipality's Infectious Disease Service, which asked family members about their interest in participating in the study. At the time of the survey, participants were cured and had permission from their legal representative in accordance with CNS Resolution No. 510/2016 (free and informed consent).

Data collection took place between July 22, 2016 and January 15, 2017. A semi-structured interview technique was used, guided by a script with themes aimed at generating narratives about aspects of daily life before, during, and after leprosy: 1) What was daily life like before leprosy; 2) What was daily life like during the disease; 3) What changed in life after diagnosis; and 4) What is life like currently.

The meetings were held at a time and place convenient to those in charge of the minors. Permission was requested to record the interview, which lasted an average of one hour and thirty minutes, and two meetings per participant were required for data collection.

Interpreting research data using narratives considers the way in which personal experiences are collected and analyzed, emphasizing the specificity of the signs of each lived experience and detaching them from theoretical generalizations¹². Thus, in addition to seeking possible connections among the stories surrounding leprosy, narratives were also important in highlighting particularities, ruptures, and discontinuities in these stories.

The project was approved by the Research Ethics Committee (CEDEP) of the Federal University of Vale do São Francisco (UNIVASF) with the opinion n. 1.448.193. To ensure anonymity, participants were identified with names that represent the flowers of the Caatinga.

Results and discussion

Of the 14 participants, 8 were female and 6 were male; they were between 8 and 14 years old during the illness and between 11 and 17 years old at the time of the interview. All attended public schools, mainly elementary school. Nine of them lived with their mother, father, and siblings, and the others lived with their grandparents, uncles, and cousins. Most of them received up to 1 minimum wage. Regarding the operational classification of leprosy, 10 had the multibacillary form and 4 had the paucibacillary form.

Next, the themes that emerged from a thorough reading of each narrative are presented, namely: the discovery of the disease, becoming aware of it; the daily life of the sick family: going through dark times; the impact of leprosy on sociability; strategies for coping and self-preservation; and expectations.

Discovery of the disease, becoming conscious

It is clear that the diagnosis of leprosy had a negative impact on the lives of children and adolescents, especially on the way the families of the participants dealt with the situation. This context is present in the disease process and causes suffering related to the fear of the unknown. It also causes fear of having to quickly learn about the disease and treatment, as well as the parents' fear of prejudice and possible negative effects on the family's daily life^{13,14}.

The worst of all was the moment when they said it was leprosy, that was the worst moment, I was very sad because a disease like leprosy I'd never heard of, when I read something like that, I thought, 'No, I don't believe it. No, I can't believe I'm going through this'. I was very nervous, I don't know, depressed and sad. (Mallow).

Related to this is the representativeness of what leprosy causes in the nuclear family, as

the family confronted with the new reality of living with a child with leprosy has negative experiences of the enormous burden of exclusion, disfigurement, and the potential consequences of the disease.

A study of caregivers of HIV-infected children has shown that family support is critical during the course of the disease, and isolation serves as a coping strategy in the face of prejudice and to avoid embarrassing situations¹⁵. The similarity to leprosy is obvious, as both are diseases that are subject to much prejudice, the experience of which negatively affects the lives of those who receive the diagnosis and is associated with stigma and fear¹⁶. Stigma occurs when the stereotype doesn't match the perception of a particular person, through the devaluation of identity, and is closely linked to acceptance when peers don't view the ill person as an equal and don't respect or consider them normal¹¹:

My mother and I never called it leprosy, we always called the spot, 'take the medicine for the spot', so we wouldn't keep talking about leprosy. Leprosy is the worst thing in the world and that's what I thought, because I never had this thing and suddenly I had it. We hide it because the prejudice is really big, and I think people would distance themselves from me. (Mallow).

The only person who knew about it was my grandmother, who lives next door, and the people from my maternal family. (Catingueira).

The discovery of the disease has yet to be addressed by researchers in the field to find strategies to raise awareness, qualify and support professionals to understand the family context and what it means to receive the diagnosis. Often the family is faced with the desire to disclose the diagnosis, but at the same time they take steps to prevent the disease from being discovered.

We hide it in our bodies. The spot on my arm passes, I say it's a burn, but the one on my face is looked at

by everyone. The health center here runs a leprosy campaign at school and encourages parents to participate, but every time my grandmother goes there, they asked me not to tell them that I already had the disease. Today I wear a long-sleeved shirt so that the stain doesn't burn and no one sees it. (Velame).

The importance of professionals who are sensitive to the specificities of childhood illness, who welcome and support the family¹⁷, who reflect on their practice and propose specific interventions to improve the quality of life of the ill and their family members, is emphasized. It is known that the fear of stigmatization of leprosy can lead to the delay of diagnosis and that a supportive professional practice has a direct impact on the acceptance of the disease and the reduction of late diagnosis¹⁸.

According to the participants' narratives, the moment when the family receives the news of the leprosy diagnosis is one of the moments when they most need help and support, as well as information and advice to reduce fear and expectations about the course of the disease, as the disease is still stigmatized in society.

The daily life of the sick family: going through dark times

Having a child with leprosy in the family affects the balance of those involved and can cause the members to form a kind of enchanted circle. The dynamics of the circle are established through silence and agreements to hide or deny the illness as a strategy to protect the ill family member from traumatic situations¹⁹. The lived experiences were similar depending on the manifestation of the disease.

My mother's situation worried me because when the lumps came out she screamed in pain, to this day she sometimes has pain when the lumps come out. But nowadays they come out just a little bit, just a little bit. I only remember mama's illness, not mine. I think I was afraid to feel the pain she

felt because I saw how she was. She was suffering so much. My mother didn't have spots, she had the ones that are just on the nerve, she had a lot of sores. The nerves were numb. Her fingers were crooked. (Purple melosa).

More than one family member can be diagnosed with leprosy, and when this is the case, those stigmatized tend to have similar experiences regarding their disease and experience similar changes in their self-image¹¹. When the experience is shared within the family or their social circle, the suffering and fear of the unknown are shared again, and the ill family member needs the support of the family to cope with any setback during the disease process²⁰.

On the other hand, the participants of this study understand the importance of the enchanted circle as support and preservation in the family, since the main support of this strategy comes from the mother. At this moment, they realize that their role in the family reassures and balances the experiences.

The one who helped me the most in this illness was my mother, even though she discovered the holes full of medicine, it was my family, because at the time of the illness everyone got together and gave me the strength to go ahead and not give up. (Pink paineira).

Who helped me with the disease was my mother, only her, my father didn't care, not at all. My mother, who took time for me when it was time to go to school, to the health center and everything, went with me, now my father doesn't do that. He kept hitting me and telling me to leave, but I wouldn't leave, my mother wouldn't let me. I stayed there on the wall, quiet, waiting for the day to pass, I stayed there so he wouldn't fight with me. (Cebola brava).

The experience takes on a different meaning depending on the type of relationship, because if the illness affects the children, they become the protected ones, and if it affects the partner, they can become a problem or a burden to take care of.

Nobody noticed that I was darker, only my grandmother, she said, 'How black is my child!'. She didn't know I was sick, we didn't tell anyone, not even the family, only the four of us at home knew. When she said I was darker and asked my mom, she said it was because of a medicine I was taking; at the time she asked what kind of medicine and my mom said it was for spots on the skin. (Coroa-de-frade).

Even if this enclosure is understood as a form of protection, some families showed increased suffering as a result of this closure. Sometimes it seemed as if the enclosure was the result of intense suffering, sometimes as if this enclosure increased the suffering. Deliberate disclosure to peers is guided by the place or importance people hold in these relationships, and deciding to whom to disclose was one of the most important issues for participants and family members. In this sense, disclosure that occurs through the presence of embodied signs of stigma tends to be a bad experience for them.

So that people wouldn't see it, when I went out with my mother, I put on pants, I just didn't wear shorts, I put cream on, but I didn't go out with the stain on my leg. The only ones who knew were my friends in the street, because when I played with them I didn't wear pants. Today my skin has improved, the spots are gone, I can now wear shorts, pants and a dress, the dryness is over. (Pink paineira).

To disclose the condition of the child or adolescent diagnosed with a stigmatizing disease, the abominations of the body, as one of the three types of stigma – abominations of the body, individual and tribal guilt, and stigma of race, nation and religion – is to deprive him or her of his encapsulation and thus bring about a deprotection¹¹.

Encapsulation crystallizes as a way of coping with the disease process, which proves to be a strategy for coping and maintaining the interlocutors. Some agreements were made, and the most important of them was to hide the sick condition. This form was expressed in

covering the spot with clothes, hiding the affected member, and monitoring by the family.

The repercussions of leprosy on sociability

One of the effects that participants experienced most was in the school context. Leprosy had to be kept secret because participants were aware that they could be bullied if they were discovered, because if their classmates were healthy, they needed to withdraw and isolate themselves to protect them.

With other friends, I was afraid to tell them because then they wouldn't want to get close to me because I had leprosy and they might get it. I don't really know what it's like and no one told me, but I thought they'd turn away from me. (Catingueira).

In addition, the unpreparedness of the teachers who accompanied the study participants on a daily basis is evident, as the classroom was divided into two groups, one with students with leprosy and one with healthy students. This shows the lack of concern with inclusion and social inequality, and the reinforcement of stigma.

The school environment, which is the main means of social interaction for both children and adolescents, was crucial for self-acceptance and acceptance among peers. It can be seen that this behavior was not based on the correct understanding of the disease, as there was no knowledge of the process/timing of transmission, resulting in a wrong and stigmatizing action. From this perspective, it is clear how much the children and adolescents envision change by making explicit the suffering and the memory of how the disease negatively changed their daily lives.

My teacher put us up front because we were sick. She brought lunch to the class and we switched plates, ate each other's leftovers, and that's why I got the disease. There was one boy who was sick and he passed it on to the others, there were about

three or four who got sick in the class, then she separated us. (Coroa-de-frade).

The disaffection from peers becomes a moment of disbelief, and if the stigma symbols are not known or immediately noticeable to those present, the affected person is self-perceived as inferior compared to others²¹. This perception raises fears that disclosure of the disease would affect their social interactions and jeopardize their relationships in their social groups, especially in the school environment¹¹.

When I got sick, everybody found out I was sick, everything spreads fast here, I didn't like it because people made fun of me at school, they said 'Eee, the sick one is here'. They walked away from me and said they didn't want to catch it. That broke my heart because they were my friends, I never thought they'd do that, and they didn't even know what the disease was. I was very sad to be excluded. I couldn't go out on the street anymore because people always called me Freddy Krueger. Everywhere I went people were prejudiced against me, I don't have any good memories. (Pink paineira).

Identity is affirmed or repressed in the social context, and in this exchange, it is continually constructed and reconstructed. The balance of power between the individual and the social environment takes place in this context, asserting one's identity against the heterogeneity of negative stigmatization by others²². As highlighted in Goffman's model, real social identity, when discovered, can be compromised and the alienated person is discredited by his or her peers because adolescents do not have the maturity or skills to strategically define their virtual social identity according to material or symbolic interests as adults do.

Real social identity is understood as the category of properties that the individual can actually be shown to possess. Virtual social identity, on the other hand, refers to a characterization we ascribe to a person based on

the traits he or she portrays, which may not correspond to reality because it is usually anchored in expected social norms¹¹.

Even though the disease causes so much suffering, there is a clear desire to hide it because if it is revealed, social interaction will be affected. Deliberate disclosure to peers depends on people's place or importance in those relationships, and deciding to whom to disclose is one of the most important issues for children and adolescents, as well as their families. In this sense, disclosure that occurs through the presence of embodied signs of stigma tends to be a bad experience for those involved in the process of leprosy.

Strategies for coping, self-preservation and expectations

In the daily lives of the respondents, there were barriers and conflicts that made health care difficult. Participants' narratives indicated that there were difficulties in diagnosis that delayed the process of being admitted as a leprosy patient. Participants experienced prejudice not only in the school environment, but also in leprosy treatment by health workers who were supposed to support and care for them.

Comprehensive care for children and adolescents is officially guaranteed as a public health policy in Brazil²³. It must take into account and respect the circumstances of children and adolescents, go beyond physical care, and address social and emotional needs.

I was very sad when I learned that I had leprosy. I was doing physical therapy on my little finger, and when I told the physical therapist who accompanied me that I'd leprosy, she wouldn't let me back in the room. She said: 'Look, I can't be close to you anymore because you aren't allowed to enter the room because you have leprosy'. She didn't sit down with me to talk. She just stayed like that, a little bit far away from me. At that time, I was very upset with what she was doing because she had an education. You have a degree and don't know

about the disease? I, who've no education, already know what the disease is. (Mandacaru flower).

Professionals caring for young people with leprosy are responsible for diagnosis, treatment, cure, and health education. However, many of them are not qualified or sensitized, which affects the quality of care; their educational practices are carried out in a one-way and impersonal relationship, in which knowledge passes through the sieve and the selection of the person who passes it on, without taking into account the experiences of those affected and without contributing to critical thinking that can help change perceptions of the disease and of the young person with the disease²⁴.

Similarly, this framework occurs within the household itself in which parents separate their personal belongings to limit transmission to other family members. This attitude is justified by the well-being of all family members and leads to a situation of exclusion at home.

Before I got sick, my life was normal, I did everything, ate everything that was put in front of me. After the illness I couldn't mix the cup, spoon and plate at home, but thank God the test was done and no one in my family was sick. (Coroa-de-frade).

In addition, there were complaints that indicated suffering. The constant taking of medicines was the most obvious complaint, understood as a responsibility that did not fit the age. As a strategy to get rid of this obligation, the medicines were hidden at home, without hesitation.

When I was taking medicine, I hid it in the holes in the house because they told me to take it and I said, 'No, mom, I don't want to take this medicine, it's too bad'. I went to the bathroom, put the medicine in the hole and said, 'Mainha, I already took it!'. I did that many times. I didn't think I'd interfere with the treatment. My mother didn't know about it, she only found out when I finished the treatment. When she saw it, there was a lot of medicine in the hole. (Paineira-pink).

The drugs were perceived as a burden in the disease because they were tangible and real, reminding them daily of their condition and making them partly responsible for their health. In addition, the amount and reactions of the medication caused suffering. They perceived that following a treatment on a daily basis is not for young people, and taking on this type of responsibility was perceived as a burden. The narratives indicate that there was no preparation, awareness, or education about what would happen.

In addition to the reported anxiety, the research indicates that the consequences of taking medication were related to taking on a responsibility or routine that was not compatible with the age, and to the side effects of the treatment, especially the hyperpigmentation of the skin that denounced their condition²⁵.

It was a struggle to take these medicines, it was a suffering, the nurse waited patiently for me to take these six pills at once, this supervised dose, the capsules were too big, one bigger than the other, I barely swallowed them, in the first months it was a sacrifice. I'd get dizzy, get headaches when I stopped taking the medicine, I'd get cramps, the cramps would only come when I stopped taking the medicine. (Mulungu).

Being the protagonist of their own story and having an embodied marker in a life context with a culture of stigmatization puts the child or adolescent at a disadvantage and a limited view of their future prospects, in which their expectations are centered on the recovered image, healthy body and daily life.

Now I'm cured, and I'm just waiting for the spots to disappear. The feeling of being discharged is a feeling of relief, a weight that's fallen off me, that's been lifted off my back. It's a relief to no longer be at the health center every month, to no longer stand in line and go back to the way I was before, to be white again and do what I like. And now I'm looking forward to becoming white and spotless and being called Galician again, because it was good to be called Galician. (Mulungu).

Ultimately, a child or adolescent with leprosy can be compared to an iceberg. What is visible is his disease, the external visualization of a person with leprosy, a brief and superficial concept that reduces the subject to his disease. However, if the consciousness of knowledge embraces the larger part of the iceberg, then one can understand that its complexity goes beyond a simple tip. In this context, a patient must be considered as a being far beyond what is attributed to him.

Final considerations

The results of this study show that the experience of leprosy in children and adolescents is a phenomenon that is difficult to understand and that the disease goes beyond diagnosis and treatment. This phenomenon tends to reflect on important aspects of this process that involve the family, peers, and professionals.

The fear of having a stigmatizing disease generates suffering and expectations arising from the unknown, and narratives show that children and adolescents' routines and habits have changed completely, depriving them of important daily activities. The fact that the children and adolescents have to stay at home because they should not be exposed to the sun due to the negative effects of the medication on skin pigmentation, as well as the exclusion by peers and the family encapsulation were the main features of this discontinuity in the social and play life of these young individuals.

The revelation of the condition in everyday life, with effects on the social development of those affected, leaves physical and non-physical traces that can last into adulthood. As the disease progresses, participants choose to remain silent about their leprosy condition in order to protect their identity and maintain social acceptance. Revealing the true condition of leprosy makes the individual vulnerable to

the consequences of being against the hegemonic, of being different from his peers, and of being contrary to what is considered healthy.

From this point of view, the empowerment of children and adolescents in the study and the sensitization of professionals, including psychological and social aspects, are necessary to change the treatment model and the approach to this group and not to consider them only as sick. This can be done through the modification and implementation of health interventions that can change the current reality, such as strengthening support groups for families affected by the diagnosis and professional qualification in child and adolescent care.

At the time of writing, knowledge about the problems and coping strategies of children and adolescents with leprosy was limited, as there are few scientific publications on this topic. Nevertheless, the results presented here are important because they show how the disease negatively affects daily life and what coping strategies participants use in the disease process.

The development of research on the daily life of children and adolescents affected by leprosy, on coping strategies such as family perceptions of this process, including gender aspects, and on how medication is presented to this group is considered relevant.

Collaborators

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Received on 09/27/2021

Approved on 05/24/2022

Conflict of interests: non-existent

Financial support: non-existent