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Original Article

Leprosy: meanings and experiences among adolescents with the disease and their family members

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Abstract: This research aimed at understanding the social representations of leprosy constructed by adolescents with the disease and their family members, including their perception about the impact of the disease in their daily life. Data of semi-structured interviews with 19 adolescents aged 12-18 years receiving medical treatment for leprosy and with 18 family members who lived in the same address were collected. Data were treated with thematic content analysis. Results showed that the emotion of fear and beliefs about contagion and prejudice were important elements of the leprosy representations. Participants perceived important negative changes in their daily life after diagnosis confirmation including suffering caused by the routine of medical procedures and physical pain. Patients perceived discrimination in the relationship with family members and friends, associated to the fear of contagion, and reported practices of concealment of signs of the disease to their peers. It was concluded that, given the permanence of a the archaic view of the disease and the impacts caused on the daily life of adolescents with leprosy and their families, it is necessary to expand information about the disease, to rethink health practices and to establish dialogic meetings in order to enable the reflection and construction of new meanings in relation to the disease, improving their quality of life.

Keywords: *Social Representation, Leprosy, Adolescent Health, Family.*

Hanseníase: sentidos e facetas do convívio para adolescentes com a doença e seus familiares

Resumo: Esta pesquisa teve o objetivo de compreender as representações sociais da hanseníase para adolescentes com a doença e seus familiares, incluindo suas percepções sobre repercussões da doença no cotidiano. Os dados foram coletados por meio de entrevistas semiestruturadas, realizadas com 19 adolescentes em tratamento medicamentoso para a hanseníase, com idade entre 12 e 18 anos, e 18 familiares que habitavam a mesma casa que o doente. Os dados foram tratados com análise de conteúdo temática. Os resultados indicaram que as representações da hanseníase eram fortemente marcadas pelo afeto do medo e pelas ideias relativas ao contágio e ao preconceito. Participantes percebiam alterações negativas importantes no cotidiano após o diagnóstico da doença, incluindo sofrimento com a rotina de procedimentos médicos e dores físicas. Eles percebiam práticas de discriminação nas relações com a família e amigos, em associação com o medo da contaminação, e relataram práticas de ocultação dos sinais da doença para seus pares. Conclui-se que, ante a permanência de uma visão arcaica da doença e dos impactos

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causados no cotidiano dos adolescentes com hanseníase e dos seus familiares, faz-se necessário ampliar os cenários diversos de informação sobre a enfermidade, repensar as práticas em saúde e estabelecer encontros dialógicos, a fim de possibilitar a reflexão e a construção de novos sentidos e significados em relação à doença, proporcionando melhorias à vida dessas pessoas.

Palavras-chave: *Representação Social, Hanseníase, Saúde do Adolescente, Família.*

1 Introduction

Leprosy has historically been a cause of strong stigma. Situations of economic-social precariousness, as well as historical neglect of endemic diseases, may increase its prevalence (TAVARES et al., 2015). Currently, it is known that leprosy is an infectious contagious disease that affects the skin and the peripheral nerves and is treated on an outpatient by a drug combination - polychemotherapy (PCT) (BRASIL, 2002). Although it is a curable disease, it is potentially disabling and of great importance to public health.

Brazil has the most unfavorable situation in the Americas in the last decades and it is the diagnosis of the second largest number of new cases in the world, for all age groups, including children and adolescents (BRASIL, 2015). This panorama show the importance of investing in effective actions for the early diagnosis of the disease, through the search and control of home-based contacts, that is, the cohabitants who share the same physical space of the patient and constitute an important link in the epidemiological chain, by the possibility of presenting hidden foci of the disease, contributing to its expansion (AUGUSTO; SOUZA, 2006).

The positive diagnosis of leprosy can lead to changes in patients´ daily lives and changes in family dynamics and routine, affecting also the daily life of people living with the patient to meet the demands of technical procedures, consultations and examinations, manifestations and adverse drug effects. Also, leprosy can activate beliefs based on the social imagery associated with the disease in the past - leprosy - contributing to everyday changes and negative psychosocial repercussions. Physical defects can engender the construction of what Fernandes and Barbosa (2016) called "peripheral bodies" devoid of "corporal capital" and associated with affections such as fear and disgust. The negative repercussions can be noted in studies carried out by Marinho et al. (2014) and Ayres et al. (2012), whose results show suffering and impact in the activities of daily living, practical life and leisure of people affected by the disease.

Previously cited research has investigated adults with leprosy. We found only a study by Ponte and Ximenes Neto (2005) to verify the adolescents´ knowledge about the disease, its reactions after diagnosis and the changes and difficulties experienced by them. There was also a shortage of work directed at the relatives of the patients.

It is understood that adolescence is not restricted to the physiological changes of puberty, which is not a "naturally troubled period" as some universalizing and timeless definitions assert. Adolescence is a socio-historical production that acquires very diverse expressions in different groups and cultures. In modern and industrialized societies, the experience of urban adolescence is strongly marked by the aspect of "moratorium": to be able to experience the new and to err; have the capacity for production and reproduction represented as belonging to the adult world, and to be forbidden in the exercise of these capacities; be linked to formal education institutions. Schools participate in the social construction of adolescence by providing spaces for living the social moratorium, extending the tutelage and teaching applied initially to childhood and delaying the entry of an entire population layer into the adult world of production and reproduction (GROPPO, 2015; SILVA et al., 2018).

Given these specific, industrialized and urban ways of adolescent construction, the adolescent´s experience may be highlighted by uncertainties, instabilities, the need for peer interaction and identity affirmation, the need to plan for the future and the professional career within the framework of formal institutions. There is evidence that adolescents are especially vulnerable to psychic suffering and attention to their mental health in Brazil is embryonic (SILVA et al., 2018).

Leprosy implies stigma and limitations of several orders and its incidence in adolescence can have dramatic consequences for self-perception and the construction of future plans. It is important to understand how the adolescents with the disease and their families perceive their daily life, their relationships, and their practices, to inform health care about aspects of mental health, to sensitize health professionals, and to provide subsidies for research and professional practices aimed at adolescents with leprosy and their families. It is important to understand not only the ways that individuals use to create, transform and interpret this problem linked to their reality, but also to know their ideas, feelings, repercussions of the disease in their intra and interpersonal relationships.

In this study, the Theory of Social Representations (TSR), developed within the scope of Social Psychology was used in this study, which has offered an important theoretical contribution to researchers who seek to understand how people give meaning to social phenomena and events of everyday life (ALMEIDA et al., 2015).

Social representations are present in all human interactions (MOSCOVICI, 2012) e, according to Jodelet (2001), they are

> [...] the form of knowledge, socially elaborated and shared, with a practical objective, and which contributes to the construction of a common reality to a social set (JODELET, 2001, p. 22).

The phenomenon of social representations are the construction of social knowledge, involving cognition. However, the development of knowledge is not restricted to the formation of rational cognitive structures, since the symbolic and imaginative character of the knowledge also reveals the dimension of affections (ARRUDA, 2014). The social representations guide and justify social practices such as social-cognitive-affective systems (MOSCOVICI, 2012; JODELET, 2001).

Considering the social and academic relevance of the subject, this research aimed to understand the social representations of leprosy for adolescents with the disease and their relatives, as well as to identify perceptions of these subjects on the repercussions of the disease in their daily life. Understanding these social representations, constructed and maintained in scenarios in which leprosy affects, can inform the professional practice in health and favor the deconstruction of archaic beliefs; can sensitize professionals and support further research.

2 Method

This research was carried out in Health Units of four medium-sized municipalities in the Brazilian Southeast. These municipalities were previously selected, since they had adolescents in treatment, a fact that does not happen in all municipalities and also because they have the Leprosy Control Program (LCP) functioning effectively. There were 19 adolescents with leprosy and 18 family members participating. Only an adolescent relative refused to participate in the survey by personal reasons. The following inclusion criteria were adopted for the adolescents: voluntary and interest in participating; be between 12 and 18 years old, both genders and be on medication treatment for leprosy. In the case of their relatives, the criteria were: to live in the same house as the sick adolescent and to be related to him.

Semi-structured interviews were used to collect data that addressed the conceptions of adolescents with leprosy and those of their relatives about living with the disease and about the repercussions in daily life after diagnosis. The questions guiding the interviews were: how to live with leprosy; what changed after the diagnosis; what people in the adolescent social networks were informed about the disease and what their reaction was; how are the intra and interpersonal relationships in the situations described.

Data collection took place from October 2014 to March 2015. There was a contact with those responsible for the Leprosy Control Program in the referred sites and their collaboration was requested to select the participants. Through the indication of the professionals, there were contacts and appointments with the adolescents and their families. Adolescents and family members were instructed to attend together on the scheduled day, so the person responsible for the adolescent could allow his participation in the research. The interviews were conducted individually at the Health Unit where the adolescents were being treated, so all institutions had a private environment, without external interference. After their consent, the speeches were recorded in audio. The interviews lasted approximately 40 minutes.

The data processing was performed according to the thematic content analysis, proposed by Bardin (2011), which includes the phases of pre-analysis, material exploration, treatment of results, inference and interpretation of collected data. This technique enables to understand the meaning of communication and its explicit and/or hidden meanings, allowing an objective and systematic description of the content of the interviews to infer the knowledge about the conditions of communication production/reception (BARDIN, 2011).

The research project was previously authorized by the Municipal Health Department of the municipalities involved and approved by the Research Ethics Committee of the Health Sciences Center of the Federal University of Espírito Santo under number 803.853. According to CNS Resolution 466 of December 12, 2012, all participants signed the free and informed consent form (TCLE), as well as the free and informed assent form (TALE) for minors, guaranteeing the confidentiality of information.

3 Results

Thirteen adolescents with a confirmed diagnosis of leprosy participated in the study, being 11 females and 8 males. As for the age group, 9 participants were aged between 12 and 15 years old and 10 were between 16 and 18 years old. Regarding their marital status, all were single. Regarding the education level, 6 were in high school and 12 were in elementary school. Only one adolescent claimed to have discontinued his studies in seventh grade. According to the occupation, 17 adolescents did not work and 2 worked with their parents (one worked with recycling and the other in a car wash). The study also included 18 family members, 14 female and 4 male, 13 mothers, 4 fathers, and 1 grandmother, aged between 28 and 65 years old. As for marital status, 12 were married, 1 was single, 4 were separated and 1 was widow. Regarding to education level, 10 had incomplete Elementary School, 4 had complete Elementary School, 3 had completed High School and only 1 had Higher Education. Everyone lived in the same house as the adolescent.

According to the analysis of the testimonies collected in the interviews, three categories emerged that will be described in the following subtopics: 1) the facets of everyday life with leprosy; 2) fear of leprosy; 3) the materialization of prejudice. Codenames with the initials of the names of the participants were used in order to ensure anonymity.

4 The Facets of Everyday Life with Leprosy

This category describes the perceptions of adolescents with leprosy and their families about daily life after diagnosis of the disease. Concerning daily living with adolescents with leprosy, most of the family members expressed being "normal" and "quiet", revealing that the disease did not represent a barrier to express their affection for the adolescent. On the other hand, family members reported increased attention, zeal, concern, and participation in adolescent care. Among these practices, they cited appointment of consultation and regular monitoring to the health service, orientation for the correct use of medication, skin care and nutrition, as reflected in the following statements:

> *It's normal, it makes no difference, we hug, we kiss, we take him to the beach, we play, we take him to the carnival, we take him to everything that we go* (Marta).

> *For me, giving medication, while he's taking everything, for me, it's normal. I take care of the correct time for the medication, in the care of being passing oil on his skin, because it has begun to dry out, so my care with him is daily* (Fatima).

However, some adolescents described the coexistence with illness as a "bad" and "difficult" experience, as explained in this speech:

> [...] *living with leprosy is difficult because sometimes you get tired of staying all the time taking medicine, having to come to the doctor to get the medicine* (Alex).

Among the repercussions in the daily life of adolescents, the medicine was mentioned as the main problem. Besides the routine mandatory of its administration, the side effects of the medication were relevant post-diagnosis changes and difficulties mentioned in the narratives. Also, participants perceived that a new daily life was established due to frequent attendance to medical appointments, examinations, body care, and nutrition, as the following speaks:

> *It was very good before leprosy, I did not need all that medicine, I did not need to feel a headache, dizziness, it was always very bad, I had to feed myself, I never fed very well. My daily life is just taking medicine* (Beatriz).

Adolescents also cited relevant deprivations in daily and leisure activities as a result of physical pain, significantly interfering with their daily lives. The speeches described below illustrate these changes:

> *I do not help my mother because I cannot, my nerves hurt and my spine hurts, if I go to clean the house for my mother I cannot do it because of the nerves and the spine hurts, it hurts all week, so she did it* (Clara).

> *Because of the pain that I cannot leave, when I attack I cannot walk, then I just wake up, brush my teeth, drink coffee and I sit all day watching television, doing nothing, it's boring. It made my life worse, I cannot do anything else, I get stuck inside the house* (Lúcia).

The analysis revealed that even adolescents who reported being "normal" to live with the disease, throughout the interview also pointed out changes in daily life and difficulties experienced after the diagnosis of leprosy, related to the daily intake of medications, adverse side effects, food, among others.

5 Fear of Leprosy

From the data set of the fears category of adolescents with leprosy and their relatives, two subcategories emerged: 1) fear of contamination and be contaminated; 2) Prejudice: fear that shuts off.

5.1 Fear of contamination and be contaminated

Although most of the family members declared that they were "normal" and "quiet" living with adolescents with leprosy, the analysis revealed heterogeneous beliefs about the transmission of the disease, triggering the explicit or implicit fear of contracting the illness of some subjects. Changes in daily life characterized by emphasis on hygienic procedures, such as separation of household utensils (cutlery, plate, glass, towels), ban on touching children or increased touch care, were cited by participants. The following statements highlight the fear associated with contagion:

> *At first, I was afraid, but I tried not to give it to her, I'm talking about it now, not even with anyone else.* [...] *she was going to get the baby, I would put a diaper on her lap* (Sara).
>
> *I avoided drinking water in the same glass, let my other thirteen-year-old daughter drink and eat the same dish without being washed, I drank from the same glass, but at first, I washed it.* [...] *now she is immune, I no longer drink in her cup with the same fear I had, but I was afraid* (Antonio).

The practices pointed out previously were justified by the relatives as an attempt to prevent the transmission of the disease. It was observed that fear related to contagion was reinforced by beliefs affirmed as unequivocal truths:

> [...] *if you drink water in the glass that she had just drunk without washing with soap I would take it* (Antonio).

Speeches of adolescents with leprosy also pointed out the fear of transmitting the disease and being "responsible" for the possible illness of others, as in the following example:

> [...] *because I have this disease, I cannot go to the pool, because I do not know, I'm afraid of passing on someone else* (Juliana).

5.2 Prejudice: the fear that shuts off

The analysis revealed that, for fear of prejudice, most both the family members and the adolescents participating opted to hide the positive diagnosis of leprosy from other relatives or only informed the "closest" people, believing that the disclosure would make adolescents vulnerable to harmful repercussions. Some of the things that show the information management process about the disease were the fear of contempt, discrimination, and withdrawal from people, fear of the dissemination of pejorative comments and moral judgment, and changes in relationships, whether in the family and non-family sectors. The following reports show the way of avoiding in talking about the disease, justified by the fear of prejudice:

> *Just in my family and a friend of mine who knows, and my aunt. I'm afraid everyone will talk, start gossiping, nobody wants to be around me* (Marcelo).
>
> *I really told just to my minister and family. I do not even like to comment, I'm afraid to be despised by people* (Fernando).

Another theme emphasized by the participants was the withdrawal from social life resulting from the fear of prejudice. The fear of being excluded made some adolescents anticipate exclusionary behavior by choosing to be isolated, which interfered greatly in their relationships in certain daily activities. This can be exemplified by the following reports:

> *I do not go out anymore, because if I go out, anywhere I go out and my cousins see me on the street, they'll talk, so I do not go out. I'm scared to go outside, it's scary! I find it difficult to be afraid because before I played, I was twenty percent happy, now I am nothing more, I am nothing more* (Isabela).

Signs of leprosy, directly associated with spots in the body, as well as the darkening of the skin resulting from the use of medication were also determinant for the fear of prejudice, shame and social isolation of some adolescents. Concealment of the body, such as the wearing of long-sleeved pants and sweaters, emerged as an attempt to avoid explanation, discrimination, and therefore not being identified with the disease by society. One of the teenagers said:

> *I really enjoyed going out, now I do not go out because of the spots on the skin.*

According to one of the relatives:

> *She began to shelter herself indoors, not even in the house but she wanted to leave her legs exposed* (Maria).

6 The Materialization of Prejudice

The prejudice was central and frequently mentioned in the participants´ speech. The analysis revealed that most of the interviewees perceived and/or experienced the prejudice inflicted by the other - family, friends and acquaintances. The perception of prejudice was not restricted to the adolescent´s home, as described in the previous category.

Both home-based contacts and adolescents described the rejection/discrimination of some people living with them after deciding to reveal the diagnosis of leprosy. Explicit prejudice occurred in different social spaces and materialized through the removal of friends and relatives, pejorative comments, refusal to touch, dubious looks and "different" behavior of those with whom they coexisted:

> *Some friends have turned away from me, do not talk to me anymore.* [...] *Because he is afraid to take it, I do not know, with disgust* (Alex).
>
> *I went to kiss my cousin on the face who was on my sister's lap, then another cousin turned to me and said: "do not kiss the boy, my God, you have leprosy, you will infect the boy." I'll hate him forever, forever I'll hate him* (Isabela).
>
> *There are some of my family who are criticizing and humiliating her because of leprosy. She sits in a place and they do not want to sit in the place she sat, afraid to take this disease* (Laura).

In association with such situations, an adolescent said: "*I was still crying*" (Bruna); family members said, "*She cried too much, got a little depressed*" (Helena) and "*He sometimes cries and is very humiliated*" (Luís).

Interviewees attributed the practices of discrimination and rejection in the networks of social relationships to misinformation about leprosy, entrenched beliefs about the contagion and the permanence of the figure of contagious, frightening and incurable disease.

On the other hand, some participants emphasized that the diagnostic revelation to relatives and friends did not lead to prejudiced practices. However, they noticed that the bonds of affection were strengthened and received support and welcome. Interviewees showed that this was because they already had a history of the disease in the family, as well as the knowledge that the disease is curable, as the following speech illustrates:

> *Back home, as my sister had had leprosy, then we already knew how to live, so she had no prejudice, she was not afraid, she did not panic, she saw that it was something with a cure. Everyone received her well, welcomed her well* (Edna).

Finally, it should be pointed out that some participants believed that prejudice had not only occurred because they had kept the disease confidential, otherwise, in their perception, exclusion, and discrimination would certainly have arisen.

7 Discussion

Social representations are forms of symbolic mediation, firmly based in communicative practices, personal experiences, and information mediated (JOVCHELOVITCH, 2000; MOSCOVICI, 2012). The results allowed knowing aspects of the social representations of adolescents with leprosy and their relatives about the disease, as well as perceptions about repercussions of the disease in their daily lives. The disease creates a fertile field for social representations to be generated, because it is an event that threatens or modifies social insertion and individual life, often provoking a collective imbalance (HERZLICH, 2005).

The results showed that the experience of illness and living with a sick family member caused changes in the daily life of the participants of the study, because the familiarity of daily life shows the singularity of the individual and is molded according to the context of life around the values, beliefs, and feelings (SALESSA; MATSUKURAB, 2013).

The representations built by the adolescents on leprosy were composed of negatively valued elements, associated with daily life permeated by fears, prejudice, social isolation, suffering and difficulties during treatment, especially in medication. These results are consistent with Ponte and Ximenes Neto (2005) findings showing the suffering and changes in the daily routine of adolescents with leprosy in the city of Sobral, Ceará, due to the symptomatology of the disease, side effects of medications and prejudice lived.

For the family members, it was no different. Despite the possible attempt to describe the coexistence with adolescents with leprosy as "natural", the analysis revealed that the pathological process in a family member emerged a new daily life. In addition to the concern and attention with their sick family member, especially encouraging adherence to treatment and self-care practices, the based home contacts also expressed their fears, especially of the contagion, leading to changes in family practices.

Thus, living with leprosy has emerged feelings such as fear, shame, worry and sadness, confirming the theoretical assumption that the construction of a shared reality arises from the work of elaborating an imaginary that involves affective mobilization, as well as selection, maintenance, and transmission of significant elements for the group and the person (JODELET, 2005; MOSCOVICI, 2012).

Among the participants, the feeling of fear was the most salient and proved to be an important guideline of practices of social exclusion of the patient. It is possible to synthesize content revealed by both family members and adolescents, regarding the main fears. These include fear of abandonment and social rejection, of pejorative comments, of revealing the disease and, in particular, of contagion.

The feeling of being susceptible to "danger" made some family and friends seek in separation and exclusion a possible solution to defend, even if they rationally knew of the absence of a genuine threat. Despite the scientific evidence that the transmission of leprosy occurs through close and prolonged contact with the patient and when the treatment is started, the person stops transmitting the disease (BRASIL, 2002), the results showed persistence of fears about the contamination of some participants, associated to practices of physical withdrawal and separation of the objects touched by the patient within the home environment.

Such practices are also noticed in the well-known research of Jodelet (2005) on social representations of madness in a French rural community. The results showed the main imperative of demarcating the difference and the separation between the "crazy" and the "healthy." The proximity to the radical alterity of madness inspired the sense of fear in the community before what was supposedly considered an uncontrollable and potentially contagious phenomenon (JODELET, 2005).

Despite the dissemination of scientific information on madness, as well as on leprosy, popular knowledge and practices can continue to be based on representations fed by former associations of disease with dirt, degeneration, and contagion.

It is possible to mention possible reasons for the persistence of the representations of the contagion of leprosy. They may be the result of the difficulty in retaining and assimilating scientific knowledge about the disease since such information is often limited.

Another possible reason is the symbolic value of the notion of contagion, since the existence of beliefs about the transmission of the disease through touch and bodily secretions, for example, finds a reason to be in symbolic processes to stigmatize the patient and determine the relationships with him (JODELET, 1998), as perceived in the speeches of some participants.

We may also suppose that the elaborations about leprosy seen as a kind of pollution, a mutilating and incurable disease, may also be related to a social construction designed to control and maintain social order (JODELET, 1998). This highlighted the history of the disease with practices of segregation and isolation of the patient and also presenting him as a dangerous presence for the society that integrates it for many years. It is considered that conceptions about the contagion are foundations of the very notion of the disease and so it remains until today (OLIVEIRA, 2011), which interferes in the relationships with the other, in general, and especially here, with the leprosy patient.

The adolescents interviewed also expressed concern and fear in transmitting the disease to people. The data suggest that some participants construct the image of a "contaminated and impure" body or in other words, the patient tends to avoid this symbolic "contagion" for other people (CLARO, 1995).

Some of them were motivated to limit their participation in daily activities, as they feared the illness of their relatives, friends, and acquaintances. It is the objective-subjective construction of a patient's "place", revealed by the speeches, with the social implications foreseen by Jovchelovitch (2000), when affirming that, when engaging in the symbolic and shared task of representing a given reality, the subjects "reveal much more than idiosyncratic visions" (JOVCHELOVITCH, 2000, p. 113).

The socially constructed fear surrounding leprosy has created new alternatives of sociability, altering the way of being and acting of the respondents, both of the relatives and the adolescents with the disease. These results attest to the importance of considering not only the informational basis of the subjects but also their values and affectivity, as a way to avoid the social discrimination of leprosy patients, as well as the self-stigmatization.

Considered as one of the oldest diseases of mankind, leprosy is associated with impurity in biblical translations, a divine plague that devolves upon infamous beings, resulting in disgust, repugnance, and fear (SAVASSI, 2010). Also, the physical degradation of the body and the compulsory isolation the patient was subjected - the latter seen as a solution to eliminate the risks of contamination of the healthy ones - contributed to the images built on leprosy and the patient with leprosy in the public space, as well as the persistence of feelings of fear and repulsion. Fear of contagion may be the reason family members experience stigma and may be associated with the cause and treatment of the disease (DAKO-GYEKE, 2018).

Considering the stigma, the participants of this study declared diverse practices regarding the revelation of the diagnosis of leprosy. The practices of concealing the disease prevailed or relied on this information only to the nearest, justified by the fear of prejudice. In studies by Vieira (2010), Lopes et al. (2010) and Santos (2006), we also found results related to patients´ choice to maintain confidentiality regarding the positive diagnosis of leprosy, due to the fear of social discrimination.

Marková (2003) emphasizes that the impossibility of a dialogic engagement contributes to generate mistrust. Based on the results of this study, it is possible to infer that the fear of prejudice inhibited a dialogical meeting of the adolescents and their relatives with people of their conviviality, generating distrust and the option to cover up the disease as the best strategy. For most of the interviewees, telling about the disease would be exposing to discrimination and possible isolation in their family and social environment.

Another aspect that deserves to be highlighted is the feelings reported by some adolescents as fear and shame of displaying the body, due to the signs of the disease - such as spots - and the side effects of the medication - such as darkening of the skin. Changes in physical appearance often cause people to behave in speculation, curiosity, and prejudice (EIDT, 2000), since the external dimension of the body is the most subjected to the formulation of judgments (QUEIROZ; OTTA, 2000) to reinforce the patient´s fear, shame and insecurity, in front of uncertainty as to how he will be identified by the "healthy" people and in which category he will be inserted (MARTINS; CAPONI, 2010).

It cannot be denied that besides constituting a biological entity, the human body is also a "source and expression of symbols" (QUEIROZ; OTTA, 2000, p. 31). Thus, Queiroz and Otta (2000) affirm that "the body is the object of domestication exercised by culture, being appropriate and modeled by it" (QUEIROZ; OTTA, 2000, p. 19). Aesthetic standards and the conception of bodily beauty are influenced in large part, by cultural processes. These processes vary according to the different cultures, but some universal standards must be considered, either in the determination of attractiveness criteria or in the aesthetic appreciation of the body. The authors add to these observations that "the ideal of beauty presupposes physical integrity" (QUEIROZ; OTTA, 2000, p. 62), so the signs that leprosy shows on the body contradict aesthetic ideals strongly based in the human being.

In a reality that exalts beauty, those who do not share the attributes of the "perfect" body and escape the norm are named and called as "different" (LE BRETON, 2006), commonly repudiated and stigmatized by a society that demands similarity and does not recognize the differences. The masking of the "marks" left by leprosy - which characterizes stigma - through changes in the way of dressing of some adolescents emerged as an attempt to hide the disease, due to the fear of discrimination and rejection of the people of their conviviality, greatly restricting their participation in networks of sociability. The psychosocial impairments that afflict the "peripheral bodies" (FERNANDES; BARBOSA, 2016) are even more devastating in the contemporary, characterized by hyperindividualism, as according (FERNANDES; BARBOSA, 2016) by an important movement of complete identification of the subject with his visible body and by overvaluing the exterior of the body in the medical field.

According to the reports collected in this research, it was observed that the segregation and isolation that some adolescents with leprosy prevailed arose not only because of the fear of prejudice but also because they were targets of social neglect, in their perception. The analysis showed that most of the interviewees experienced and/or observed practices of prejudice by friends, acquaintances and even close relatives, after entrusting them to the diagnosis of leprosy. Among these practices, there were people moved away, became "different" and did not exhibit "the same friendship," avoided physical contact, casting dubious looks and offensive comments. For them, such practices were stimulated mainly by the lack of information about the disease, especially in the contagion. Recent studies by Leite et al. (2015), Marinho et al. (2014) and Cid et al. (2012) also confirmed different situations of prejudice experienced by people affected by the disease.

Despite all the current knowledge about the transmission, treatment, and cure of leprosy, the reports have demonstrated belief adherence. Moscovici (2009, p. 21) argues that the prejudices

> [...] it is not similar with the perceptions and knowledge of themselves or others, that it is not absolutely information of the knowledge that we have, but of factors of belief, even collective memory [...].

Together with the hegemonic meanings that organize the construction of the leprosy object in social thought, according to a process of objectification (MOSCOVICI, 2012), a figurative nucleus is formed with an image revealing a patient who is polluted, disfigured and mutilated. This figurative nucleus helps to construct the representation of a serious, dangerous and highly contagious disease, contributing to the strengthening of the distance between the "sick" and the "healthy" person.

When interested in the debate about the antiquity and permanence of certain themes circulating in the daily life of social relations, Moscovici (2009) shows emblematic *thematas* that help in understanding the asymmetrical relationship between a discriminating majority and a discriminated minority, which, in the case of adolescents with leprosy, as in the case of other minorities, it justifies the practices of the majority.

The *themata* of the pure and the impure (the clean and the dirty) stands out that "defines the minority as an anomaly within the majority" (MOSCOVICI, 2009, p. 27). It should be recalled that leprosy patients were considered to be sinful and impure, confined in isolation institutions. Even if divine punishment, karma, is no longer evoked, and before the abolition of compulsory hospitalization, purity and impurity continue to be expressed by images in their social representation.

It is observed that leprosy continues to be a stigma, bringing them closer to social marginality, viewed with disqualification and discredit, as fear-provoking and representing a threat, generating behaviors of rejection and separation inflicted by the majority on the minority present in the same community, preventing the approximation in daily life (as they describe, in other cases, Jodelet (2005) e Moscovici (2009). Thus, the practice of institutionalizing leprosy patients in the past seems to be recreated at present by the production of walls the rituals of separation and exclusion.

As predicted by the Theory of Social Representations, the permanence of themes and beliefs about leprosy, widely diffused in different contexts and temporalities, contributes to making the stranger a family process (MOSCOVICI, 2012). It seems to justify that Moscovici (2009) claims that prejudice refers to a belief that is not subject to reflection, that is, it is not a cognitive irrationality, but an irrationality of belief or common sense, and adds that "If there is prejudice, it is because every action, every new judgment receives before an old sense" (MOSCOVICI, 2009, p. 29).

The prejudiced practices of family members, friends, and acquaintances imposed on some adolescents with leprosy have substantially affected them, influencing them in the perception of their illness, causing them changes in daily life, such as the tendency to be isolated from social interaction. It can be said that for these teens, "looking out" – "leaving home" - has become a threat to the ego and identity. The result is limited or non-existent interaction between them and society in general (ASAMPONG et al., 2018).

However, some participants reported that relatives and friends did not adopt prejudiced practices when communicating the diagnosis of leprosy, because they had already had a history of the disease in the family and knew that the disease was curable.

The composition of the research group enabled to highlight two positions of the adolescent with leprosy: on the one hand, there are those who adopted a protective and welcoming attitude, in an attempt to establish no social or interpersonal difference, preserving the quality of the relationship; on the other, there were those who tended to categorize, ward off, and control a threat that infiltrated - contamination.

The different positions of individual reinforce the interpretation that people are not only "consumers" of the social imaginary and social representations, but above all, they are agents that put them in movement and that recreate them according to their insertion in the social, historical spheres and cultural, evidencing active participation and autonomy as subjects of representation (JOVCHELOVITCH, 2000). This perspective allows discussing the possibility of re-signification or transformation of social representations and practices, especially in the sphere of prejudice.

8 Final Considerations

Taking the social representations about the living with leprosy for adolescents with the disease and their relatives as a field of research, as well as the repercussions of the illness in the life of these subjects, the results indicated changes in daily life, fears, and prejudice after the diagnosis of the disease.

Regarding the psychosocial repercussions of leprosy on the lives of the interviewees, the analysis revealed changes in the daily routine due to regular attendance at the health service, routine compulsion and side effects of medication, physical pain and signs of illness, fear of contagion and prejudice.

Fear was highlighted in the discursive group context - especially the fear of contamination - and proved to be an important guideline for the practices of separating domestic tools and leaving the patient within their home environment. The results also showed that the fear of prejudice resulted in sharing only the closest ones or keeping the diagnosis of leprosy as a family "secret", as well as the attempt of some adolescents to cover up the "spots" in the body that to avoid stigmatization in the context of interpersonal and intergroup relationships, interfering greatly in their social participation.

Also included in the daily life of some interviewees there was the separation, discrimination, and changes in the behavior of relatives and friends after making the diagnosis and treatment of leprosy public, emerging a complex range of negative connotations. In this context, it is worth emphasizing that the prejudiced attitude towards adolescents seemed not to be limited only to the lack of information about the disease, but also showed loaded with symbols, images and beliefs associated with the conjuncture of the disease in the past – "leprosy", approaching of a serious, mutilating and highly contagious disease.

In this sense, the process of constructing the social representations of adolescents and their families about the experience/coexistence with leprosy was influenced not only by lived experience but also as a result of social interactions in the different contexts - family, school, church, as well as through the social interlocution mediated by the media.

Therefore, for the representations and impacts caused in the daily life of adolescents with leprosy and their relatives, it is necessary to establish dialogic meetings and to expand the various information scenarios on the disease to allow the reflection and re-signification of hegemonic representations about it. Also, health policies and actions should incorporate a strategic axis aimed at investigating the imagery of people living with leprosy to approach their subjective demands and to transform the present and produce a future different for the patients, as well as for their relatives, freeing them from the heavy burdens that still are in this illness, which we hope to offer through this study.

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Author´s Contribution

Fabiana Drumond Marinho was responsible for developing the research, design and review of the article. Luziane Zacche Avellar was the lead author of this research with contributions in the development, conception and review of the article. Luiz Gustavo Silva Souza, Susilene Maria Tonelli Nardi and Gilma Corrêa Coutinho contributed to the conception and review of the article. All authors approved the final version of the text.