



Chapter 1

Teenager with leprosy and self-stigma: The role of education

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ABSTRACT

Based on the context, established by the high number of leprosy diagnoses among children and adolescents, the serious Brazilian public health scenario related to the disease, and the campaign "Towards Zero Leprosy", part of the UN 2030 Agenda, this work aims to contribute for the development of strategies aimed at intervening in the stigmatization of adolescents by the disease through the development of socio-emotional skills faced with questions of self-esteem and self-image of adolescents affected by leprosy. This research has an inductive approach, of a basic nature and exploratory objective through a bibliographic review and analysis of secondary data, to contextualize the theme, and build a theoretical framework in the state of knowledge.

Based on the knowledge produced by Garcia et al (2003), Cruz (2013), Pontes and Ximenes Neto (2005), Colli (1968), and Kauffman, Marian, and Neville (1982), this work is based on the notions of impact of leprosy stigma in adolescents, mainly concerning self-image and self-stigma. As result, data perspectives and strategic actions foreseen in the documents in the national fight against leprosy were placed, discussing the role of education in the Specific Objective 1 of the third pillar of the National Strategy. Considering the Leprosy Epidemiological Bulletin 2022 and the National Strategy to Combat Leprosy 2019-2022, it is understood that it is the role of education to collaborate so that adolescents affected by the disease understand the concepts of stigma and incidence and critically reflect to deconstruct them.

Keywords: leprosy, self-stigma, self-esteem, self-image, education.

1 INTRODUCTION

Leprosy is one of the oldest diseases of humanity, with traces found in India and Egypt, mentioned even in the most famous book in history: the Bible. Of a chronic and infectious nature, it is a stigmatizing disease, that is, associated with socially pejorative values, which affects the individual's life in addition to physical issues, having a great psychological and social impact.

Brazil still has a serious public health scenario related to leprosy, with more than 90% of cases in Latin America, the country is in second place in the world ranking of new cases of the disease, behind only India (WHO, 2021).

The disease is caused by a bacillus called *Mycobacterium leprae* and affects the peripheral nerves, such as the superficial nerves of the skin and nervous trunks of the face, neck, arms, below the elbows, and knees. Internally, it can affect the eyes, mucous membranes, spleen, liver, and bones, among others. Being transmissible through the respiratory tract, contamination occurs through prolonged contact with the

infected person without treatment, however, most people have immunity against this bacillus, therefore, only susceptible organisms develop the disease (BRASIL, 2017).

As symptoms, the Practical Guide on Leprosy (2017) mentions

"whitish, brownish or reddish spots, with changes in sensitivity to heat and/or painful to the touch; tingling, shocks, and cramps in the arms and legs that develop into numbness; papules, tubercles, and nodules usually without symptoms; decrease or loss of hair, localized or diffuse, especially in the eyebrows; infiltrated skin with reduced or absent sweating at the site; decrease or loss of sensation in the areas of the affected nerves, mainly in the eyes, hands, and feet; decrease or loss of strength in the muscles innervated by these nerves, mainly in the upper and lower limbs and sometimes the eyelids; edema of hands and feet with purple fingers and dry skin; fever and joint pains, associated with painful lumps, of sudden appearance; sudden numb spots with pain in the nerves of the elbows, knees, and ankles; stuffy, sore, and dry nose; dryness and feeling of sand in the eyes" (BRASIL, 2017, p. 9).

If the symptoms are not treated initially, the condition evolves in most cases slowly and progressively, with risks of physical disability, which can affect people of any gender or age, including children.

The World Health Organization (WHO) considers leprosy a neglected disease, since it is endemic in socially fragile populations, contributing to the maintenance of situations of inequality in the world. During 2019 and 2020, the Global Leprosy Strategy was developed through a broad consultation process involving key actors involved in the fight against the disease.

The strategy aims to contribute to the Sustainable Development Goals, part of the UN 2030 Agenda and was built on four pillars: the implementation of a personalized plan for "zero leprosy" in each of the endemic countries, the expansion of prevention and integrated active detection of cases, treatment of leprosy and its consequences, preventing new disabilities and combating stigma and guaranteeing human rights.

Considering this fourth pillar, the objective of this article is to understand the role of education in the development of strategies aimed at intervening in the stigmatization of adolescents affected by the disease, based on questions of the self-esteem and self-image of adolescents diagnosed with leprosy.

2 METHODOLOGY

This article seeks to analyze the role of education in the development of strategies aimed at intervening in the stigmatization of adolescents affected by the disease, based on questions of self-esteem and self-image of adolescents diagnosed with leprosy, observing the challenges faced and ways to positively impact them through of specific pedagogical practices.

This research has an inductive approach, of a basic nature and an exploratory objective through a bibliographical review and analysis of secondary data, to contextualize the theme, build a theoretical framework in a state of knowledge, understood as a "descriptive study of the trajectory and distribution of scientific production on a certain object, establishing contextual relations. (UNIVERSITAS, 2000 apud UNESP, 2015)

3 THEORETICAL BACKGROUND

When approaching the scenario involving leprosy, it is necessary to establish a psychosocial perspective, since the illness process goes beyond medical issues, impacting the individual socially and psychologically in profound ways. Garcia et al (2003) state that “we can no longer understand leprosy only as a bacillus, even knowing that knowledge of microbiology is extremely important”, further stating that “the understanding of the human being as a whole is necessary” (GARCIA et al, 2003).

The first aspect that should be highlighted, then, in this context, is the segregation of people affected by the disease. According to the WHO, leprosy is endemic in the lower socioeconomic classes, Garcia et al (2003) associate this characteristic with the vulnerability of the immune system to the bacillus and the restriction of access to information, both more incisive in these populations. In addition, this association can be linked to issues of understanding the infectious condition, treatment, and other issues that go beyond the biological aspects.

According to Cruz (2013), “the symbolism that this disease took on in the historical context, leading to the systematic segregation of these patients, subjected to traumatic mechanisms of exclusion and stigmatization for a long time, produced representations about ‘being a leper’”. This scenario remains present even after the replacement of the term leprosy by leprosy more than 30 years ago, even today, the socially rooted negative aspects affect the social representations of these patients, with emphasis on the impacts of stigmatization on adolescents.

Leprosy represents a series of losses and insecurities for patients, considering that among communicable diseases, it is one of the main responsible of consequences of permanent physical disability (BRASIL, 2006). Under the psychosocial perspective, the group affected by the disease may face losses related to social and family references, with curtailment of socialization. In addition, the emotional structure of this group is commonly affected by feelings of insecurity, affecting their stability capabilities, creating difficulties in facing adverse situations and maintaining a positive self-concept (KAUFFMAN, MARIAM, NEVILLE, 1982)

In this perspective, considering the above picture about the historical burden attributed to the disease, patients affected by leprosy, with a certain frequency, have difficulties in the construction of a favorable self-image. Self-image is considered to be the image constructed by the individual about himself, which plays a decisive influence, even more so, in adolescence, bringing consequences on self-perception, socialization, and even on the development process of the adolescent's personality (GARCIA et al, 2003).

The negative perception of self-image leads to the patient's self-exclusion, depending on the values attributed to himself, impacting the potential for socialization with self-associations linked to the social representations of the disease. The adolescent, by appropriating the stigmatizing notions of his condition, starts to adopt it for himself, discrediting the positive possibilities regarding his own experience in society.

It should be noted that society, considering the current scenario involving overexposure on social networks and the aesthetic standards imposed as a form of value judgment, tends to advocate the aesthetic conditions of the individual, on the other hand, those who do not meet the established standards end up for assuming less favored roles in power relations and social influence.

In adolescence, this condition is exacerbated. In this period of transformation and development towards biopsychosocial maturity, the aesthetic profile has an even greater weight, directly affecting the social role that the adolescent will assume in adult life. In this way, the physical aspects resulting from leprosy make the patient, in most cases, carry out a stigmatizing self-assessment, recognizing himself as having less value in front of his peers.

Garcia et al (2003) characterize as stigma “a situation outside the social standards accepted as normal, in which an individual presents and is known by others, and becomes rejected for this characteristic”. Thus, considering leprosy, there is the possibility that the diagnosed adolescent has difficulties in developing his social role, based on his perception of himself and from his evaluation of the disease, both with the history of stigma and in terms of regarding their experience as a patient.

If their perception is negative, the adolescent develops self-stigma, validating the social stigma in an internalized way, compromising their self-image and self-esteem, which leads to greater psychosocial effects. Garcia et al (2003) state that the patient assumes a self-deprecating position, rejecting or denying himself, this posture makes him look for escape points through self-exclusion, for example.

In summary, the stigmatized social representations of leprosy are identified as protagonists in the difficulty of treatment adherence, in addition to implying serious psychosocial conditions, especially in the case of adolescent patients.

Colli (1988) defines adolescence as "a gradual phase between childhood and adulthood that is characterized by profound somatic, psychological and social transformations", it is a transition phase in which the individual searches for his identity, in addition to having their biopsychosocial development accelerated, generating changes in all spheres. The individual ceases to be recognized as a child but is not tied to the role of an adult, either.

By mentioning the psychosocial impacts from the perspective of specificities related to adolescence, Pontes and Ximenes Neto (2005) consider that, for adolescents who experience this phase of transformations and adaptations, the diagnosis may imply the construction of their lives. The authors point out that the fear of rejection, already present in the phase, can be aggravated by leprosy, generating behavior changes in self-perception and self-care.

4 RESULTS AND DISCUSSION

The Leprosy Epidemiological Bulletin, published in January 2022, documents data from the Notifiable Diseases Information System (Sinan) between 2010 and 2020, also including preliminary data

for the year 2021, presenting data to reinforce the actions of the National Strategy for the Confrontation of Leprosy 2019-2022, whose objective is a Brazil without leprosy.

To achieve this, the Strategy seeks to reduce the number of the disease in the country by the end of 2022, meeting three goals, namely:

- 1) Reducing the total number of children with grade 2 physical disabilities to 30/million;
- 2) The reduction to 8.83/million the rate of people with grade 2 physical disabilities;
- 3) Implementation of channels for recording discriminatory practices against people affected by leprosy and their families in all Federative Units.

The Bulletin emphasizes the importance of producing and disseminating information about leprosy in the country, as it is the information that enables guidelines and decision-making in favor of correct actions in Public Health (BRASIL, 2022).

As for the scenario of this article, the Bulletin states that in the period from 2011 to 2020, 19,101 new cases of leprosy were diagnosed in children under 15 years of age in Brazil, which represents a reduction of 61.9% in the rate of detection of new cases in this population, from 5.22 in 2011 to 1.99 in 2020, making the current parameter average. This reduction, according to the Bulletin, is present in the five regions of the country, however, a fluctuation in the rate was observed in the North, Northeast, and Midwest regions. Considering the age group (under 15 years old), the occurrence of new cases indicates active transmission foci, an aspect treated as a signal for the endemic monitoring of the disease (BRASIL, 2022).

Therefore, although there are already tangible results of the National Strategy, the scenario is still worrying in the country. Furthermore, based on the third pillar of the strategy, the country must promote social inclusion by combating stigma and discrimination.

In this perspective, the specific objectives are the promotion of social inclusion by addressing all forms of stigma and discrimination, strengthening the capacity for active participation of people affected by leprosy in spaces of social control and health services, the support for inclusive development models for people affected by leprosy and the promotion of access to social and financial support services and programs (BRASIL, 2021).

As a means to implement the third pillar of the Strategy, the document presents strategic actions for each of the specific objectives. Considering the outline of this article, we will detail the actions planned for Specific Objective 1, which aims to promote social inclusion by addressing all forms of stigma and discrimination, highlighting then: the use and support for the use of tools that promote knowledge and critical reflection on stigma, social participation and empowerment, the promotion of spaces for discussion and appropriation of the concepts and dimensions of stigma and discrimination, articulation with state and municipal education departments so that all children and young people affected by leprosy have access to education, the encouragement and establishment of health education strategies, focusing on people affected by leprosy, guided by the development of critical-reflective thinking with a view to producing autonomy

and empowerment, the preparation and updating of materials for health education with language appropriate to different realities and the performance of educational campaigns as a strategy to promote citizenship.

Associating the aforementioned actions and the notions of self-stigma covered above, it is necessary to understand the role of education in the scenario, as a training agent, contributing to the young people affected by the disease to develop critical-reflective capacity about themselves, empowering themselves, so that, thus, the stigmatizing bias of the disease is not internalized, strengthening the positive feeling of self-esteem and self-image.

Education plays a role in ways and transforms individuals in favor of citizenship, understood as the exercise of responsibility and social action, which prioritizes respect for diversity, the right to equal opportunities for all, and justice. Nussbaum (2010) highlights the importance of education for social development since it is through formative processes that we achieve critical thinking, fundamental for life in society. Cunha and Heckman (2007) state that, in addition, socio-emotional development is fundamental for the exercise of citizenship both individually and collectively.

When paying attention to the promotion of social inclusion by addressing all forms of stigma and discrimination, it is up to education agents to create spaces that favor students' critical-reflective abilities, thus validating the perspective of inclusive education as a social process of adaptation to guarantee the inclusion of people and diversities – social and cultural.

Freire (2005) attributes to education the responsibility of raising popular awareness in favor of transforming reality, prioritizing dialogue, respect, and the cultivation of criticality – from the bridge between the student's reality and the classroom.

When thinking about issues of stigma and discrimination involving adolescents affected by leprosy, Garcia et al (2003) state that "our culture does not educate us to take care of ourselves". However, education, by promoting the theme based on dialogue and respect for the specificities of the subjects, enables the individual to build knowledge, deconstructing limitations with historically established stigmas, encouraging new perceptions about the disease and its consequences, both of the affected individual and those around him (FREIRE, 2005).

Oliveira and Muszkat (2021) also state that socio-emotional skills are fundamental for the integral development of individuals, as well as for their social interactions to take place healthily. So, when education takes on the role of the socio-emotional trainer of its students, it contributes to them having better social performance.

When considering the previously discussed scenario with adolescents affected by leprosy and the psychosocial difficulties they face, socio-emotional education is an ally in coping with the stigma and discrimination of this group, even impacting issues of self-stigma, helping the patient to perceive themselves with respect, improving your self-esteem and self-image.

Given these conceptions, it is possible to understand that this individual, by developing socio-emotional skills, has better chances of living with the disease, dealing in a more balanced way with feelings of insecurity and fragility, and critically identifying stigma and discrimination, without internalizing them.

However, for this scenario to materialize, the role of education and its agents is fundamental through training and support to the patient, encouraging him to feel capable of facing and overcoming the adversities arising from his condition.

5 CLOSING REMARKS

Considering the notions presented, it is evident that the notions of stigma attributed to leprosy are the result of a long historical process, reported since ancient Egypt, permeating cultures and resulting in a limited perception of the situation. Given this, patients affected by the disease must deal, in addition to the possibility of severe physical consequences, with psychosocial issues that aggravate the scenario of coping with the disease.

Even more so in today's society, where aesthetic issues are overvalued, impacting individuals' representations and social actions. When dealing even more specifically with adolescents affected by leprosy, specific difficulties resulting from this phase of life are perceived, which is full of transformations, marked by the biopsychosocial maturation of the subject, implying how he sees himself and plays his role social, resulting in many cases of self-stigma, self-exclusion, and self-depreciation, resulting from a negative self-image assessment of these adolescents.

Finally, when analyzing the data obtained in the 2022 Leprosy Epidemiological Bulletin and the 2019-2022 National Strategy to Combat Leprosy, it is understood that it is the role of education to collaborate so that adolescents affected by the disease understand the concepts of stigma and discrimination and reflect critically to deconstruct them.

Thus, by developing a better perception of the concepts and appropriating socio-emotional skills, these adolescents tend to have better chances of living with the disease until the cure, dealing in a more balanced way with feelings of insecurity and fragility, critically identifying the stigma and discrimination, without internalizing them.

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