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PERCEPTION OF ADOLESCENTS ABOUT LEPROSY

PERCEPÇÃO DE ADOLESCENTES SOBRE A HANSENÍASE

PERCEPCIÓN DE ADOLESCENTES SOBRE LA LEPRO

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ABSTRACT

Objective: to analyze the adolescents' perception about leprosy. **Method:** this is a qualitative, descriptive study of 30 adolescents from a public school, carried out from August to November 2016. Data was collected from the dynamic face game; the speeches were transcribed and analyzed according to the Content Analysis technique in the Thematic Analysis modality. **Results:** there is little knowledge about leprosy in adolescents, without discernment about the general aspects of the disease, associating it with other diseases. It is perceived that they have family and television as the main sources of information about the disease, and the lack of knowledge about leprosy generates an atmosphere of fear, doubt, anguish and concern, mainly because they think that the disease has no cure, causes social isolation, and can be transmitted to their family members. **Conclusion:** it is concluded that adolescents perceive leprosy as a serious, incurable disease that causes fear, shame and social isolation. **Descriptors:** Leprosy; Communicable Diseases; Adolescent; Perception; Qualitative Research; Nursing.

RESUMO

Objetivo: analisar a percepção de adolescentes sobre a hanseníase. **Método:** trata-se de uma pesquisa qualitativa, descritiva, constituída por 30 adolescentes de uma escola pública, realizada no período de agosto a novembro de 2016. Coletaram-se os dados a partir do jogo dinâmica da face, cujas falas foram transcritas e analisadas conforme a técnica de Análise de Conteúdo na modalidade Análise Temática. **Resultados:** verifica-se, nas falas dos adolescentes, pouco conhecimento sobre a hanseníase, sem discernimento sobre os aspectos gerais da doença, associando-a a outras enfermidades. Percebe-se que eles têm a família e a televisão como principais fontes de informação sobre a doença, e o desconhecimento sobre a hanseníase gera uma atmosfera de medo, dúvida, angústia e preocupação, principalmente, por pensarem que a doença não tem cura, causa isolamento social, e pode ser transmitida a seus familiares. **Conclusão:** conclui-se que os adolescentes percebem a hanseníase como uma doença grave, incurável e causadora de medo, vergonha e isolamento social. **Descritores:** Hanseníase; Doenças Transmissíveis; Adolescente; Percepção; Pesquisa Qualitativa; Enfermagem.

RESUMEN

Objetivo: analizar la percepción de los adolescentes sobre la lepra. **Método:** se trata de una investigación cualitativa, descriptiva, constituida por 30 adolescentes de una escuela pública, realizada en el período de agosto a noviembre de 2016. Se recogen los datos a partir del juego dinámico de la cara, cuyas palabras fueron transcritas y analizadas de acuerdo con la técnica de Análisis de Contenido en la modalidad Análisis Temático. **Resultados:** se verifica, en las conversaciones de los adolescentes, poco conocimiento sobre la lepra, sin discernimiento sobre los aspectos generales de la enfermedad, asociándola a otras enfermedades. Se percibe que tienen la familia y la televisión como principales fuentes de información sobre la enfermedad, y el desconocimiento sobre la lepra genera una atmósfera de miedo, duda, angustia y preocupación, principalmente, por pensar que la enfermedad no tiene cura, causa aislamiento social, y puede ser transmitida a sus familiares. **Conclusión:** se concluye que los adolescentes perciben la lepra como una enfermedad grave, incurable y causante de miedo, vergüenza y aislamiento social. **Descriptores:** Lepra; Enfermedades Transmisibles; Adolescente; Percepción; Investigación Cualitativa; Enfermería.

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INTRODUCTION

It is known that leprosy in children under fifteen is still common in endemic countries, such as Brazil. It is worth noting that, although the annual percentage change in leprosy between 2001 and 2016 was -5%, with a decreasing trend in children under fifteen years of age, some states and capitals remain hyperendemic, such as Mato Grosso and Cuiabá, respectively.¹ It is noteworthy that these findings denote the continuous horizontal transmission of leprosy.²

The peripheral nervous system, the skin, the reticuloendothelial system, the bones, the joints, the mucous membranes, the eyes, the testicles, the muscles and the adrenals are mainly affected by the disease and, when left untreated, can evolve with deformities and physical disabilities.³

Regarding the health-related quality of life in pediatric patients with leprosy, there is a decrease in the physical and educational domains, with the presence of musculoskeletal manifestations, such as arthralgia, arthritis and myalgia.⁴

The quality of life also suffers, as well as interference in the psychosocial field, especially when there is a lack of knowledge about the disease, with difficulty in coping, feelings such as sadness and shame, both associated with fear and apprehension of discrimination. The diagnosis is concealed by many individuals with leprosy to avoid discrimination and social restraint as a form of self-protection.⁵

The lack of knowledge on the part of this population and the presence of stigma and prejudice in relation to leprosy have been identified in studies carried out in other Brazilian states,⁶⁻⁷ these are situations that make it difficult to control the disease, and investment in health education strategies is recommended to this public, since they promote the construction of knowledge, favoring prevention, early diagnosis and timely treatment.⁷

The most promising place for this practice is the school, as verified in an integrative review study on educational practices of leprosy with adolescents.⁸ It becomes a favorable environment for reaching this public and promoting knowledge, with competence for basic training and socialization.⁸

In this perspective, the application of educational games is used as one of the intervention strategies, since the playful one has good acceptability and contemplates criteria of an effective learning.⁸⁻⁹ The game

strategy is also used to collect data with adolescents, recognized for promoting interaction, socialization and concentration to conduct critical discussion based on playfulness, and is recommended for data apprehension.¹⁰

OBJECTIVE

- To analyze the perception of adolescents about leprosy.

METHOD

This is a qualitative, descriptive study conducted in the period from August to November 2016, with adolescents in a randomly chosen public school in Cuiabá, Mato Grosso, whose school management authorized the collection of data.

Participants were selected based on the inclusion criteria: adolescents aged ten to 14 years, who were in the classroom on the day of the educational workshop and who agreed to participate in the study by signing the Term of Assent and, home, the Free and Informed Consent Term (FICT) signed by the parents or guardians, totaling 30 adolescents.

Data was collected from the application of the game called "face dynamics", conducted by three nursing undergraduate students who received training prior to field entry. It consists of the game in the delivery of two plaques by the researchers, each teenager, with a drawing illustrating a happy face and a sad face. The adolescents, from each questioning made by the researchers, should raise one of the plaques and say why. It is reported that the questions that guided the dynamics were: "What is leprosy?; What do you think about leprosy?; What do your parents, friends and neighbors think? Have you ever had the disease?; If so, tell me about your experience; What are your fears, doubts and feelings about leprosy?".¹¹

Five meetings were held, with groups of six students, each of which lasted approximately 50 minutes, and took place in conference rooms, courtyard and an unused classroom.

The speeches obtained from the dynamics were recorded, transcribed and organized, analyzing them later with the application of the Thematic Content Analysis technique.¹²

After the transcription of the data, the identities of the participants were preserved, being identified with codes, beginning with the initials of the names, followed by the age and the school year, for example: (M13-7); (AJ12-6).

This study is part of a matrix research entitled "Health Education and Active Search

Freitas BHBM de, Blanco e Silva²F, Silva KF da et al.

for Leprosy in Children under 15 Years in Cuiabá, MT", approved by the Research Ethics Committee of the Júlio Muller University Hospital under the opinion 1,579,925 and CAAE 53659616.5.00005541, June 8, 2016.

RESULTS

By the analysis of the interviews, the emergence of three categories was made possible: "Perception of adolescents on leprosy"; "Access to information on leprosy" and "Adolescents' concern about leprosy".

♦ Adolescents' perception about leprosy

In the face of the initial questioning about the definition of leprosy by many adolescents, the sad face plaque was affirmed in the sequence:

M13-7: It's just like cancer;

L14-8: It's a disease that kills;

G12-6: It's sad because people can not talk to their friends, they have to stay home locked up;

V12-6: Yeah, I think this disease is dangerous and without treatment;

D13-7: Illness that leaves spots on the body;

G14-8: It is a red or white color or patch that appears on the body, it brings shame and the person can pinch, bite, and they will not feel it;

AV13-6: I think leprosy, for those who have this disease and [...] like that, because there are people who have the disease and hide and do not have the courage to count and do not treat, then the person who has the disease is ashamed of themselves and the disease, they have to look for a health clinic;

B13-6: Sad because it is a very bad disease, that no one will want to have it because there is no cure, they get a lot of spots on the skin and such.

It is evidenced, through the lines, that many adolescents confuse leprosy with other diseases, believe that it has no cure and causes death. It was found that the general aspects of the disease, such as etiology, transmission, diagnosis and treatment, are unknown by adolescents, and they reveal signs and symptoms as the main characteristic of leprosy and correctly mention only the presence of spots and loss of sensitivity.

It is revealed, through the speeches, that they associate the disease with the feeling of sadness and shame and social isolation, affecting the demand for health care in the face of the suspicion of the disease.

♦ Access to information about leprosy

They stand out as main sources of information of the adolescents about the disease:

Perception of adolescents about leprosy.

AC14-8: My father said that it is a disease that the body parts fall off;

G13-7: I've never heard anyone mention it because, most of the time, no one knows about it;

AC13-7: I've heard about it on television, but no one has spoken to me personally;

D14-6: I saw about this disease in an interview in the television news report;

J14-8: My mother thinks it has a cure and my father thinks it does not have one. I asked them because my friend had leprosy and she went to the hospital and almost died;

V12-6: My mother said that it is leprosy and said that it is transmitted by air;

AR13-7: My grandmother said it is a very dangerous and easily infectious disease.

For the participants of this research, the family and television are the main references for information about the disease. Leprosy is referred to as leprosy by the family of these adolescents, but they contradict themselves as to treatment and cure and know the form of transmission. It is verified, however, that there is the adolescent who never received information about the disease, emphasizing the lack of knowledge in their environment.

♦ Adolescents' preoccupation with leprosy

The adolescents were questioned about their feelings about the disease, and they raised the sad face plate. The reports showed concern about acquiring the disease and about the impossibility of a cure, the possibility of transmission to loved ones of the family, feelings of shame and social isolation arising from the disease, as the speeches reveal:

J14-8: I'm afraid to get it because it's rare and I can pass it on to my family;

M13-7: I am afraid that the most important people in my life will get the disease and not treat it or be embarrassed to say that they have the disease and can die, but they are rebuked in the name of Jesus and it will not happen;

N14-7: I'm afraid that I and other people will catch it because it's very contagious; hence the person can not quit because sometimes people can catch the disease, so it is very difficult to treat too, so it is kind of dangerous;

L14-7: And [...] I'm afraid to get sick because it's, like, I got the disease, I'm going to be ashamed to leave the house, I'll be ashamed to talk to my colleagues, play with my colleagues, talk to them, even because she is transmissible. So [...] there are several people who also have prejudice, then I think that's bad;

B12-6: I'm scared of getting it and not knowing, then, being depressed at home,

not going out to talk to the neighbors and end up dying.

DISCUSSION

It was possible to verify, through this study, that there is the ignorance and the presence of false conceptions culturally constructed about leprosy, which reinforce the maintenance of stigma and prejudice in society, undermining its control. These findings are similar to other studies carried out with adolescents in other regions of Brazil.^{6,13}

It was observed that few adolescents in this research know the definition, etiology, signs and symptoms and treatment of leprosy, as well as another qualitative approach involving fifteen adolescents, which identified that they had scarce knowledge about leprosy, because they all answered in succinct sentences, without any explanation.⁶ In another study with adolescents, there was also a similar result, highlighting the knowledge deficit and the little debate by schools and society.¹⁴

Adolescent concerns about the disease, such as fear of discrimination and social isolation, are believed to be commonplace in the face of ignorance of the disease.⁵ It is stated by them that many individuals with leprosy can conceal the diagnosis, to avoid discrimination and social restriction, impairing treatment, and this was actually verified in the speeches of individuals with the disease.⁵

The importance of educational activities that promote the construction of knowledge about leprosy is reaffirmed, due to the lack of knowledge found and concerns about the disease. Health education promotes the spontaneous demand of patients and the contact with health services, through the suspicion of the disease, the elimination of false concepts attributed to it, information about its signs and symptoms, and the importance of timely treatment.¹⁵⁻⁶

It is recalled that, contrary to what the participants of this research think, leprosy has a cure and its treatment occurs through multi-drug therapy, offered free of charge in Brazil, via the Unified Health System (UHS), however, it becomes a chronic condition to the disability and physical deformity that can occur when the diagnosis is late.¹⁷

It is noted that leprosy is an ancient disease that has a distressing image in the history and memory of mankind, since from the earliest times it is considered a contagious, mutilating and incurable disease, causing rejection, discrimination and exclusion of the patient, called leprosy by society.¹⁴ The negative feelings, such as fear,

sadness, shame and suffering, reported by adolescents, are experienced as the same ones experienced by individuals diagnosed with the disease.⁵

In Brazil, Law 9.010 / 95 was created, as a complex condition, as one of the strategies to reduce the stigma of the disease, which authorized the change in the use of the term leprosy for leprosy as an initial action in an attempt to reduce the prejudice caused by the disease.¹⁴ It is noticed, however, that even after 22 years of the change of nomenclature, situations of stigma and prejudice still exist, considered potential barriers to the control of this aggravation.¹⁸

It is added, given the misinformation received by adolescents, as verified in this study, that it is up to health professionals to carry out health education actions with this public, to increase their knowledge and access to health services.¹⁸ School is recognized as an ideal environment for this practice, since it is in this space that the construction of the knowledge and values that often lead the students to have intelligent attitudes, becoming information disseminators.⁶

It is also understood that the participants of the research have the family as an important source of information, however, it is noticed, through their speeches, that they have a limited knowledge about the disease, thus preserving the older, most culturally established concepts. In this sense, community and family health education is recommended in order to expand the population's knowledge of disease control, since within society the family will always be the first reference of an individual, especially in childhood and adolescence, since the knowledge acquired through the family and its generations establishes an important cycle in cultural maintenance.¹⁹

It is inferred that another source of information about the disease to this population was the television, as verified in the results. It was revealed, in a study carried out in a public high school, involving 200 students in the age group of 13 to 24 years, that 168 participants of the research have already heard about leprosy; of these, 75 through television, 23 through health professionals, 17 in the school and only six through the family. Thus, the media is an important information vehicle.¹⁴

It is understood that media, such as radio, television, the internet and other mass media, associated with the knowledge of society, is an important ally for the dissemination of information about the disease, with a view on prevention and control, since most of the

population has access to some communication vehicle. Through the use of technologies, people are allowed to get in touch with many contents in an instant, mainly the internet.⁷

Thus, it is important that health professionals recognize the potential of information and communication technologies in adolescent health education and appropriate this resource to address such relevant issues as leprosy.²⁰

CONCLUSION

It is concluded that adolescents perceive leprosy as a serious, incurable disease that causes fear, shame and social isolation. This perception of a mistaken conception of the disease, culturally constructed and transmitted mainly by the relatives, originates; therefore, social stigma and prejudice were present in some of the adolescents' speeches.

Thus, it is considered that health education actions are essential in assisting these clients, especially in schools, the environment where adolescents spend most of their time, through the playfulness and active participation of those involved. It is recommended, therefore, the intensification of health education actions, together with this population, as a means to make the subject emancipated and endowed with knowledge.

The study participants have the family as an adjunct to the information exchange on leprosy, and it is suggested from the results that new research be done with the families, since these are considered references for adolescents.

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