





# LEPROSY: COMPULSORY INTERNMENT AND FAMILY MISHAPS IN THE LIGHT OF ORAL HISTORY

HANSENÍASE: INTERNAMENTO COMPULSÓRIO E OS PERCALÇOS FAMILIARES À LUZ DA HISTÓRIA ORAL

LEPRA: HOSPITALIZACIÓN OBLIGATORIA Y CONTRATIEMPOS FAMILIARES A LA LUZ DE LA HISTORIA ORAL

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## ABSTRACT

**Introduction:** leprosy is a secular disease maintained for many years as incurable, leading to segregation of the patient. The exclusionary mechanisms against the leper had the premise of protecting the healthy population, while they constituted obstacles to the maintenance of the family bond. **Objective:** to analyze the effect of compulsory leprosy treatment in hospital-colonies on family relationships, from the perspective of those who are related to a ex-patient. **Method:** qualitative study, using thematic oral history. The colony was composed of 52 relatives of ex-leprosy patients and the network of 10 collaborators, of both sexes, aged 44 to 76 years. The interview was used, with comprehensive questions, submitted to thematic content analysis. The survey was approved with Opinion No. 650,654/2014. **Results:** through the analysis, three categories emerged: disruption of family organization, family distance and changes in family support, which address the consequences on family relationships, established through the experience of having a relative affected by leprosy and victimized by compulsory hospitalization in hospital-colonies. The distancing changed the relationships and the family bond between the former leprosy patients treated in an asylum environment and their families. **Conclusion:** the described stories report damages experienced in the past because of the family break suffered by the study collaborators regarding the policy adopted as prophylaxis and control of leprosy. Given this part of the disease history reported in the present study, and its epidemiological characteristics, it is relevant to consider the subjectivity of individuals with leprosy, providing comprehensive care.

**Keywords:** Life Change Events; Family Relationships; Leprosy; Nursing.

## RESUMO

**Introdução:** a hanseníase é uma doença secular mantida por muitos anos como incurável, levando à segregação do doente. Os mecanismos excludentes contra o leproso tinham a premissa de proteger a população sadia, ao mesmo tempo em que se constituíam como empecilhos à manutenção do vínculo familiar. **Objetivo:** analisar o efeito do tratamento compulsório da hanseníase em hospitais-colônias nas relações familiares, na perspectiva daquele que possui parentesco com um ex-doente. **Método:** estudo qualitativo, utilizando-se da história oral temática. A colônia foi composta pelos 52 familiares de ex-doentes de hanseníase e a rede por 10 colaboradores, de ambos os sexos, com idade de 44 a 76 anos. Utilizou-se a entrevista, com questões abrangentes, submetida à análise temática de conteúdo. A pesquisa foi aprovada com Parecer de nº 650.654/2014. **Resultados:** mediante a análise, emergiram três categorias: desestruturação da organização familiar, distanciamento familiar e alteração no suporte familiar, os quais abordam as consequências nas relações familiares, estabelecidas mediante a experiência de se ter um parente acometido pela lepra e vitimado pelo internamento compulsório em hospitais-colônias. O distanciamento modificou as relações e o vínculo familiar entre os ex-doentes de lepra tratados em ambiente asilar e seus familiares. **Conclusão:** as histórias narradas relatam danos vivenciados no passado como consequência da ruptura familiar sofrida pelos colaboradores do estudo frente à política adotada como

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*profilaxia e controle da lepra. Diante dessa parte do histórico da doença relatada no presente estudo, e de suas características epidemiológicas, torna-se relevante considerar a subjetividade dos indivíduos com hanseníase, proporcionando cuidado integral.*

**Palavras-chave:** Acontecimentos que Mudam a Vida; Relações Familiares; Hanseníase; Enfermagem.

## RESUMEN

**Introducción:** la lepra es una enfermedad secular considerada durante muchos años como incurable, segregando al paciente. Los mecanismos de exclusión contra el leproso tenían la premisa de proteger a la población sana, al mismo tiempo que constituían obstáculos para el mantenimiento del vínculo familiar. **Objetivo:** analizar el efecto del tratamiento obligatorio de la lepra en hospitales-colonias sobre las relaciones familiares, desde la perspectiva de alguien relacionado con un ex paciente. **Método:** estudio cualitativo, utilizando historia oral temática. La colonia estaba compuesta por 52 familiares de ex pacientes de lepra y la red de 10 colaboradores, de ambos sexos, de 44 a 76 años. Se utilizó la entrevista con preguntas amplias, sometidas a análisis de contenido temático. La encuesta fue aprobada con el dictamen No. 650,654 / 2014. **Resultados:** a través del análisis surgieron tres categorías: desestructuración de la organización familiar, distanciamiento familiar y cambios en el apoyo familiar, que enfocan las consecuencias en las relaciones familiares, establecidas a través de la experiencia de tener un familiar afectado por la lepra y victimizado por la internación obligatoria en hospitales-colonias. El distanciamiento alteró las relaciones y el vínculo entre los ex pacientes con lepra tratados en un entorno de asilo y sus familiares. **Conclusión:** las historias narradas reportan daños sufridos en el pasado como consecuencia de la ruptura familiar de los participantes del estudio ante la política adoptada como profilaxis y control de la lepra. En vista de esta parte de la historia de la enfermedad reportada en el presente estudio, y de sus características epidemiológicas, resulta relevante considerar la subjetividad de las personas con lepra, brindando atención integral.

**Palabras clave:** Acontecimientos que Cambian la Vida; Relaciones Familiares; Lepra; Enfermería.

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## INTRODUCTION

Leprosy, also known as morphea, is characterized as a secular disease, therefore, it is considered as one of the oldest evils in the history of mankind, marked by social exclusion, stigma, abandonment, fear for having been considered for a long time as incurable, mutilating and contagious.<sup>1,2</sup>

According to the epidemiological data collected in the countries that are part of the five regions (Africa, Americas, Eastern Mediterranean, South-East Asia and Western Pacific) of the World Health Organization (WHO), at the end of 2017, 192,713 patients with leprosy were registered as “under treatment”, corresponding to a prevalence rate of 0.25 per 10,000 inhabitants. In the same year, 210,671 new cases were reported in 150 countries, and the finding rate for new cases was 2.77 per 100,000 inhabitants. It should be noted that

India, Brazil and Indonesia represented 80.2% of the patients notified in the world in 2017.<sup>3</sup>

Regarding the history of leprosy, when there was no polychemotherapy treatment, the colonies for isolation fulfilled a sanitizing role that was socially legitimized to keep lepers from the healthy population. On a compulsory basis, those affected by the disease were forcibly separated from their families and admitted in the asylum, prevented from raising their children in the colony, which were intended for boarding schools, where they were severely treated.<sup>2</sup>

The structuring of the segregation and isolation policy reinforced the prophylaxis model that tried to keep the sick away, characterized as disturbing elements of society. The exclusionary mechanisms against the leper had the premise of protecting the healthy population, while they constituted obstacles to the maintenance of the family bond of the one affected by the disease.<sup>4</sup>

The removal of the child from the family was justified in prophylaxis measures. Thus, removing the child from living with the sick family member was a way to prevent the child becoming ill. On the one hand, in the boarding school, children grew up without the physical and emotional contact of their parents; and on the other h, in the colony, the family separation generated a feeling of revolt, often associated with the ignorance of the destiny taken by the child and the difficulty in establishing family ties.<sup>5</sup>

An example of a segregation space is the extinct *Hospital Colônia São Francisco de Assis*, located in the city of *Natal*, state of *Rio Grande do Norte - RN*, which served as a setting to enclose the victims of leprosy for 65 years, from 1929 (opening year) to 1994 (when it was deactivated). The *Educandário Oswaldo Cruz*, also in *Natal*, opened in 1942 was allocated to the children of inpatients at this hospital.<sup>6</sup>

In addition to the consequences of Hansen's bacillus infection on the skin and on the peripheral nervous system, such as the possibility of developing deformities and physical disabilities, the emotional repercussions, changes in daily habits and implications for the breakdown and distance of the affected family are emphasized regarding those affected by leprosy and victims of compulsory isolation.<sup>6</sup>

In general, the family is characterized as a strongly structured social group through the maintenance of the bond and affinity relationships, which can be established through the genetic connections transmitted by relations of descent, inbreeding and can also be constituted by means of socially formed bonds and by love.<sup>7</sup>

From the relationships established by the individuals that constitute the family group, the roles of family support stand out, such as: providing information exchange, supplying members with material and emotional support, strengthening

in individuals the sense of love and appreciation of the bond with the another, enabling the organization and conservation of an identity and a space for social protection, in addition to helping to assign meaning to life experiences.<sup>8</sup>

Considering the family environment as a network interconnected by interaction and with mutual influence among its members, so that complications in the life of an individual can reflect on the entire group,<sup>9</sup> it is assumed that during the institutionalization period of treatment of Hansen's disease occurred an important change in family relationships and structure due to the segregation and exclusion experienced by the patient.

In this perspective, the question is: what is the influence of leprosy in the establishment of family ties between ex-patients treated in hospital-colonies and members of their family? In order to answer the proposed question, the present study aims to analyze the effect of compulsory treatment of leprosy in hospital-colonies on family relationships, from the perspective of those who are related to an ex-patient.

The current situation that involves leprosy highlights the preponderance of the burden of stigma and discrimination associated with the disease and affected people as elements that hinder early detection and completion of treatment. Many patients suffer the impacts of social exclusion and stigma that often reverberate in the family.<sup>3,10</sup>

## MATERIAL AND METHODS

This is an exploratory, descriptive, qualitative study, using thematic oral history as a methodological framework. Oral history involves a systematic set of procedures for collecting narratives. Thematic oral history modality is used in order to reveal a specific episode experienced by the collaborator; the name given to the study participants.<sup>11</sup>

The colony was composed of 52 relatives of ex-leprosy patients who were segregated at the *Hospital Colônia São Francisco de Assis*, of both sexes, aged between 34 and 85 years, registered in the Movement for the Reintegration of People Affected by Leprosy in *Rio Grande do Norte* State (MORHAN-Potiguar).

The network is characterized as a subdivision of the colony made from rationalized cuts to decide who will participate in the study,<sup>11</sup> analogous to the inclusion and exclusion criteria. For structuring the network, first and second degree affinity relationships were considered between the collaborator and the former leprosy patient; men and women; age over 40 years; residents of *Natal-RN* during the period of data collection; and who agreed to collaborate freely with the study. The exclusion criteria were non-preserved mental faculties; individuals with communication barriers that could

impair the effectiveness of the interview, as well as those with whom it was not possible to contact.

The zero point is understood as a collaborator who has extensive knowledge about what one wants to research in the history of the group and, for this study, the coordinator of MORHAN-Potiguar was selected. From this, the other research participants that made up the network were recruited, adding 10 collaborators selected based on the inclusion and exclusion criteria (it was not possible to contact 20 members of MORHAN-Potiguar, 15 were not in *Natal* during the period of data collection and seven refused to participate in the study).

Prior to the interview phase, employees were invited to participate in the survey by telephone. The interviews were conducted in the months of June and July 2014, at dates and places chosen by the employee. A questionnaire containing questions about the characterization of the study sample (degree of affinity with the family member segregated in the *Colônia São Francisco de Assis*, sex and age) was used as an instrument of data collection, in addition to open questions that directed employees' memories to the purpose of the study (talk about your experience as a family member of a former leprosy patient asylum at *Hospital Colônia São Francisco de Assis*; talk if the isolation of your relative at *Hospital Colônia São Francisco de Assis* influenced the establishment of bonds between you). In the post-interview stage, he was grateful for the availability to participate in the study.

The interviews recorded on an audio recorder were transcribed, textualized, transcribed and authenticated by the collaborators with the signature of the assignment letter.<sup>11</sup> The transcribed material was analyzed through thematic content analysis.<sup>12</sup>

Considering the ethical precepts of research involving human beings, the collaborators were informed about their participation in the study and signed the Free and Informed Consent Term, in addition to being presented with color names, as a guarantee of preserving their anonymity. The research was approved by the Research Ethics Committee of the *Universidade Federal do Rio Grande do Norte* (UFRN), under number 650.654/2014 and CAAE 25922214.3.0000.5537.

## RESULTS AND DISCUSSION

The description of the characterization of the study participants addresses the degree of affinity between the research collaborator and the family member who was admitted to the *Colônia São Francisco de Assis*, as well as sex and age, according to the data in Table 1.

The measure of compulsory isolation of leprosy patients in hospital-colonies built on the suburbs of urban centers sought

Table 1 - Characterization of the collaborators of the study

Colaborator	Family who was hospitalized	Sex	Age
Mister Black	Father and maternal grandmother	Male	44 years
Miss Red	Father	Female	74 years
Mister Yellow	Father	Male	66 years
Mister Blue	Father	Male	76 years
Miss Green	Father	Female	73 years
Mister Purple	Maternal grandmother	Male	64 years
Miss Orange	Father	Male	58 years
Mister Brown	Father and mother	Female	58 years
Miss Pink	Father	Female	65 years
Mister White	Mother and brother	Male	66 years

Source: research data.

to protect the health of the healthy community. Despite this prerogative, parents' hospitalization in the colonies generated problems in relation to the fate of healthy children, which were generally ignored by other family members in the face of fear of contagion and stigma of the disease.<sup>5,6</sup>

It was up to the State to legitimize the creation of preventive measures, based on the discourse of preventing the child from living with the patient, reducing the possibility of contagion, as well as providing a destination for the "orphans of living parents".<sup>6</sup> It is emphasized that only two (Mister Black and Mister White) of the 10 collaborators who participated in the study did not reside in boarding schools. The other collaborators, after the separation from their family members caused by the internment at *Colônia São Francisco de Assis*, were taken to live at *Educandário Oswaldo Cruz*. Both institutions were in the city of *Natal*, in *Rio Grande do Norte* State.

The entire institution is seen as a space in which individuals living in a similar situation reside and work, separated from society, in order to lead a secluded and formally managed life. Among their claims, the entire institutions can be aimed at people who are said to be incapable of taking care of themselves and who also provide some threat (even if not intentional) to the community, such as lepers. This type of space is said to be an incompatible element with the family because it suppresses the potential of homes and domestic life external to the institution, as family and domestic life is replaced by the group life of inmates.<sup>13</sup>

Inherent in such aspects, the textual results of thematic oral history submitted to thematic content analysis<sup>12</sup> identified three thematic categories that emphasize the impacts on family relationships experienced by the collaborator of the study. They address the consequences on family relationships

established through the experience of having a relative affected by leprosy in the period when the prophylaxis of the disease was limited to compulsory internment in hospital-colonies. The distancing changed the relationships and the bond between family members and former leprosy patients treated in an asylum environment, according to the content unveiled in the categories: destructuring of family organization, family distancing and changes in family support.

That said, it is up to democratization and sharing the version that employees have regarding the repercussions that the absence of effective treatment and the existence of a segregationist health policy for the leper generated in the family sphere.

## DESTRUCTURING THE FAMILY ORGANIZATION

The compulsory isolation of the leprosy patient adopted in Brazil in the 20<sup>th</sup> century, officially extinguished by law in 1962, was considered as one of the main strategies of the period with the purpose of controlling and abolishing the disease. In this sense, the patient was removed from social life and, when isolated, the healthy society would be protected from the feared disease.<sup>14</sup>

The discovery of the bacillus associated with proving the infectiousness of the disease ratified the practice of treatment based on the isolation of the patient, restricting the patient freedom and exclusion from society, leading the patient to a secluded life in the setting of hospital-colonies, also called leprosariums.<sup>15</sup>

The restriction caused by official health policies has altered, in the lives of those affected by the disease, the family role that can be understood in three areas: the factor of social protection of its members, especially in processes of change; the paradoxical character, which can form a coherent identity or contrary to the principles of society; and its performance in the health care of its members.<sup>16</sup>

The reports obtained during the interviews carried out, according to the assumptions of oral history, materialized in written product the recalls repressed in the collaborators' memories when expressing a past of implications in the organization and family experience. With the patient going to the leprosarium, the children were also removed and taken to boarding schools with consequent disruption and destructuring of the family organization.

*[...] My father spent five years in the hospital, my mother was alone in the countryside and for a long time I had no direct contact with my father, with my family! There was no family presence on a daily basis [...] (Mister Blue).*

*[...] My mother passed away and my two brothers who lived in the colony are still alive... It is different from my relationship with my brothers who stayed with me, because we are closer. We were raised together [...]* (Mister White).

*[...] I didn't know my mother because she passed away, committed suicide when she lived in the colony and until then I hadn't had the opportunity to see her [...]* (Miss Brown).

Health policies were based on the segregation and isolation of leprosy patients in closed institutions and on the margins of society, moving away patients from their families and from the community considered healthy, conceiving themselves as the only measure for controlling the disease. The patient's segregation in compulsory isolation culminated in the breakdown of several families.<sup>17</sup>

The family is considered an essential unit for the formation and development of its members, transmitting to the new individuals their cultural habits, rules, values and behavioral patterns and health habits. The bonds built in family relationships, such as support and affection, are presented as elements of social protection.<sup>9</sup>

It was found that collaborators showed dissatisfaction with their living conditions in the past due to the family breakup they suffered when they were children. The breakdown changed the way of living in the family, impairing communication and changing the family bond, with consequences rooted in feelings of suffering, as seen in the following reports:

*[...] The word "leprosy" is very harsh, it was part of our life because it separated the whole family [...]* Due to the disease, there was a change in my bond with my father, because we had no communication [...]

*[...] That is why the bond between us changed and the family was all distant. My grandmother in the colony and my grandfather living in the countryside [...]* (Mister Purple).

*[...] Leprosy generated the separation of my family. My father, my mother and my brothers... My father died when I lived in the boarding school and was always like that, distant because of isolation [...]* (Mister Orange).

The policies adopted in the context of leprosy have changed the context of several families, leading to their deconstruction with the hospitalization of the patient in hospital-colonies and their relatives in preventive care. The modification of the family core implied changes in the development of people and in

the socialization of individuals affected by the disease, with no benefits regarding the control of the disease.<sup>18</sup>

The implications of the existing stigma surrounding the disease and the patient as a threatening element to the process of social interaction are emphasized, as far as that it goes beyond the sphere of the patient and can spread among family members. The stigma of leprosy, reinforced by compulsory isolation, reached people who never had the disease, such as the healthy children of patients segregated in hospital-colonies.<sup>19</sup> Illness in leprosy surpassed the pathophysiology in the presence of Hansen's bacillus, including several aspects such as fear, loneliness and family disorder.<sup>20</sup>

## FAMILY DISTANCE

The impact caused on the patients' lives deeply affected the family, as it disregards the affective and parental relationships established between the individuals. Hospitalization in colony hospitals weakened patients' family ties, leaving them in a situation of family helplessness.<sup>5</sup>

When considering characteristics inherent to the family, this is configured as an essential basis for supporting the individual. The family group is emphasized as the first unit of social interaction and socialization of people; therefore, the family is an institution necessary for the development, support and realization of the subjects.<sup>21</sup>

The measures for disease control that led to the compulsory isolation of the patient disregarded their social relationships. Hospitalization in hospital-colonies weakened patients' family ties.<sup>5</sup> This distance between family members was highlighted during the interviews, showing loneliness in the absence of belonging to a family group, as well as the lack of not having lived with parents and grandparents.

*[...] I always thought that everyone has a family, and we don't! My father's isolation damaged our family because everyone was separated [...]* (Miss Red).

*[...] If it weren't for the isolation, the family relationship would be different: father and mother together, all sleeping in the same house, without problems... Eating the same food, drinking the same beverage and breathing the same air [...]* (Mister Blue).

*[...] I missed my grandparents, the things they taught me [...]* They were like my parents! At the boarding school, I was arrested and had no way to talk to them [...]

The isolation and segregation of family members with leprosy in hospital-colonies has had consequences for the lives of children taken to boarding schools, and for those who were subject to the care of distant relatives. The pain of separation, the denial of childhood, the lack of care and affective relationships constitute damages that have not been forgotten, as well as the fact that they did not understand the process of family separation.<sup>18</sup>

Many of the interviewees describe the slight contact with their parents, as they underwent separation shortly after birth. This immediate separation generated ambiguous expressions, sometimes marked by the emotion of not having a family, sometimes demonstrating a feeling of conformity when getting used to the absence of the family, starting to live as if they never belonged to a given family, without even carrying the surname of the parents.

*[...] But I never had contact with my mother, and I missed her... Lack of having a mother around... At the same time, I was used to it because I was never raised by her [...]* (Miss Brown).

*[...] As I was separated since I was a child, I had no understanding and I got used to the distance [...]* And I grew up without having my father around and I ended up being registered by my grandfather, who was like my stepfather [...] (Mister Yellow).

*[...] The experience of my parents' detachment was very bad and that's why I didn't have my father and mother's last name. My name is three proper names and it doesn't have their names [...]* (Miss Pink).

Many women have experienced the segregationist burden of not being able to exercise full motherhood like most healthy women. Although they generated and gave birth to healthy children, they were distanced from maternal contact, making it difficult to establish family bonds. Because they were raised apart from their relatives, the feeling of not recognizing the other as a family member is common in the lives of those separated during compulsory internment.<sup>5</sup>

## CHANGE IN FAMILY SUPPORT

The support function for individuals, one of the characteristics of the family group, is structured and provided by each of its members according to their specificity, when considering the respective potentials and limitations of each group, providing affection, responsibility, availability and incorporation of values.<sup>22</sup>

This role was not present in the lives of the collaborators in this study, who suffered from the separation and distancing of their sick and isolated family members in the *Colônia São Francisco de Assis*. The strategy adopted in the prophylaxis of leprosy with isolation from parents and the consequent removal of their children interrupted the structuring and maintenance of affective bonds in the family, and the distancing of isolated children in preventive care made their lives difficult by making it impossible to receive support and family support.<sup>5</sup>

Family separation has generated emotional impacts that have not been forgotten. The segregation of the patient interrupted the process of family construction with certain individuals, negatively influencing the transmission of values and exchange of affection between relatives, so that the marks of the absence of the hospitalized family member were reported by the study collaborators.

*[...] Without a father to guide and give advice [...]* Without hugging [...] We saw that everyone had a family and I couldn't even communicate with my father [...] (Miss Red).

*[...] If it weren't for the hospitalization it would be different, because my father was a very good person, very affectionate, and as he was isolated, we missed attachment. I didn't have that link with anyone [...]* (Miss Green).

*[...] During my childhood, my father was hospitalized several times and I missed him in the family. The internment made it difficult for him to participate in my education, in the relationship and in the daily communication between us [...]* (Mister Black).

*[...] We never forgot about our mother. I missed her, the hug, the lap [...]* (Mister White).

Individuals in a family develop several roles that keep the family group structured, such as: actions to provide information exchange, supply members with material and emotional support, share the sense of love and value the bond with the other. Such roles enable the organization and continuation of a social identity, in addition to assisting in the attribution of meaning to life experiences.<sup>23-25</sup>

In the current situation that involves leprosy, the family environment operates positively in the evolution of the treatment and cure of leprosy, as the family group provides support and support to the patient, contributing to coping with the disease.<sup>24</sup> In this perspective, the strategies of disease control developed by the health team, with emphasis on nurses,

should involve actions aimed at the leprosy patient, the family and their contacts, in order to clarify doubts about the disease, fight stigma and favor appropriate social interaction.<sup>26,27</sup>

It is reinforced that the prophylactic measure adopted by excluding sick people in hospital-colonies started to be questioned in the face of innovations related to the treatment of the disease, by reinforcing the stigma in the face of leprosy, in addition to the repercussions installed in the family context.<sup>28</sup> Such conceptions, such as those observed in the categories that emerged in the present study, were useful because they could promote the implementation of democratic health guidelines, in addition to enabling the development of inclusive actions.

Although compulsory isolation for the treatment of leprosy does not happen anymore, the marks of this legacy exist and permeate society's images.<sup>29</sup> Therefore, the topic discussed is important because, among others, it allows the discussion and reflection of some public health policies, such as that focused on cases of mothers in vulnerable situations.

As this is a qualitative research conducted with a small number of participants, the results limit the possibility of generalizations and comparisons. However, the critical-reflective and scientific character of the present investigation emphasizes the relevance of the work, which expands the possibility of discussions related to the theme.

## FINAL CONSIDERATIONS

The stories stated by collaborators report the damage experienced in the past as a result of the family breakup suffered due to the policy adopted for the prophylaxis and control of leprosy. Study participants were separated from their parents, siblings and grandparents, prevented from enjoying the tenderness, warmth and family education, causing psychological, social and educational damage.

The strategy adopted in the prophylaxis of leprosy with isolation from parents and the consequent removal of their children interrupted the structuring and maintenance of affective ties in the family, and the distancing of isolated children in preventive care made their lives difficult by making it impossible to receive support and family support.

Given the history of the disease and its epidemiological characteristics today, it is important to consider the subjectivity and feelings experienced by individuals with leprosy, providing comprehensive care aimed not only at the patient, but also at the individuals with whom he interacts, especially those present in the family environment, promoting clarification about the disease. The promotion of health actions focused on the family is preponderant when considering that the problems faced by the patients equally affect those with whom they relate, as well

as the inclusion of families in the care process enhances actions favorable to health.

Although advances in the conduct of treatment until the cure of the disease are evidenced, leprosy carries with its historical marks of social segregation of those affected by the disease and their families. In this perspective, the importance of favoring reflections on the conduct of all those affected by leprosy is emphasized, by rescuing the implications that the disease of the past has had on the lives of family members of ex-patients treated in an asylum environment.

The replacement of the hegemonic paradigm, based on medical specialties, by the health surveillance care model expanded the possibilities of actions beyond cure, by including the prevention of injuries, as well as health promotion and recovery, with an emphasis on the subject and the family. In this context, it is up to health professionals, such as nurses, to develop a work in the perspective of overcoming social adversities, proposing and monitoring treatment by teams working in the space of the patient and families, conceived as a support structure for users during the treatment of the disease.

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