

T'sarat/leprosy: paths taken by relatives of former patients treated in the asylum environment¹

T'sarat/hanseníase: caminhos trilhados por familiares de ex-doentes tratados em ambiente asilar

T'sarat/lepra: caminos tomados por los familiares de los pacientes tratados en el entorno de asilo

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How to quote this article:

Pinheiro MGC, Simpson CA, Miranda FAN, Mendes FRP. T'sarat/hanseníase: caminhos trilhados por familiares de ex-doentes tratados em ambiente asilar. Rev Fun Care Online. 2019 jan/mar; 11(1):47-52. DOI: <http://dx.doi.org/10.9789/2175-5361.2019.v11i1.47-52>

ABSTRACT

Objective: To assess the understanding that relatives of former leprosy patients treated in hospitals colony have about the disease. **Method:** Qualitative study, focusing on oral history. The 52 relatives of former leprosy patients who were segregated in Cologne Hospital São Francisco de Assis composed the colony. The network consisted of 10 employees, both sexes, aged 44-76 years. Data collection was guided by guiding questions that directed the memories of employees for the purpose of the study. The interviews were recorded, transcribed and analyzed for thematic content analysis. The research was approved by the Research Ethics Committee of the Federal University of Rio Grande do Norte, CAAE 25922214.3.0000.5537. **Results:** Resulting in two categories: The story and the last story in this. **Conclusion:** Respondents reflected rise leprosy control policy in the past, as well as adopted in the present front of the disease.

Descriptors: Life change events, Leprosy, Social stigma, Family, Nursing.

RESUMO

Objetivo: Averiguar a compreensão que familiares de ex-doentes de hanseníase tratados em hospitais colônia têm sobre a doença. **Método:** Estudo qualitativo, enfocando a história oral temática. Os 52 familiares de ex-doentes de lepra que foram segregados no Hospital Colônia São Francisco de Assis compuseram a colônia. A rede foi constituída por 10 colaboradores, ambos os sexos, com idade entre 44 a 76 anos. A coleta de dados foi norteada por questões abertas que direcionaram as lembranças dos colaboradores para o propósito do estudo. As entrevistas foram gravadas, transcrita e analisadas pela análise temática de conteúdo. A pesquisa foi aprovada pelo Comitê de Ética em Pesquisa da Universidade Federal do Rio Grande do Norte, CAAE 25922214.3.0000.5537. **Resultados:** Identificaram-se duas categorias: a

- 1 Elaborado a partir de dissertação de mestrado. Trajetos de exclusão e reclusão: História Oral Temática de familiares atingidos pelo tratamento asilar da hanseníase. 2014, Universidade Federal do Rio Grande do Norte.
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história no passado e a história no presente. **Conclusão:** Os entrevistados refletiram sobre política de controle da lepra no passado, assim como a adotada no presente frente à Hanseníase.

Descritores: Acontecimentos que mudam a vida, Hanseníase, Estigma social, Família, Enfermagem.

RESUMEN

Objetivo: Conocer el entendimiento de que los familiares de los ex pacientes de lepra tratados en hospitales colonia tienen sobre la enfermedad. **Método:** Estudio cualitativo, centrándose en la historia oral. Los 52 familiares de los ex pacientes de lepra segregados en Colonia Hospital São Francisco de Assis componen la colonia. La red se formó por 10 empleados, de ambos sexos, con edades entre 44-76 años. La recolección de datos fue guiado por preguntas abiertas se centraron en el propósito del estudio. Las entrevistas fueron grabadas, transcritas, analizadas para el análisis de contenido temático. Fue aprobado por el Comité de Ética de la Universidad Federal de Rio Grande do Norte, CAAE 25922214.3.0000.5537. **Resultados:** Lo que resulta en dos categorías: La historia y la última historia en esto. **Conclusión:** Los encuestados reflejaron suba política de control de la lepra en el pasado, así como adoptó en el presente frente a la enfermedad.

Descriptor: Acontecimientos que cambian la vida, Lepra, Estigma social, Família, Enfermeira.

INTRODUCTION

The Hansen's Disease (HD), also known as leprosy, is a secular disease considered one of the oldest ills in the history of mankind, marked by social exclusion, stigma, abandonment, and fear for having long been considered incurable, mutilating and contagious.¹

The social imagery generated around leprosy and the stigmatizing burden on the disease and the patient excluded their social conviviality, becoming accentuated by the form of treatment adopted and guided by compulsory isolation in the colony hospitals.² In *Rio Grande do Norte (RN)* State, the scenario adopted for the segregation of the patient was the *Hospital Colônia São Francisco de Assis*, located in *Natal* city, which was founded in 1929.³

The hospitalization of the HD-bearing patient in colony hospitals, as a form of disease prophylaxis, has modified the scenario of social relations of the patients, then breaking bonds between people of their familiarity, as friends and family members, thus destroying family bonds.⁴

The sick individuals were compulsorily removed from their homes and separated from their relatives, friends, their work and the community where they lived to be kept in leprosy hospitals, which functioned as a separate city, where the lepers tried to rebuild their lives. That had worsened in quality and in their life trajectories.³

Having a family member with HD was synonymous with social disorders, and many relatives of those affected by the HD were also temporarily isolated by the possible probability of carrying the disease, then suffering strong stigma from the society.⁵

With the advances in pharmacology research and the evidence that isolation did not stop the disease, the policy of compulsory hospitalization began to be questioned by researchers and was officially abolished in 1962. Nevertheless,

given the social and economic situation experienced by those individuals affected by the HD, it became impossible to eradicate the program, then lasting longer.⁶

With the Polychemotherapy (PCT) onset, healing became part of the context involving HD. The HD treatment is carried out at the outpatient level, where the medicines are available free of charge, and when the diagnosis and treatment are established in the initial phase of the disease there is prevention of disability and breakdown in the HD transmission chain.⁷ Thus, it is observed that there has been a change in the conduct in relation to the disease and to the patients, so that there are two stages concerning the disease trajectory: the leprosy history, understood as a disease without cure, linked to stigma and social segregation; and the HD history, established by the introduction of PCT treatment.

Despite the aforementioned, HD is still considered a public health problem in Brazil, which according to epidemiological statistics occupies the second place in the world in number of cases of the disease. The national picture of the spatial distribution of HD prevalence in the various heterogeneous regions indicates the presence of transmissibility of the disease.⁸

The retrieval of events that marked the history of HD, through reports of members of the family of former patients who were isolated in the *Hospital Colônia São Francisco de Assis*, in *Natal/RN*, has the potential to register historical aspects involving the HD. Beyond this issue, it favors the recognition of how such individuals have lived history in the past and see the disease nowadays, since the correct knowledge about it is fundamental to reduce prejudice, to diagnose early and to control the HD.

Aiming to assess the understanding of relatives of former HD patients who were treated in colony hospitals, the present study is expected to stimulate the rethinking of health practices, developed by nurses and other professionals, in the face of sensitization through knowledge of the reality of how those affected by HD were treated in the past. Hence, they will be able to reflect on the development of an integral care plan aiming to appreciate those affected by the disease and the people directly involved.

METHODS

It is a descriptive-exploratory study with a qualitative, which has focused on Oral Thematic History as a methodological reference.

The oral history is configured in a systematized process for the use of narratives recorded in the present time and transferred from the oral to written documents. As a complex practice and composed of different stages (project design, definition of the colony and study network, questionnaire elaboration, interview, transcription and analysis), the use of oral history is aimed at obtaining useful answers for society in order to bring to the present experiences lived in the past.⁹

Among the modalities of oral history, it was decided to work with thematic oral history that has its conduction governed by the existence of a central focus which justifies the act of the interview, in which one searches for details of

the personal story of the narrator with revelation of related information to a central thematic.⁹

The study colony (population) was given to the 52 families of former HD patients who were segregated at the *Hospital Colônia São Francisco de Assis*, and are also enrolled in the Reintegration Movement of People Affected by the HD from the *Rio Grande do Norte (MORHAN-Potiguar)*. The members of the colony are of both genders, and within the age group from 34 to 85 years old.

The network (sample) consisted of 10 collaborators, whose training was based on the initial interview, the zero point, with collaborator who is the son and grandson of a former HD patient and is currently a volunteer of the *MORHAN-Potiguar*, therefore, has experience regarding the theme addressed by the study.

The following criteria were adopted: first and second-degree relationship between the collaborator and the former HD patient; Men and women over the age of 40; residing in *Natal/RN* during the period of data collection; and who agreed to collaborate freely with the study. The exclusion criteria were: absence of preserved mental faculties; and individuals with communication barriers that could impair the interview effectiveness.

During the contact with the collaborators, in the pre-interview, the objectives of the research were presented, clarifying the importance of participating in the study, informing about the recording and the guarantee of privacy. The stories told during the interviews, which occurred at a date and place chosen by the collaborator, were guided by comprehensive questions that direct the employees' memories for the purpose of the study and recorded in an electronic device. In the post-interview period, the employee was thanked for participating in the study.

According to the technical and methodological assumptions of oral history, after recording the reports, then the interviews transcription was carried out. The established texts were authenticated by the collaborators with the signing of the assignment letter, an instrument used in works with oral history in order to establish the ethical and legal link between the interviewee, the interviewer and the research.⁹ The established texts were analyzed based on the premises of the thematic content analysis,¹⁰ allowing the identification of thematic axes, which were discussed with the scientific literature.

The research was performed in *Natal* city over the period from June to July 2014. The project was approved by the Research Ethics Committee from the *Universidade Federal do Rio Grande do Norte*, under the Legal Opinion No. 650.654/2014 and the *Certificado de Apresentação para Apreciação Ética (CAAE)* [Certificate of Presentation for Ethical Appraisal] No. 25922214.3.0000.5537. The collaborators received clarifications about their participation in the study and signed the Free and Informed Consent Term. Aiming to preserve anonymity, subjects are here presented by color names.

RESULTS

Ten collaborators were interviewed, male (six) and female (four), aged from 44 to 76 years old. The subjects interviewed are related to former HD patients hospitalized in the *Hospital Colônia São Francisco de Assis*, in *Natal/RN*, as shown in **Table 1**.

Table 1 - Description of the relationship between the collaborator and the relative who was admitted to the *Hospital Colônia São Francisco de Assis. Natal, 2014*

Collaborator	Family Relationship Degree*	Hospitalized Patient
Black	First and second degree	Father and maternal grandmother
Red	First degree	Father
Yellow	First degree	Father
Blue	First degree	Father
Green	First degree	Father
Purple	Second degree	Maternal grandmother
Orange	First degree	Father
Brown	First degree	Father and mother
Pink	First degree	Father
White	First and second degree	Mother and brother

Source: Research data.

*Consanguineous relatives, as established by the Brazilian Civil Code.

Through the analysis of the thematic oral histories narrated by the collaborators of the study, two categories were identified, as follows: whereas "The history in the past" emphasizes the segregationist policy adopted through the practices of compulsory isolation; "The history in the present" highlights the existence of treatment and cure for HD, as explained by the collaborators.

DISCUSSION

Based on the narratives analysis, the reflections made by the collaborators regarding the HD control policy before and after the introduction of the polychemotherapy treatment will be presented and discussed.

The history in the past

The leprosy history is permeated by taboos and symbolic beliefs that have trivialized the sick people. Notoriously known as a dreaded disease, it bears the mark of the notion of sin, guilt, aversion to signs and symptoms, as well as suffering, rejection, and isolation.¹¹ In the mythical and religious denotation, it represented the representation of evil, then strongly stigmatizing the sick people.¹²

Through scientific advancement and the assertion of leprosy as an infectious and contagious disease transmitted by bacteria, the elite sectors charged the state with protective measures for the healthy population, culminating in the social remoteness and territory of the patient. The discourse of the state was based on the preservation of the labor force aiming the nation development.¹³

In the past there was no treatment proposal and the prophylaxis of the disease circumscribed in the scenario of the old colony. Considered as a purely social issue, compulsory isolation reflected negatively in several social and family spaces through forced capture of the patient and separation of their families.⁴

In the stories told, it was observed how painful the episode of isolation marked the family rupture in the life of

the collaborators. The abrupt withdrawal of the family bed was based on laws that forced the capture of the patient to leave them in leprosaria, and this rejection resulted in damages and feelings of suffering in the life of those who witnessed the day of separation, as can be seen in the following reports:

That was a very difficult day because we were forcibly removed from the house and we were not expecting it. They said that we went to Natal to do some exams and we left very sad, because I knew that I would stay away from home without knowing if I would return or not. (Mrs. Green)

My grandmother was removed from the house and placed on top of a Jeep, full of armed army men, who told her to forget the family because she would never see them again. (Mr. Black)

In the year 1956 my mother and my brother came to the Hospital Colônia São Francisco de Assis on a truck, loaded like an animal. (Mr. White)

I arrived at the Educandário with three years old on May 1st, 1952. That day we were brought from Mossoró city: Me, my sister, and my father, who had the disease... I still remember it as if it were today, they caught us, put on a truck and we were transported thus. (Mrs. Pink)

Compulsory isolation was scientifically recommended at academic meetings by officials in the affairs of the period, based on the absence of treatment and the possibility of transmission and contamination of other persons. In Brazil, the practice of compulsory isolation was legally established, consubstantiated in the assumption of protecting the healthy society by withdrawing the patient from the streets.¹³ The following speech portrays the collaborator's understanding of the separation episode, rooted in the absence of treatment leprosy.

At the time of isolation there would be no probability of treatment at home, first because of prejudice, second because of the health policy of the time and third because the medication was not effective. (Mr. Black)

The colonies had an autonomous life and the patients sought to reproduce in their everyday life aspects of the external society that had excluded them, including the formation of new family ties. The inmates were separated from their children and many of them were kept in institutions called *preventórios*, which had the function of prevention, since it was believed that the child would have a high probability of developing the disease because it was the son of a patient, justifying his departure from Especially where they would be examined periodically.³

The association of leprosy of the past with the absence of cure was reported by the study's collaborators when they remembered experienced episodes that culminated in family split.

We lived in the school because we were the children of lepers and before there was no cure. (Mr. Yellow)

When my grandmother came to the colony I was five years old and I stayed with my grandfather in Macaíba city, but they came back to pick me up a month after she left home. As I lived with her, when she came I had to come too and I was hospitalized in the Educandário. (Mr. Purple)

In former times, when the person had the ugliest disease in the world, he had to isolate and separate father from son (Mr. Orange)

Another point addressed by the collaborators regarding leprosy was the use of this term to differentiate its meaning in relation to the HD at the present time. In Brazil, the replacement of the word "leprosy" with "Hansen's disease" occurred with the purpose of reducing prejudice and discrimination. The use of campaigns in radio, television, schools and distribution of educational pamphlets is a mediator to publicize the new denomination, associated with the existence of treatment and healing.¹⁴

The collaborators, in their reports, explain that the meaning of the word is in consonance with the context, denoting the difference between leprosy and HD, referring to the leprosy as a notion of physical deformities and segregation.

By that time we did not call of HD, it was leprosy and it was very heavy ... Whoever was in the colony was distant from the family, and I was afraid because I saw those people missing their ears, missing a finger... (Mrs. Green)

At that time the people called leprosy, today they call HD... At that time there was no such thing and it was necessary to separate the children from the parents. (Mrs. Brown)

Thankfully today the HD is different from leprosy. Because the people were afraid even of the people who were the children of a leper. There was a myth of the big ear woman who killed a child to eat the liver because they said that the child's liver was healed. (Mrs. Pink)

In line with the lines, the term "Hansen's disease" attempts to modify the phantasmagoric of leprosy in the past, while the imaginary of the disease remains alive in the memory of employees and of society in general.¹² On the other hand, the change in nomenclature is associated with changes in coping with the disease, with the adoption of polychemotherapy treatment and policies for its control and elimination.¹⁵

The history in the present

The Hansen's Disease (HD) is an infectious disease caused by the Hansen bacillus, a name used in honor of the Norwegian physician Gerhard H. A. Hansen, who identified the bacillus. The use of the radical "hansen" was also adopted to name of HD, replacing the term leprosy, then denoting a scientific view of the disease.¹⁶

With the technological and scientific development in the area of pharmacology, patient isolation has ceased to be compulsory and its regulation has taken place through the approval of the Regulation No. 165/BSB, dated from

05/14/1976, which modified the HD control policy in determining the end of patient isolation and the adoption of ambulatory treatment.¹⁷

The change in the operationalization of the disease is an achievement for the health area and for rehabilitation of the patient in the social sphere. The conduct of the disease and the patient currently ruled in the absence of isolation is expressive in the speech of the study collaborators, who carry with them the experience of the sad reality of the past and the consequences resulting from the segregation of their relative in the colony.

Nowadays, the HD continues in some places expanding, however, there is cure and the accompaniment is performed at home... The sick person no longer has the problem of being isolated and distant from the family. (Mr. Blue)

Currently, when you have the disease that does the treatment and has a cure... You do not have to separate from the family. (Mrs. Brown)

Today is a common disease, there is medication available, we do treatment at home, along with the children. (Mr. Yellow)

Now, there is treatment and if we had it then, we would not have separated and he would not have to go away without knowing each other. (Mrs. Pink)

Although the isolation and compulsory hospitalization of the HD patient refers to the disease in the past, it is emphasized that the reactions of the society towards the sick person vary. While some patients choose not to share their diagnosis with the family, fearing rejection, others communicate and receive family support.¹⁸

This ambiguity of behavior is associated with the double face of leprosy and HD history, so that the discoveries and changes in the standard treatment allow for a (re) categorization of individual individuals. The presence of cure and breakdown in the transmission chain by initiating appropriate treatment, as well as the dissemination of this information to society, increasing the number of people informed about HD, modifies the social posture in front of the disease and the patient.¹

The existence of drug treatment and cure were mentioned by the collaborators, who emphasized this change in the conduction of the HD patient, unlike that experienced in the segregator and excluding past.

Today is HD, because it was a man named Hansen who discovered the bacillus, and with that he became Hansen's bacillus, isn't that right? With this discovery came the remedy. (Mrs. Pink)

Today everything is different because the HD has the medicine treatment and has a cure. The treatment is different. It's better, performed at home... You can stay with everyone. My neighbor's husband had HD and was treated at home. (Mr. White)

Today, the person who has HD can already prove early on that they have the disease and do their medication at home. Many people end the treatment and you do not even know they had the disease. (Mr. Green)

The HD is a normal disease and child can be raised under these conditions! Before it was in the colony, we had this whole impact, and today the treatment is done at home and has a cure! But if it takes time to treat those deformities. (Mrs. Red)

The PCT, introduced in the 1980s, is the standard HD treatment regimen recommended by the World Health Organization and is the main responsible for the reduction in the number of cases of this disease at a global level.¹⁹ It is important to note that, in addition to treatment with PCT, the HD control policy requires the development of actions for the prevention, control and treatment of physical disabilities, as these complications are responsible for psychosocial effects and preconception.¹¹

The MORHAN is another structural axis involved with disease control actions in Brazil, preparing to mediate the construction of effective public policies, as well as working with social movements of people involved with the cause to eliminate prejudice and stigma around of the disease.²

Prejudice and discrimination were present in the daily life of leprosy patients and their families, when society was unaware of elements related to the epidemiological chain of the disease. Unlike today, according to the stories stated here, it was observed in the statements of the collaborators the association between the existence of treatment and reduction of prejudice and discrimination towards the HD.

If today's treatment were the same in the period that my family members were hospitalized, our relationship would be different... There would be fewer psychological and social sequelae with regard to the marks of the disease, prejudice and separation from the family. (Mr. Black)

Formerly there was a lot of prejudice; today is not so much because it does not take more after it deals. (Mr. Purple)

But the HD today is different from the old one... It's good because it can be dealt at home and nobody discriminates. (Mr. Orange)

In the scenario involving the disease caused by the Hansen bacillus, on the one hand, the emotional impacts resulting from the compulsory hospitalization generated by leprosy patients in the past and their relatives were not forgotten and remain alive in their memories;² On the other hand, even today the HD continues to exclude and stigmatize the individuals who are affected by the disease and, often, their relatives.⁴

Despite the existence of treatment, there remains an image of the HD patient associated with the deformities and physical disabilities, stigma and prejudice experienced in the past.²⁰ HD inherits the leprosy myth that has always accompanied the disease. This circumstance is understandable

when referring to the exclusion suffered in the past, so that having the HD goes beyond the acquisition of changes in the skin and peripheral nerves, also acquiring an identity associated with disease in the past.¹⁸

In the continuity of the process involving health actions aimed at the disease, it is necessary to develop campaigns that associate the two terms, leprosy and HD, emphasizing the differences in the conduct of the patient with treatment and cure, and then dismissing hospitalization.²¹

In the meantime, it is recommended to think about the adoption of a policy towards the social reintegration of those affected by the HD, similar to what happens with other stigmatized contingents, for instance, policies aimed at individuals with special needs and also those with mental disorders.¹

FINAL CONSIDERATIONS

The history of HD left scars in the memory of those who experienced the experience of having a family member affected by the disease and isolated in a colony before the introduction of drug treatment and the existence of a cure. The study's collaborators reported their experiences, demonstrating how painful the occurrence of isolation marked the family rupture in their lives. And although they did not have the disease, they were also affected by the prejudices that circumscribed the sick individual.

When asked about their understanding of leprosy, the answers predominated in a duality, comparing leprosy of the past with present HD, showing that many of the difficulties experienced in the past, such as the absence of cure and family segregation, were overcome in the context current situation that involves the HD.

Many HD patients now feel compelled to diagnose the disease, which puts their family and work environment at risk when the disease is unknown. This condition requires the development of strategies to overcome challenges related to the beliefs, stigma and prejudices faced with HD, as well as the elaboration of a comprehensive care plan involving people close to the patient in order to clarify the disease and increase therapy adherence.

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Recebido em: 01/05/2017

Revisões requeridas: Não houve

Aprovado em: 16/05/2017

Publicado em: 01/01/2019

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