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LEPROSY UNVEILED BY NURSING PROFESSIONALS WHO WORKED AT A COLONY HOSPITAL

A HANSENÍASE DESVELADA POR PROFISSIONAIS DE ENFERMAGEM QUE ATUARAM EM UM HOSPITAL COLÔNIA

LA LEPRA REVELADA POR PROFESIONALES DE ENFERMERÍA QUE TRABAJARON EN UN HOSPITAL COLONIA

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ABSTRACT

Objective: to analyze the opinion of nursing professionals who worked at a colony hospital for leprosy on patients' life. **Method:** exploratory and descriptive study, with a qualitative approach, conducted with 5 nursing professionals who worked at the Colony Hospital "São Francisco de Assis", through semi-structured interviews, transcribed and analyzed using the content analysis technique proposed by Bardin. The study was approved by the Research Ethics Committee of the Federal University of Rio Grande do Norte (UFRN), under the Protocol 461,403 and the CAAE 19476913.9.0000.5537. **Results:** 3 thematic axes were identified: I - The socialization process of inmates; II - Prejudice, stigma, and discrimination; and III - Social exclusion versus social inclusion. **Conclusion:** through the experience reported by professionals, it is inferred that the policy of compulsory isolation was a determination that caused many transformations in the life of a person with leprosy, changes involving not only the personal sphere, but also the family, social, and economic spheres. **Descriptors:** Nursing; Leprosy; Colony Hospital.

RESUMO

Objetivo: analisar a opinião de profissionais de enfermagem que atuaram em hospital colônia de hanseníase sobre a vida dos pacientes. **Método:** estudo exploratório e descritivo, com abordagem qualitativa, realizado com 5 profissionais de enfermagem que atuaram no Hospital Colônia "São Francisco de Assis", por intermédio de entrevistas semiestruturadas, transcritas e analisadas por meio da técnica de análise de conteúdo proposta por Bardin. O estudo foi aprovado pelo Comitê de Ética em Pesquisa da Universidade Federal do Rio Grande do Norte (UFRN), sob o Protocolo n. 461.403 e o CAAE n. 19476913.9.0000.5537. **Resultados:** foram identificados 3 eixos temáticos: I - O processo de socialização dos internos; II - O preconceito, o estigma e a discriminação; e III - A exclusão social *versus* a inclusão social. **Conclusão:** a partir da vivência relatada pelos profissionais, infere-se que a política de isolamento compulsório foi uma determinação que provocou inúmeras transformações na vida da pessoa com hanseníase, mudanças que envolveram não só o âmbito pessoal, mas, também, o familiar, o social e o econômico. **Descritores:** Enfermagem; Hanseníase; Hospital Colônia.

RESUMEN

Objetivo: analizar la opinión de profesionales de enfermería que trabajaron en un hospital colonia de lepra acerca de la vida de los pacientes. **Método:** estudio exploratorio y descriptivo, con abordaje cualitativo, realizado con 5 profesionales de enfermería que trabajaron en el Hospital Colonia "São Francisco de Assis", a través de entrevistas semi-estructuradas, transcritas y analizadas mediante la técnica de análisis de contenido propuesta por Bardin. El estudio fue aprobado por el Comité de Ética en Investigación de la Universidad Federal de Rio Grande do Norte (UFRN), bajo el Protocolo 461.403 y el CAAE 19476913.9.0000.5537. **Resultados:** 3 ejes temáticos fueron identificados: I - El proceso de socialización de los internos; II - El prejuicio, el estigma y la discriminación; y III - La exclusión social *versus* la inclusión social. **Conclusión:** desde la experiencia reportada por los profesionales, se infiere que la política de aislamiento obligatorio fue una determinación que provocó muchas transformaciones en la vida de una persona con lepra, cambios que implican no sólo la esfera personal, sino también la familiar, social, y económica. **Descriptores:** Enfermería; Lepra; Hospital Colonia.

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INTRODUCTION

Leprosy is a chronic infectious disease of great relevance to public health, due to its highly disabling power. It mainly affects the age group that is active in economic terms and it is manifested through skin lesions and on peripheral nerves, with the possibility of leading to the onset of disabilities and physical deformities. They are capable of causing problems such as decreased work capacity, limited social life, and psychological problems. And they are also responsible for the stigma and prejudice concerning this disease.¹⁻³

The history of Brazilian public health, related to leprosy control, is marked by authoritarian conducts for the sole purpose of extinguishing this disease in the social environment under the regime of compulsory confinement in colony hospitals. They began to be built in the 18th century, and in the early 19th century people with leprosy started being discriminated, harassed, and isolated. The construction occurred by means of donations made by religious people and the civil society. Initially, the primary objective of these asylums was protecting the population considered healthy against those diagnosed with leprosy.⁴

In Brazil, the practice of isolating people with leprosy began with the construction of the first “leper colony” by the colonial government of D. João V, in the 19th century. This practice not only in Brazil, but worldwide, was considered the only way to control the spread of disease and it was maintained until 1940.⁵

In the state of Rio Grande do Norte, the first colony hospital was created with the health policy of Oswaldo Cruz. Its foundation took place on January 14, 1929, during the First Republic, by the public health physician Dr. Manoel Varela Santiago, director of this colony for nearly 30 years. This colony came to receive nearly 300 inmates.⁶

The isolation strategy was used at the same time that a structure to support it was created. However, it was only with the advancement of science that started occurring changes in government policies. Since then, new strategies were gradually adopted and, in 1962, the policy of compulsory isolation was abolished, by means of the Federal Decree 962.⁴⁻⁶ In this context, nursing professionals worked in a significant way to mitigate the disability degree generated by leprosy, the stigma, as well as they contributed a lot to improve the quality of life of patients with leprosy.⁷

In the action scene, it is crucial that nurses and the other professionals from the health network consider patient's psychological weakness and provide a humanized care, based on solidarity and fraternity, relying on the effectiveness of their participation.⁸

Given the above, the following question was adopted: “What is nursing professionals' opinion about the life of people with leprosy at a colony hospital?”. To answer it, this objective was set:

- To analyze the opinion of nursing professionals, who worked at a colony hospital for leprosy, on patients' life.

METHOD

This is an exploratory and descriptive study, with a qualitative approach, conducted with five nursing professionals who worked at the Colony Hospital “São Francisco de Assis”, in Natal.

The instrument used for producing data had a semi-structured interview script consisting of two parts: The first corresponds to information that characterized the respondent, containing full name, fictitious name, age, gender, birthplace, marital status, home and email address, contact telephone number, education level, profession/occupation, and religion. The second part referred to the research question, which is: “How was your experience as a nursing professional at the colony hospital for people with leprosy?”.

The interviews were conducted at participants' household and workplace, by using an audio recorder. Initially, the research purpose was explained and, then, the data collection instrument was introduced. Finally, the freedom and spontaneity so that participants could answer the proposed questions was guaranteed, as the testimonies were recorded.

For analyzing the interviews, we used the thematic content analysis technique, proposed by Bardin, as it represents a set of techniques for communications analysis that allow the inference of knowledge on the conditions of production/reception of messages. For its implementation, the following steps were considered: pre-analysis, material exploration, or coding, processing of results, inference, and interpretation; then, 3 thematic axes were identified: I - The socialization process of inmates; II - Prejudice, stigma, and discrimination; and III - Social exclusion versus social inclusion.

We complied with Resolution 466/12, from the National Health Council (CNS), which

regulates research involving human beings. The study was approved by the Research Ethics Committee of the Federal University of Rio Grande do Norte (UFRN), under the Protocol 461.403 and the CAAE 19476913.9.0000.5537.

RESULTS

The survey had 5 participants, 1 man and 4 women, with ages ranging from 53 to 77 years. Out of these, 3 were born in the state of Rio Grande do Norte, 1 in Alagoas, and 1 in São Paulo. As for the education level, only 1 reported having complete High School and the others have complete Higher Education. Regarding marital status, 1 said to be married, 2 divorced, and 2 widowed. Concerning the occupation/profession, 3 were nurses, 1 retired, and 1 nursing technician. In relation to religion, 2 reported being Spiritualist and 3 Catholic. All were named after a precious stone, to ensure the confidentiality of discourses.

I - The socialization process of inmates

Through the research subjects' reports, there is evidence of the socialization process that starts within the colony itself, with the professional/user relation, the emotional bond established between a professional and an inmate, the learning provided by interdisciplinarity and the interface observed in volunteering, which was constant there.

From within the colony itself, there was almost nothing to occupy their time. Now, from outside to inside the colony there were many. Lots of activities, lots of religious groups, Evangelical, Spiritualist, Catholic, they conducted many activities with patients. [...] Many people from outside, many people involved with all religions held parties to them, Mother's Day, Christmas. There were a lot of parties. (Sugilite)

We started working on their socialization within São Francisco itself. We built new housing units, the pavilions were knocked down, they were pavilions with isolated rooms, they no longer exist. We created community environments and worked on the medical care for these patients. Then, we extended the lab area, the hospitalization area. Within these years, we also worked on the area at the level of their retirement, and many of them were leaving, they got married, some of them were re-integrated into their families, so it became restricted to patients who were living there. [...] There were Spiritualist groups conducting a work with them weekly in terms of festivities, charity bazaars. (Desert Rose)

In spite of efforts by professionals to reintegrate leprosy patients who were

confined there, there was not a big interest shown by the State to reverse the context in which the inmates were submerged:

As I got close to them, I started stimulating self-control, i.e. show that they were there, but they were human beings like us, they were human beings like us and that they might get out of there someday because it had already happened in other states and here, in Rio Grande do Norte, it took a long time because we noticed that the health authorities had no interest to help those human beings who were confined there [...] There in the colony, I did the "psychotherapy" work, "gospel-therapy", and "prayer therapy", everything to help at the moral level, self-esteem, etc. (Imperial Topaz)

Their life was like this within the hospital. There was a group of volunteers. They were high society ladies living here in Natal and they made that hospital visit every month, they took snacks, then gathered around the old cinema and every St. John, Easter, Christmas they were at the hospital and gave gifts for them. Other times, those who were there, too, were Spiritualist people, because there was also a Spiritualist center there, they made visits to patients. That was a good time for them. (Tourmaline)

II - Prejudice, stigma, and discrimination

Prejudice, stigma, and discrimination, although present in the daily life of a person with leprosy, in a society that was still unaware of the ways how this disease is transmitted, were not observed in the reports analyzed, evidencing that they perhaps existed in the relation between professional and user.

I found no resistance from management, there was no issue regarding prejudice, discrimination. (Dendritic Agate)

All professionals there were old professionals, professionals who had much love for what they did there, all of them, indeed. I have already interacted, as I said earlier, there at the Colony São Francisco, in activities with my Spiritualist group. (Sugilite)

When I arrived, I visited one by one, I even greet and the staff said: "huum, you greeted", I shook their hands because nobody did that... I remember I came and visited everybody... it was important because I also got to know better, to study, the patient, her/his life and it was very valuable for me, even today. (Desert Rose)

In the relation user/relatives, user/society; this triad could be noticed in the stories told.

The professionals who worked there showed no stigma or prejudice. I have never witnessed, but for those who did not work, it was really difficult to interact with them

outside... Within the service, there was no discrimination. Outside, the stigma of leper colony remained. (Rose of the Winds)

I noticed a lot of anguish, a lot of revolt, a lot of sadness, abandonment, discrimination, prejudice. They did not want some relatives knew they were there, they asked to say that they were in another state, some were considered dead because of the shame they had to know they were infected with leprosy. (Imperial Topaz)

Until the time when I worked there, Vitaliano, when he went to the bank, if he arrived in the bank and the queue was long and he did not want to wait, he looked at the people and said: - this is leprosy- in an instant people moved away from him. But they said to him: - there is nothing more you can do, it will not communicate the disease. He said: - But I say it and people move away. [...] The staff working there consisted of nursing technicians and assistants, at that time there were a few nursing technicians and assistants, female nurses, physical therapists, psychologists, dieticians, social workers, dermatologist, general practitioner, a multidisciplinary team. There was an outpatient sector that served a demand nearby. They did not care only for patients, they also cared for people from the outside. I did not notice any bias, there was no prejudice! I went to their households, sat, ate snacks, there was no problem. (Tourmaline)

III - Social exclusion versus social inclusion

The constant dynamics of activities provided both by the professionals who worked at the colony and by volunteers was relevant to the demystification process regarding the person with leprosy, as well as the social inclusion practice.

They felt excluded because they knew they were there because they had been excluded, but they faced that in a natural way, because they had no way out. (Sugilite)

My intention was involving undergraduate students in a university outreach project, because I am a professor, so that they knew the reality, both concerning leprosy and the previous history, in order to understand better how it happened in the past and how it happens recently, then, at that time, it was seen both by the society and the health field, the issue of inclusion. Working out the social inclusion of these people with leprosy. We made the visits, we had to make regular visits to this couple, we provided support, more in terms of guidance to avoid trauma regarding the extremities, if there was some other injury, another lesion. (Dendritic Agate)

There were plays there, people from the outside came, especially Spiritualists who

had no kind of prejudice, they went there. They joined patients and staged those plays, which were very good. There was a lot of people there, because what has broken the wall, the wall separating people from the outside from those inside was ignorance, because now we know that in 1943 there already existed treatment with sulfone, it was not as good as it is today, but it already existed and few people knew it. (Imperial Topaz)

DISCUSSION

The respondents' reports showed that compulsory institutionalization has brought many family, psychological, and emotional changes for people with leprosy. According to professionals who have worked at a colony hospital, pursuing their profession along with this population, excluded at the time, became an important factor for professional and personal improvement.

I remember a patient came to the hospital with leprosy, I am not recalling who, and the family moved away, they started walking away and the social worker had to look for the family and we sat and talked to that family. Her husband moved away, she was newly married, her husband turned away and everyone started walking away and we had to bring them close to her so that they could see it was not that bad. (Tourmaline)

My experience was valuable because, I, although I was from the health field, I was afraid of leprosy. I was afraid of being infected, even knowing that I had to comply with safety measures to work there, such as glove, overcoat, and everything else, but I was afraid. (Sugilite)

Leprosy brings significant losses to the daily life and interpersonal relationships, causing suffering beyond pain and discomfort, strongly related to physical damage, with great social and psychological impact.⁹

This disease is marked by strong social stigma. Throughout history, patient isolation was the main measure to tackle leprosy, but this action was not enough to control the disease and helped increasing the fear and stigma associated with leprosy.¹⁰

It is very clear, in the speeches, the major benefit involved in a good living relationship that was established between users and nursing professionals, both in terms of coping with social bias related to this disease and regarding the psychological impact caused by compulsory confinement.

Social bond is an indispensable factor for the patient and it causes direct behavior changes towards the disease. Depending on the way how it is established with the outside

world, the patient takes a positive or negative position, since the movements related to her/him reinforce or reduce stigmas created by the patient her/himself.¹¹

Speaking of stigma, we notice 3 different types: the first related to body abominations, physical deformities; the second related to individual feelings of fault, perceived as weak willingness, tyrannical or unnatural passions, false and rigid beliefs, dishonesty, which are derived from mental disorders, alcoholism, homosexuality, unemployment, radical political behavior, among other reasons. And the third type, related to tribes, races, nation, and religion. These 3 types of stigma converge to a common point: in the social relation to others, it drives away those who are met, destroying the possibility of a positive attention to these individuals.¹²

Despite people spoke, back then, of inmates' socialization, it is noticeable in subjects' speeches, there was a strong fear of interacting with the world outside to the colony on the part of people suffering from leprosy. Concern regarding acceptance by society and prejudice were factors that permeated the world of institutionalized individuals.

Concerning leprosy, stigma is a real phenomenon and it affects people's life in its various aspects: physical, psychological, social, and economic. It represents a set of factors such as belief, fear, bias, feelings of exclusion, which affect patients with the disease. Stigmatization itself, shame of deformities and attitudes expressed by community members contribute to social isolation.¹³ Once the idea of social exclusion is resumed, it is defined and understood as any social condition or situation of need, difficult access, segregation, discrimination, vulnerability, and precariousness in any sphere.¹⁴

It was from the perspective of lack of affection, as well as family, social, and economic problem that the institutionalized leprosy patients submerged within the period of compulsory admission. The professional practice towards this State policy allowed this moment to be regarded more smoothly, as it was perceived in most interviews.

CONCLUSION

This study has allowed a part of the history of leprosy in Rio Grande do Norte to be revealed. By means of participants' experience, we could notice that the policy of compulsory isolation was a determination that posed numerous transformations to the life of

a person with leprosy. These changes involved not only the personal sphere, but also the family, social, and economic spheres.

In the context of social isolation, stigma, prejudice, and social exclusion, nursing professionals worked in a positive way so that the experience of people admitted to the colony was not seen in an even more traumatic manner. Nowadays, there is an increased knowledge about this disease, however, episodes of discrimination, prejudice, and stigma are still observed by professionals in their work environments. Thus, unveiling the history of leprosy constitutes a key strategy to fight such practices.

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