HANSEN’S DISEASE AND DENIAL OF HISTORY: TRAJECTORY OF SEPARATED CHILDREN

ABSTRACT

Objective: to know the life trajectory of children of leprosy patients who were institutionalized in the preventorium/educational establishment. Method: this is a descriptive and exploratory study, with a qualitative perspective, which used the approach of the oral history of life as a methodological reference. We have interviewed ten patients coming from the Osvaldo Cruz Preventorium, in Natal /RN/Brasil, who were actually children of former leprosy patients. The interviews were conducted from two guiding questions and, subsequently, analyzed in the light of the Content Analysis Technique. This study was approved by the Ethics Research Committee, protocol nº 024/2012. Results: three thematic axes were identified: 1. Loss and damages: the family disintegration and reintegration and the denied childhood; 2. Unforgettable: remarkable things that they do not forget; 3. Expectation for experiencing the novelty: in search of other ways or destinations. Conclusion: the separation of parents that were leprosy patients has influenced in the lives of the collaborators of this study, however, despite these painful memories, they managed to overcome the difficulties and rebuild their lives. Descriptors: Hansen’s Disease; Oral History of Life; Resilience; Nursing.

RESUMO


ORIGINAL ARTICLE

HANSEN’S DISEASE AND DENIAL OF HISTORY: TRAJECTORY OF SEPARATED CHILDREN

LA LEpra Y LA NEGACIÓN DE LA HISTORIA: EL CAMINO DE LOS HIJOS SEPARADOS

Izabella Bezerra Lima1, Ana Michele de Farias Cabral2,clélia Albino Simpson3

RESUMEN

Objetivo: conocer la trayectoria de vida de los hijos de pacientes de Hansen’s Disease que fueron institucionalizados en preventorio / escuela primaria. Método: estudio descriptivo y exploratorio, de abordaje cualitativo, que utilizó el método de la historia oral de vida como referencia metodológica. Foron entrevistados diez egressos del Preventorio Osvaldo Cruz, en Natal/RN/Brasil, que eran probablemente hijos de ex pacientes de lepra. Las entrevistas se realizaron a partir de dos preguntas orientadoras y, posteriormente, analizadas a la luz de la Técnica de Análisis de Contenido. Este estudio fue aprobado por el Comité Ético de Investigación bajo del Protocolo nº 024/2012. Resultados: se identificaron tres temas principales: 1. Pérdidas y daños: la desintegración y reintegración en la familia y la infancia negada.; 2. Inolvidable: cosas notables que no se olvidan.; 3. Expectativa de vivir el nuevo: en busca de otras formas o destinos. Conclusión: la separación de los padres enfermos de lepra ha influido en las vidas de los participantes en este estudio. A pesar, todavía, de estos recuerdos dolorosos, se las arreglaron para superar las dificultades y reconstruir sus vidas. Descriptores: Lepra; Historia Oral de la Vida; Resiliencia; Enfermería.
The Hansen’s disease is characterized for being a chronic infectious and contagious disease caused by the *Mycobacterium leprae*, which manifests itself by dermatological and neurological signs and symptoms: lesions in the skin and in the peripheral nerves, especially in the eyes, hands and feet. Its great spot is the impairment of the peripheral nerves, which results in a high potential to provoke physical disabilities that might, even, evolve to deformities.\(^1\)

The term Hansen’s disease has emerged to replace the term “leprosy”, in tribute to the Norwegian scientist Gerard Amauer Hansen, who discovered its causative agent. The term leprosy portrayed, for a long time, this disease as a disfiguring, incurable, contagious and impure evil, which led many people to be segregated and separated from their families.\(^2\)

In Brazil, with the increase of the leprosy endemic and the lack of a treatment that could lead to the healing, it was established, in 1912, the compulsory isolation of all cases of leprosy in asylums-colonies. Next, a set of prophylactic measures was defined, which are listed below: census of patients; measures for providing nosocomial or home isolation; treatment; monitoring of those that were not admitted; systematic examination of communicants; preservation of the leper’s offspring and, ultimately, sanitary education. These measures have generated reforms in leprosariums, as well as the creation of preventoriums and dispensaries.\(^3\)\(^4\)

The first ones were intended to isolate the most severe cases of the disease (virchowian and borderline cases); the dispensaries, which operated in the health centers, were intended to examine the contacts, suspect people and meet the simplest cases (tuberculoid and indeterminate cases); and the preventoriums, also called educational establishments, had the mission to raise and educate the children of the inpatients.\(^6\)

Nonetheless, when studying the history of stigmatized groups, it is essential to perform the study of those who, for whatever reason, were regarded as lepers and, therefore, as such, have suffered exclusionary measures. The pathway of this disease allow us to state that part of the medieval viewpoint about the disease and its carrier managed to reach the XXI century and that, despite the science advancement, exclusionary measures continued to be practiced for the sake of defending the welfare of the community. Even after discovering an effective therapy against the disease, emergency, segregation and violence measures continued to be practiced against the sick subject, being that they have also reached its family members.\(^5\)

The practice of compulsory isolation allowed the leprosy stigma to reach people who have never carried the disease, such as the case of healthy infants, children of leprosy patients, decreasing their chances of life and forcing them to hide their situation, as inpatients or originating from preventoriums, if they wanted to compete on equal terms when they went to look for a job or establishing social relationships. This policy, both in Brazil and in other countries, generated social problems that caused direct repercussions on the behavior of the sick subjects. One of the consequences of isolation was the frequent situation of family abandonment.\(^6\)\(^7\)

The preventoriums were emerging in all the national territory, built through the private initiative and not by means of government resources. Solidarity campaigns were undertaken to build preventoriums intended to care of infants who were children of lepers who lived in the colonies.\(^8\) In Rio Grande do Norte, with the creation of the San Francisco Colony, in 1929, it was concomitantly created the preventorium/educational establishment, in a similar way to what happened in other Brazilian states.

Even if only one of parents was affected by the Hansen’s disease, the children of patients, born in colony hospitals, should be separated from their parents after birth and could not be breastfed by their respective mothers or any woman who were leper or who had coexisted with a patient with Hansen’s disease. Moreover, the children were kept until the adolescence at home or special preventoriums that, when located within the colony hospital area, would be attached to the housing zone of the healthy people.\(^6\)\(^7\)

The interaction between parents and children could only occur when the parents had medical conditions to receive them, constituting another factor that hindered the contact. With the advancement in the disease treatment and its decreased incidence, it was no longer necessary to conduct the compulsory admission, which was abolished by law in 1954. Thus, patients could return to their places of origin. Nevertheless, only in 1987, the children of patients were allowed to stay in the institution. But it was not an immediate fact, being that some problems in the adjustment between parents and children were perceived, since, for many years, they had no bonds of coexistence and, therefore, it was preferable that the children remained in
the educational establishments until the maximum allowed age, because of the argument that there were no conditions to study and obtain a profession within the colony.8

In this context, besides the importance of understanding the history of life of leprosy patients or former patients, it is primarily interesting to know and understand the history of life of those who were segregated and isolated in preventoriums, who were directly affected by the leprosy stigma, although they had never been carriers of the disease. Thus, seeking to answer the following question: To what extent the removal of parents has influenced in the history of life of the children of carriers of Hansen’s disease? - The mapped out goal for this study was to know the life trajectory of children of leprosy patients who were institutionalized in preventoriums/educational establishments.

**METHOD**

This is a descriptive and exploratory study, with a qualitative perspective, which used the approach of the oral history of life as a methodological reference, in order to know the life story of separated children in the context of the history of leprosy.

The oral history is able to show the worldviews of the people, expressed through the testimony of their experiences. It is a systematized process that is previously planned in a project, in which the orality is registered and transported to the written medium, where it allows to perform analysis of social and individual contexts, which should be linked and interdependent. Among the modalities of oral history, we opted for the oral history of life, in order to value the memory of individuals, through freedom promoted to stakeholders with sights to list the testimonies on the lived experiences and, consequently, redeem their existential moral, as well as the subjectivity of details.9

The works on the oral history of life are consisted of different elements that are articulated in stages, which should drive the investigation with living sources. Accordingly, this study was comprised of two parts: 1. Thematic and theoretical foundations (choice of theme, justification and network formation) and 2. Operational stage (the interview itself and the post-interview).9–10

In this work, the target community was composed of children of former leprosy patients that were admitted to preventoriums/educational establishments; and the colony was characterized by 10 people originating from the Osvaldo Cruz preventorium/educational establishment, in Natal, Rio Grande do Norte, Brazil. The inclusion criteria were: children of former patients actually proven; residents in Natal/RN, of both sexes, aged over 18 years; with cognitive, intellectual and emotional conditions preserved; and who were willing to participate in this research. The collaborators were identified through the existing medical charts (60 entries) in the MORHAN RN.

The origin of the network or zero point was the collaborator who stayed longer in the Osvaldo Cruz preventorium/educational establishment, given that the network was formed from it, through the appointment of other persons to be interviewed.

After the first contact with the collaborators and presentation of the research objectives, clarification of the importance of their participation, as well as the information about the recording of statements and warranty of their privacy, the interviews were conducted in a place chosen by the collaborator itself, without external interferences. The interviews lasted an average of 2 hours and were preceded by the registration of the identity of the respondent, as well as the place and the date of the meeting. The reported stories were recorded in an electronic device; they were initiated by using two cut-off issues - “Tell me how your life in the preventorium/educational establishment was” and “Tell me how your life after the preventorium/educational establishment period was”.

To assure the confidentiality of information and the anonymity of research stakeholders, the subjects were identified by names of angels (Angel Gabriel, Angel Raphael, Angel Miguel, Angel Ariel, Angel Daniel, Angel Uriel, Angel Mikael Angel Aniel, Angel Caliel and Angel Rochel). This denomination was well chosen, because the collaborators were true promoters of transformation in the history of life of the researchers.

The recordings were thoroughly heard, subsequently, transcribed, then transcreated, after the second contact with the collaborators and, finally, conferred by them, enabling them to actively participate in the text review. The speeches were analyzed following the Content Analysis Technique, which is defined as a set of analysis techniques of communication that aims at establishing a correspondence between the linguistic/semantic structures and the psychological/ sociological structures, by
identifying behaviors, ideologies and attitudes of utterances.11

Due to its relation to researches involving human beings and by following the ethical and legal precepts of the Resolution nº 196/96, this study had to be approved by the Ethics Research Committee from the Rio Grande do Norte's League Against Cancer, Department of Teaching, Research and Community Education (Opinion nº 024/2012), on March 27th, 2012. The subjects were invited to participate and those who agreed, subsequently, have signed the Free and Informed Consent Form.

RESULTS

We have interviewed ten subjects: five men and five women. The youngest was 33 years old and the oldest was 77 years old. One of the subjects was illiterate; seven studied until the elementary school, and two had studied until the middle school. Regarding the marital status, seven were married or were in a stable relationship, two were divorced or separated and one was widowed. When asked about the occupation, four women mentioned that they did not work outside the home and another one said that she was pensioner. The remaining subjects reported to act as: rescuer, mason, autonomous, military and tourist guide. None of them acquired Hansen’s disease throughout the years that they were in the preventorium/educational establishment or later.

In the analysis of life stories, three thematic axes have been identified: 1. Loss and damages: the family disintegration and reintegartion and the denied childhood; 2. Unforgettable: remarkable things that they do not forget; 3. Expectation for experiencing the novelty: in search of other ways or destinations.

Axis I - Loss and damages: the family disintegration and reintegartion and the denied childhood

From the told stories, we have realized how much the family breakdown was painful in these children. This brutal separation caused unimaginable damages and the consequent collapse brought overwhelming results in the past and in the coming history, that is to say, feelings that were suffered and hushed in a requested, required, and irrevocable silence, as noted in the reports below:

Then my mother lived alone with the children and my father lived in the leprosarium, in the São Francisco de Assis Colony. Then, he came to see us on the weekend; sometimes, he spent the night to sleep with my mother. Most of the time, we were created alone. (Angel Gabriel)

When we least expected it, a letter arrived asking for my father to take us to the Natal city, but he was not willing to come. Before that, two of our brothers fled away, the eldest brother and the other to my grandmother’s house[…] but they asked for bringing him back too, because he was a minor, the other was not, she was oldest, was eighteen years. (Angel Daniel).

[…]only by reason of my mother being sick, my father ended forgetting her, because she was hospitalized for many years and then he built other families[…]. (Angel Uriel)

In the preventorium/educational establishment, the children, inhumanly called “litters”, suffered physical aggressions and punishments, which were frequently reported in the speech of the collaborators.

As kid, I peed on the mattress; so I was subjected to put the mattress on the floor and go to the sport court on my knees with the mattress over the head. For example, if we were playing soccer and hit a lamp, we would be punished and placed in a small dark room. (Angel Raphael)

There was a lady who beat me too much, because everything was a reason to receive slaps or other forms of aggression…(Angel Miguel)

We were pretty affected through slapping and were put on the ground with beans’ seeds below the knee. Thus, we cried a lot because of it. (Angel Gabriel)

[…]regard to the penalties, there was a small dark room where children were placed and confined during all time of the day. Everyone feared greatly when they spoke “you did that, go to the dark room!” That was a kind of cage[…] the food was placed by the window and everyone got desperate when there was a prisoner there, they got worried about what would happen to him there, whether it would be beaten or not. (Angel Daniel)

In contrast, the care, or the lack of it, offered in the preventorium/educational establishment, created situations extremely unfavorable to the development and evolution of the children who lived there. The pains caused by the separation, the absence of parents, the constant mistreatments, the denial of childhood and the indignity present in the daily resources of educating have raised irreparable damages.

Because they are in the process of maturing, children did not understand the family separation. The consequences of disruption have emerged in the lives of those who were moved away from their parents, as well as for those who continued to live close to them.

Hansen’s disease and denial of history...

English/Portuguese

J Nurs UFPE on line., Recife, 7(6):4340-7, June., 2013
The problem was because we could not touch their feet or hands. We suffered a lot, we cried because we wanted to embrace our mothers, but they [guardians] did not allow us to do that; since we could be contaminated by the disease. (Angel Miguel)

At that moment, one child was with her, in her arms, and they did it [took away]; we did not understand why they did that. We know that it was their ignorance, had been ordered. After my mother became an inpatient here, my dad got a bit crazy, then he showed no affection for his children, there were only mistreatments, mainly towards the biggest ones[...]. (Angel Daniel)

**Axis II - Unforgettable: remarkable things that they do not forget**

What became unforgettable, for the collaborators, were remarkable memories associated with the daily life of the preventorium/educational establishment and the working routine of those times; the studies and the learning, which generated, in many of them, a sense of gratitude and yearning; the friends and affective bonds that they built. The speeches below describe a little more about these remarkable memories.

I remember I loved to be in the nursery. There, I took care of children younger than me[...]. (Angel Gabriel)

There was a chart with the services where you were conducted to be helper in the kitchen; so we got to wash the dishes, clean the kitchen, other one got to serve in the cafeteria; things we thank God, because it was how we learned. There was a sewing room where they taught us to sew up, embroideries. There were also leisure moments and parties. St. John's Celebration, Christmas, all well organized. (Angel Daniel)

I'm so thankful to God, because that was the place where I got the best skills of life, I learned to read, write, and all my brothers reached it too[...]. (Angel Daniel)

*My Life in the Oswaldo Cruz* had some quite favorable days, we picked up a ball to play with, but also had days when we got up early, five/half past five in the morning to water the vegetable garden[...]. We were small and, in order to see my mother, I had to stretch myself and the teachers were all close to us for preventing an approach. (Angel Raphael)

We traveled by truck and when we reached the colony, the truck stayed parked under a cashew tree and the nurse was in front of us, then the sick people, our parents, sat in front of us, we remained on the truck, we sang for our mothers [moment of commotion, cry on the part of the collaborator]. We had no right to go there, give a hug, a blessing was only received by us, then the sick people, our parents, not ask for a blessing. I remember it was a stage, they were up there and we were underneath. We were small and, in order to see my mother, I had to stretch myself and the teachers were all close to us for preventing an approach. (Angel Miguel)

We could not visit our parents. When my father was there and had a slashed leg due to the illness, he was called Zorro, because he was a cowherd, had a horse and came to visit us, riding on a horse. It was embarrassing, because I could be in the arms of my father, my mother, like any normal child, but it was not possible. (Angel Gabriel)

**Axis III - Expectation for experiencing the novelty: in search of other ways or destinations**

Nonetheless, the marks of separation from parents and those ones arising from the stigma and discrimination that they experienced were reported with excitement, as if they still felt the pain of not being able to get closer to their parents, being cherished or protected by them. Indeed, just a distant look remained for those children, when they had the opportunity to visit the colony. These visits have become unforgettable memories, even for the youngest kids.

...separation from my father, I could not give him a hug or a kiss, neither the people of my family who were there at the leprosarium. Often, I was afraid to get sick. But, I asked God, as a child, to be healthy, because that disease was very complicated at that time[...]. It was a great satisfaction to see my mother, my father. My father did not see at all, since he was admitted, but my mother came to visit us on Sundays. (Angel Gabriel)

When we went to the colony, we had the privilege to come once a month. When we reached the colony, we should not to get close to them, since we could not[...], could not ask for a blessing. I remember it was a stage, they were up there and we were underneath. We were small and, in order to see my mother, I had to stretch myself and the teachers were all close to us for preventing an approach. (Angel Miguel)

We traveled by truck and when we reached the colony, the truck stayed parked under a cashew tree and the nurse was in front of us, then the sick people, our parents, sat in front of us, we remained on the truck, we sang for our mothers [moment of commotion, cry on the part of the collaborator]. We had no right to go there, give a hug, a blessing was only received from far, over the truck, and when the our mothers were willing to give us money, we could not receive. Therefore, someone received in a package, a plastic bag and talked about what had to be purchased for the child, whatever it was, however, we had no right to receive anything from their hands. (Angel Daniel)

With the arrival of the manhood or the possibility of leaving the preventorium/educational establishment,
those children were reintegrated to their families and each one was building its life as far as it could or should do. Many of them have not finished their studies, since they had to work and help their parents, who were newly arrived at the São Francisco Colony; others were live together with relatives and helped to educate their younger siblings and, subsequently, were building their own families.

Today, my occupation, perhaps mirroring my mother, my father, I am a rescuer and my life is wonderful. I have my house, my family, my two children[…] (Angel Raphael)

When I came out of the educational establishment, I went to see other things that happen in the social life. I still was a child, but I remember that my mother went to work and I remained taking care of my brother, I prepared the lunch and still had to go to school. The responsibility came early and even now I remember that[…] (Angel Gabriel)

When I left the Oswaldo Cruz, I had nothing, not even some resource to survive. I took the bed where I slept, put on top of a cart, the pillow, the sheets; I went to Lagoa Seca and even slept in a small rented room. After I left there, I became a policeman, got married[…] (Angel Aniel)

When I left that place, the situation of my parents was still precarious. My mother made tapioca, coconut candy, when I left there, I already started to work, we went to the beach for selling popsicles, coconut candies, I helped a lot; all the money I got was passed to the hands of my father and my mother[…] I started working at sixteen years old at a company, as mason assistant[…] at the age of eighteen, worked as a doorman. Today, I work in a company and I have been there for twenty-three years[…] the little that I have won, it was with great vigor, my faith. I have six children and four grandchildren, all blessed by God. (Angel Rochel)

When asked about the possibility of indemnification, due to material, psychological and social losses that they suffered, because of their admission to the preventorium/educational establishment, the collaborators have expressed themselves in favor, by understanding that suffered a large rupture in their family bonds, even knowing that it is no longer mandatory to hold the compulsory isolation for carriers of Hansen’s disease since 1954. However, they proved to be resilient, as they have managed to turn their stories, through hard work and willingness.

I think the compensation is something that the justice will determine, since our parents received[…] the Federal Government has to assess it, since our parents received, no matter whether is two, three, one hundred, one thousand reais, it doesn’t matter. We have the right, because we have passed through a hard coexistence. (Angel Mikael)

Regarding the compensation, if it is my right, let this right be so, if it is not, let’s go forward. (Angel Aniel)

Regarding the discussion on the indemnity, I think we surely deserve it, because we were educated with our parents caged in a colony, they could not work, that’s to say, educated by the hands of others, without receiving anything […] (Angel Caliel)

DISCUSSION

The speeches of stakeholders have revealed the psychological, social and educational damage that those children suffered in the past, now adults, as a result of the family disruption that they have suffered due to the leprosy stigma and the compulsory isolation. They were separated from their parents and could not even hug them or shake their hands. The speech below depicts this reality well, as well as the fact that the family relationships are stronger than any possibility of illness.

When I left the educational establishment and could be with my mother, I enjoyed, I lay on the bed with her and said: “Sir, if I got to have this disease, which my mother had, I will have, but I’ll stay beside her. So I stayed with her until the day in which she died, every day I was with her in the colony. (Angel Daniel)

Thus, it is reflected on the families in their individual and collective context, in which there would be no error in stating that these families were destroyed, whereas the admission to the leprosariums and the confined coexistence in the educational establishments withdrew the essential family core from its basic tasks, which are the personal development of children and the socialization of its members.12

The non-socialization of patients is consensually unquestionable, considering that the isolation is opposed to such a process, thereby remaining the community life among peers. However, regarding the development of children born before the reality of leprosy, there was the proposal to minimize the suffering generated by separation, through the monitoring in the educational establishments, or preventoriums, with a view to promoting the socialization and the development of children of leprosy patients. Hence, the coexistence in the same physical space contributes to configure the family core and strengthen bonds; however, it was broken, thus forming an irreparable harm.12
The care of the newborn should transcend the satisfaction of physiological needs, such as lactation, protection and hygiene. Thus, the provision of security, affection and attention underlie the social, affective and cognitive formation and development, besides being a right to the citizenship.\textsuperscript{11}

However, despite many unpleasant memories and suffered physical violence, characteristic of a banking education, the research subjects were able to have a positive viewpoint about the years in which they have been institutionalized. They reiterated that, in the preventorium/educational establishment, have learned to read and write, as well as some activities that were useful to their lives, such as: cooking, caring for children and making shoes. Furthermore, all respondents rebuilt their lives and formed new families, after they left that place.

Given the above, it should be raised the concept of resilience, understood as the human capacity to adapt itself and transform situations of risk and vulnerability into potentialities, through association among the attributes of the individual and its family, social and cultural environment.\textsuperscript{145} The overcoming of adversity takes place through a redefinition of the problem, but this procedure does not eliminate it, since it is part of the history of life of the subjects.\textsuperscript{16}

For the subjects of this study, as noted, there was a denial of their history. For some interviewees, the memories are still surrounded by tears, but there is an attitude of acceptance and overcoming. Accordingly, it should be remembered that the resilience is a psychological process that is developed throughout the life, from the binomial: risk factors x protective factors. The latter are potential characteristics in promoting resilience, since they minimize the negative effects of the life experiences.\textsuperscript{17} The dreams and the expectation of giving a better life to their parents, in this perspective, might be considered protective factors that pushed up those children and teenagers to become courageous, cheerful and “well-resolved” adults.

The overcoming of an adversity is associated to the reliance on the family support, with the hope that the “life will improve”, with the existence of a life goal and with the support of health care professionals. In this regard, recognizing that the Nursing is intrinsically related to the care of the subject, it should be recognized that the knowledge and the understanding by nursing professionals about the beliefs and the history of life of the subjects, their target audience, strengthens the promotion of protective factors and, consequently, the promoting of resilience, both in the context of leprosy and in the context of another process of illness.\textsuperscript{18}

\section*{CONCLUSION}

It was observed in this study that the separation of parents that were leprosy patients has influenced in the lives of the collaborators of this study, in an irreparable manner, given that these adults were forced to live their childhood phase and part of their youth far away from the tenderness and the protection of their parents and their family environment. Accordingly, they were subjected to punishments, physical and psychological violence, as well as the marks arising from the leprosy stigma.

All these bad experiences were not decisive in rebuilding their lives. They managed to give a new meaning to these experiences, formed families, had children, took care of their parents, found a craft or an occupation and conquered their dignity and happiness by means of their own capacities; featuring a resilient behavior.

It is hoped that this study will be a promoter in the fight for compensation of those people who were forcibly removed from the conviviality of their parents, in a time that the compulsory admission had already been extinguished and that the treatment for Hansen’s disease had already achieved very positive results in relation to the healing, as well as helping to record the history of this disease that was considered one of the most terrible evils of the mankind.

\section*{REFERENCES}


English/Portuguese
J Nurs UFPE on line., Recife, 7(6):4340-7, June., 2013

Hansen's disease and denial of history...