DOI 10.18471/rbe.v31i2.17541

THERAPEUTIC ITINERARIES IN SEARCH OF DIAGNOSIS AND TREATMENT OF LEPROSY

ITINERÁRIOS TERAPÊUTICOS EM BUSCA DO DIAGNÓSTICO E TRATAMENTO DA HANSENÍASE

ITINERARIOS TERAPÉUTICOS EN BUSCA DEL DIAGNÓSTICO Y TRATAMIENTO DEL HANSENÍASIS

Daiane Freitas Carneiro[1]
Mila Michele Batista da Silva[1]
Mariana Pinheiro[1]
Iací Proença Palmeira[2]
Everson Vando Melo Matos[3]
Angela Maria Rodrigues Ferreira[4]

Objective: to analyze the therapeutic itinerary of patients in search of the diagnosis and treatment of leprosy, its difficulties, and perceptions about the disease. Method: this is a qualitative and descriptive study. Twenty patients with leprosy in the active registry until March 2016 participated in the study in a Health Center School in the city of Belém, Pará. A semi-structured interview was applied, and the technique of thematic content analysis was applied. Results: two thematic categories emerged: "Perception of the disease" and "Mishaps of the suspicion to the diagnosis and treatment". There are still negative perceptions about the pathology and many steps to go through to the diagnosis of leprosy. Conclusion: the search for the leprosy diagnosis showed a succession of diagnostic errors, from the private network to the basic health network, delineating a tortuous path. The perceptions of patients are linked to prejudice, whether of other people or self-prejudice.

Descriptors: Collective Health. Leprosy. Health Surveillance.

Objetivo: analisar o itinerário terapêutico de usuários em busca do diagnóstico e tratamento da hanseníase, suas dificuldades e percepções acerca da doença. Método: estudo qualitativo e descritivo. Participaram da pesquisa 20 usuários com hanseníase em registro ativo até março de 2016 em um Centro de Saúde Escola no município de Belém, Pará. Foi realizada entrevista semiestruturada e aplicada a técnica de análise de conteúdo temática. Resultado: emergiram duas categorias temáticas "Percepção sobre a doença" e "Percalços da suspeição ao diagnóstico e tratamento". Ainda existem percepções negativas sobre a patologia e muitos percalços a percorrer até o diagnóstico da hanseníase. Conclusão: a busca pelo diagnóstico da hanseníase apontou uma sucessão de erros diagnósticos, da rede privada à rede básica de saúde, delineando um percurso tortuoso. As percepções dos usuários atrelam-se ao preconceito, seja de outras pessoas, seja o autopreconceito.

Descritores: Saúde Coletiva. Hanseníase. Vigilância em Saúde.

Objetivo: analizar el itinerario terapéutico de usuarios en busca del diagnóstico y tratamiento de la hanseniasis, sus dificultades y percepciones acerca de la enfermedad. Método: estudio cualitativo y descriptivo. Participaron de la investigación 20 usuarios con hanseniasis en registro activo hasta marzo de 2016 en un Centro de Salud Escuela en

---

[1] Students of the 9th semester of the Nursing course of Universidade do Estado do Pará. Belém, Pará, Brazil. daianefreitas.c@gmail.com; milamichelle94@gmail.com; mariana.pinheiroufpa@yahoo.com

[2] Nurse. Assistant Professor III of the Nursing Course at the Universidade do Estado do Pará. Belém, Pará, Brazil. iaci_palmeira@yahoo.com.br

[3] Master in Health, Environment and Society in the Amazon of Universidade Federal do Pará. Belém, Pará, Brazil. everson.melo1@gmail.com

[4] Nurse. Adjunct Professor II of the Nursing Course of Universidade do Estado do Pará. Belém, Pará, Brazil. amrferreira2008@hotmail.com

el municipio de Belém, Pará. Fue realizada una entrevista semi-estructurada y aplicada la técnica de análisis de contenido temático. Resultado: surgieron dos categorías temáticas "Percepción sobre la enfermedad" y "Percances de la sospecha al diagnóstico y tratamiento". Aún existen percepciones negativas sobre la patología y muchos percances a andar hasta el diagnóstico de la hanseniasis. Conclusión: la búsqueda por el diagnóstico de la hanseniasis mostró una sucesión de errores diagnósticos, de la red privada a la red básica de salud, delineando un curso de tortura. Las percepciones de los usuarios están unidas al perjuicio, sea de otras personas o del auto-perjuicio.

Descriptores: Salud Colectiva. Hanseniasis. Vigilancia en Salud.

Introduction

Leprosy is a chronic, infectious disease whose etiological agent called as Mycobacterium leprae (M. lepra) has high infectivity, that is, it can infect several people, but it has low pathogenicity. Because of this, few people get sick. It is a pathology of compulsory notification and mandatory investigation throughout Brazil(1). This pathology mainly affects the skin, the mucosa of the upper respiratory tract, the eyes and the peripheral nerves, causing physical incapacities. The most obvious signs and symptoms are spots, lack of sensitivity, cramps, muscle pain, thickening of nerves, limitations in vision, walking with difficulty and shortening of nerves, muscles, and joints(2-3).

Leprosy is a millennial disease. It represented a social threat, since it was highly contagious and deadly because the treatment was unknown. In this way, those affected should be isolated so as not to transmit this "evil" disease and, consequently, they were excluded from social interaction. Currently, with the advancement of science, the treatment is effective, and it has a cure. However, it is still considered a stigmatized disease. although it is a curable pathology, the complexity of diagnosis to cure is still wide(4-5).

The course of the patient with the first symptoms of leprosy until the treatment starts is considered long. Thus, studies on therapeutic itineraries have been used by researchers to understand these trajectories in different diseases. Such studies become important tools for understanding people´s health needs(4,6-7). Understanding the therapeutic pathways of leprosy is important, since it enables to apprehend some fragility in the health service. The Ministry of Health (MOH) recommends that both nurses and physicians need to have knowledge to identify the signs and symptoms of the disease, especially in basic care(4).

The results of this study will be great to the professionals who work at the ambulatory and hospital level, enabling the improvement of their knowledge and, consequently, the improvement of the provision of assistance in health services. This study should signal the operationalization of leprosy control actions in a specific demand of the municipality of Belém and elicit reflections on mechanisms capable of improving such services.

A search was carried out in a database about the study object called "therapeutic itinerary of leprosy patients" analyzing the existing literature in a period of ten years and identifying possible gaps that indicated the necessity or not of carrying out such study. The descriptors "Therapeutic itineraries" and "leprosy" were used. The isolated use of the descriptor "Therapeutic Itineraries" generated 64 manuscripts, but the association of "Therapeutic Itineraries" with "leprosy" generated a single article made in Bahia, pointing out a knowledge gap. The above indicated the need to undertake studies on the subject.

The objective of the study was to analyze the therapeutic itinerary of patients in search of the diagnosis and treatment of leprosy, its difficulties, and perceptions about the disease.

Method

Qualitative and descriptive study. Data collection was between November 2015 and

March 2016 and carried out at a Health Center School in the municipality of Belém, Pará, a teaching unit providing care to the population, with an average of five new cases of leprosy per month. The Health Center School offers a differentiated service, as it is aimed at integrating teaching assistants in primary health care and also research and extension to the community through the connection between teaching.

The study population consisted of 30 patients diagnosed with active leprosy until March 2016. Of them, 20 participated in the study, after applying the following inclusion criteria: to be in the active registry until March 2016; Living in Pará, independent of the municipality of origin; Any age, gender and clinical form of leprosy. The criterion of exclusion was to be a carrier of psychic problems that hinder to answer the interview questions. Participants were approached according to their attendance at routine periodic consultations at the Health Center. The objectives of the study were explained, as well as the risks, benefits and voluntary nature of participation, ensuring confidentiality and anonymity through the alphanumeric codes (P = Participant), being "P1, P2, P3 ...".

The data were collected through an interview conducted according to a semi-structured script, organized in two parts to allow a glimpse of the perception of patients with leprosy on the disease and also the knowledge of the therapeutic itineraries from the perception of the signs and symptoms until the elucidation of diagnosis and treatment. Thus, the script was composed of open and closed questions, containing questions related to sociodemographic and disease-specific data, such as gender, age, marital status, education, family income, and clinical forms of the disease.

The open questions were formulated: What are the conditions of access to the Basic Health Unit (UHB)? (Purpose of the question: Exploring distance and accessibility conditions: bus lines, transportation costs, time of attendance, time spent to reach the UHB); How did you feel when you received the leprosy diagnosis? (Purpose of the question: Exploring the reaction of the patients and the friends and family to the knowledge of the diagnosis); What is the time between suspicion and diagnosis? (Objective of the question: Exploring how many times the health unit searched, which examination (s) was carried out until the diagnosis was closed, what difficulties were found and if care was sought in another unit); What is the time elapsed between diagnosis and initiation of treatment with polychemotherapy (MDT)? (Purpose of the question: Exploring the opinion about the care given to the unit by the professionals, as well as the time to receive the first supervised dose of MDT); Have you used home treatments? If yes, which ones?

The reports were recorded after consent and transcribed. Subsequently, they were submitted to the thematic content analysis technique(8), followed by three phases: pre-analysis, at which point the documents to be analyzed were chosen; Material, the classification of the data, followed by the treatment and interpretation of the results. They were categorized and discussed based on studies on the subject, even with different objects, due to the scarce literature found.

Ethical principles were respected by Resolution number 466/12 CNES/MOH. The study was approved by the Committee on Ethics in Research with Human Beings of the State University of Pará, 1,329,783.

Results and Discussion

Participants were between 11 and 74 years old, with no age group representation. Most of them (70%) were male, in agreement with another study(9), whose results showed that some social conditions of gender facilitate the involvement of leprosy in men, such as greater frequency of displacements to work; Frequent ingestion of alcoholic beverages; Less demand for health services and different self-care practices with the body - women take better care of their bodies; 60% of the participants had high school; In the religion variable, 95% declared to be Catholics; 85% came from the city of Belém; And 60% lived with family income between 1 and 2.5 minimum wages.

Some studies(10-11) show that the monthly family income of the patients with a leprosy diagnosis is relatively low, that is, the pathology affects more people in the lower class of society, where monthly income ranges from one to three minimum wages. Family income is one of the factors that influence the manifestation of leprosy.

From the information obtained by patients with leprosy, sections were selected that express their perceptions about the changes in their health and the therapeutic itineraries in search of the specific treatment. Two categories emerged: one related to the perception of the disease and another related to the mishaps from the suspicion to the diagnosis and the treatment.

Perception of the disease

In this category, it was possible to highlight the contraposition of ideas related to the health-disease process of the patients and the conception of society before them. Most of the perceptions were negative. There were reports of sadness, fear, worry, scare and panic, not being prepared to receive the news of illness. Only two participants did not report these perceptions regarding the outcome of the diagnosis.

Diagnosis, information, and counseling can have an emotional impact on patients with leprosy and lead to the appearance of psychological reactions suggestive of non-acceptance of the disease: denial, revolt, concealment of the disease or even disclosure restricted to the most intimate relatives(12). In general, when patients receive confirmation of the diagnosis of leprosy, they feel confused, sad, fearful and ashamed. These feelings point to the need for follow-up with a psychologist to help them understand the disease, confronting the difficulties it brings and preparing them to live with leprosy until their cure(13).

The reports of P5 and P3 show a negative understanding regarding the health-disease process. Even one of them needs assistance from the multi-professional team for the understanding and acceptance of the disease:

> [...] *it was difficult, I was not prepared, I did not expect it, I even needed a psychologist. Not that I have anything against the disease, but by participating in certain activities, I felt that it could never happen to me.* (P5).
>
> *I was panicked, desperate, for my grandchildren also had leprosy.* (P3).

The moment of the discovery of leprosy triggers various feelings, such as sadness, revolt, and non-acceptance, since the meaning of the disease depends on the meaning attributed to it, and this is due to several factors superimposed on patients, such as past experiences, cultural prejudices, and information obtained by the media(14). A participant with a history of previous and high cured treatment was surprised and indignant when diagnosed again with the disease.

> *I was awe, I confess, however, we have to know how to live with it and how to treat it. This is the second time that I have this disease, 25 years ago I had this pathology, and now it has appeared to me again.* (P14).

The reactions of family members and close friends of patients may vary according to their cultural and socioeconomic conditions, so some of them prefer not to communicate to family and friends for fear of being discriminated and abandoned(13). Revealing or not diagnosing leprosy is a dilemma for patients, highlighting the prejudice in other people and also self-prejudice. The speeches of the participants are illustrative:

> *It gave me sadness, not because of my diagnosis, but because my friends of my work mistreated me when they knew and when I went to take care of myself... they started talking, they moved away from me, they separated things. Some of them stopped talking to me.* (P10).
>
> *I felt ashamed of them, because a friend of mine, had someone in her family with the disease, the day I went to get the result I found her and it was the same one that read to me the result, after the confirmed diagnosis, she did not want me to take her hands, leaving me traumatized.* (P3).
>
> *I felt a bit of prejudice, I think that's the word. I felt this way because it was unexpected because I did not feel anything. I also felt a little depressed, I was afraid [...]* (P18).
>
> *I felt a little sad. We have prejudice of ourselves. We have to lift our heads and move on. After the doctor had explained that there is a cure, I felt more comfortable, I put on my head that I had to do the treatment correctly.* (P20).

The suffering of the patient with leprosy is not restricted to the fear and rejection of others since he also experiences self-rejection. Participant 2, referring to his behaviors before starting the treatment, mentioned the lack of knowledge about the modes of contagion, which was circumvented after the guidelines received from the unit team. The prejudices about leprosy cause the patient to reject himself, isolating from his social group and causing him to adopt a self-flagging stance(15):

> *I have a small daughter (she will be a year old in a few months), so we (my wife and I) were very sad because I could not have direct contact with her if I did not start the treatment. It was a bit difficult because we want to stay with the family, but we are afraid to transmit the disease. Only after I came to the unit and the doctor guide me, I was well informed, and nowadays it is very quiet.* (P2).

Thus, it is observed that there are still negative self-conceptions among patients, as well as prejudiced and discriminatory attitudes of others towards them. Such perceptions may result from ignorance about the contagion of the pathology or from the age-old stigma still entrenched in some social groups, leading them to self-isolation.

Mishaps from the suspicion to the diagnosis and the treatment

In this category, the patient´s progress and his mishaps are evidenced, from the first signs and symptoms of the path he/she travels in search of diagnosis and treatment. The path of suspicion to diagnosis is long, and it can be explained by the lack of information from the population regarding the signs and symptoms of the disease, delaying the search for a health service, as well as operational failures in basic care(4).

The lack of knowledge of the professional and the population about the disease, the delay of the diagnosis, the results of negative tests and the incorrect diagnosis emphasize the pilgrimage of the patients searching the adequate diagnosis and treatment. This delay of the diagnosis can lead to aggravation of the disease, being observed in the speech of the P6 when feeling "delayed in the life" by the lack of information on the disease, causing its aggravation:

> *I did not suspect leprosy, as there were no blemishes. A long time ago there was a numbness in my foot and I thought it was a bad circulation. After a while, a spot appeared, I went to a dermatologist, who asked for tests and diagnosed leprosy.* (P1).

> *In fact, I never suspected it because I thought it was a skin problem. I looked for the [Unified Health System] SUS, I did tests, and it was nothing. They always said to come back another day, until they told me about the unit of the university, taking three years to get the diagnosis... We feel retarded in life because if I had noticed it at first, I did not reach the advanced stage.* (P6).

> *I went to the School Center, and they sent me to Evandro Chagas, the place where I did the tests, cut everything (cut my ear), but did not say anything. I did other tests, they did not give me anything either. I returned to the Unit and was asked for a biopsy in April 2015. However, I only received the result on November 2nd.* (P3).

These reports contradict the one recommended by the guidelines of the Program for the Control of Leprosy(1) (PCL), emphasizing the existence of resources available for the control of the disease, but for this, it is necessary the early detection of cases, treatment in the initial stage of the disease and the adequate follow-up of the patients to avoid aggravation and get the cure.

It is worth mentioning that the signs and symptoms of leprosy have certain peculiarities, such as the absence of pruritus and altered sensitivity. However, 95% of the participants had histories of late, and they were misdiagnosed in their therapeutic itineraries, propitiating the progression of the disease and hindering the control of this endemy:

> *A spot appeared on my belly, I even did an examination to see if there was anything, but the result was negative. I did not care, after a year and a few months, his disease worsened. I arrived here with several body injuries and swollen hands.* (P13).

> *I made everything in a private hospital. The doctor who took care of me gave me medicine to the whole body. I asked if it was leprosy, he said it had nothing to do with this disease. I used the medicine, but it did not work, it was as if I only passed water from the pot. Conclusion: I paid the consultation, the medicine and it did not work. I continued to have a lot of pain in the joints, and it got really bad, it was when I went back to the private doctor, and I did the tests, yes, I got leprosy.* (P19).

Leprosy control measures are priority actions for health, and the diagnosis is primarily clinical, with detection of signs and symptoms by the team of doctors and nurses, mainly in basic care, through the Family Health Strategy (SHF), as well as at all levels of complexity(1).

Late diagnosis seems to be associated with a lack of professional training in the health services to diagnose the disease earlier, contributing to the worsening of symptoms and the consequent maintenance of M. lepra transmission(7,16). It was found that the participants first sought care in other institutions - public and private - as well as in other municipalities and professionals of other specialties, without success. Thus, they went to the Health Center School for being a reference, to be linked to a university and to have specialized service in the area of dermatology:

> *I did the lymph twice for SUS. I also did several private tests, which they also did not attest to leprosy... The sensitivity test, I did six times and it did not prove anything. That's when I came to this unit and they found the disease.* (P6).

The demand for the Health Center School and diagnostic elucidation were late and the disease was already polarized. Treatment started on average within one to thirty days. In this way, weaknesses are perceived in Unique system of Health (SUS) health services, because patients go a long way to arrive at the correct diagnosis, opting, in most cases, for a particular service, for understanding that the care is faster, ease of taking the exams. However, even in private services, the patient does not always have the correct diagnosis. In many cases, this only occurs when they are sent to the referral center in the state capital(7). Thus, the long path to diagnosis takes patients to other specialists and diagnoses are often erroneous. circulatory problems, spine, allergies and various dermatoses were among the most cited:

> *This stain came and I did not care for it. I went to the doctor there in the city where I live, he said it was an allergy due to a lot of alcohol. I went to a private dermatologist and he did a skin biopsy, confirming this leprosy.* (P18).

> *I went to a private dermatologist whose diagnosis was allergy. He gave me an injectable antibiotic for a month, but it did not work. I consulted with a rheumatologist who detected the spot, alerting me to the possibility of being leprosy. I went to the other dermatologist, who asked for a biopsy with a medical specialist and it was diagnosed as leprosy.* (P12).

> *I went to a private doctor and he said that I had diabetes. The disease was getting serious, nodules appeared in my body and I had a fever. I looked for several doctors and had several different diagnoses, I did it from MRI. I went to an orthopedist, he wanted to do surgery on my knee (he said until my menisci were out of place). I took many remedies with very strong effects, but without any results.* (P20).

The large number of tests performed by the patient and the various erroneous diagnoses contradict the differential diagnosis of the disease. Some signs and symptoms can be compared to those of other dermatoses, since cutaneous manifestations occur. However, specific tests and tests may be replaced by clinical examination during the first visit. Laboratory tests are requested for the definition of treatment and adequate evolution of the patient(1,4).

In some reports, the lack of qualification of some professionals regarding leprosy emerges, lacking a greater commitment with respect to signs, symptoms and diagnosis.

> *About four months ago, an injury appeared, but I did not suspect leprosy, I treated it differently. Since I did not improve, I went to two dermatologists who diagnosed and treated as another disease, only a third dermatologist gave me the correct diagnosis.* (P4).

> *The dermatologist only used creams, she never asked me for a test. I urged her to request some testing so I could have a diagnosis of what I had. She wanted to gave me other creams again and I was seeing that it was not solving. I went to another dermatologist from another unit, who also always used creams, pills and soap. The spot growing more and more, so I asked the doctor to ask for tests; After that, leprosy was diagnosed.* (P5).

It is noteworthy the difficulty of professionals, especially those not connected to the network of basic health care, for suspicion of leprosy. In some cases, there were signs of spots and nodules, signs suggestive of leprosy, especially when associated with previous history and epidemiological linkage. Health professionals in charge of anamnesis and diagnosis should be prepared to recognize the signs and symptoms peculiar to this disease, as well as to rule out the possibility of other dermatosis by differential examinations(1).

The delay in diagnosis was not directly related to the socioeconomic situation of the patients. Most were diagnosed late, on average two months to three years after the beginning of the search for care. It was found that the late diagnosis of leprosy may be associated with the insufficient training of health professionals and also with the delay in the results of exams, often unnecessary for the beginning of the treatment, since the clinical examination is paramount to the diagnosis:

> *A couple of months, because I first looked for a dermatologist, who diagnosed allergy, I had an injectable antibiotic for a month not taking effect.* (P12).
>
> *It took a long time to get the diagnosis. I did a biopsy in April and until September the result had not yet been given.* (P3).
>
> *One year since the first investigation and it was suspected. The first doctor she saw it did not suspect it. Until I came back with another doctor who requested a biopsy, it lasted a year. Until the treatment starts, another year and six months. The worst thing is that this is not a unit of the SUS [Unified Health System], but rather private and with indications from friends. If it was for SUS units it would have taken much longer.* (P9).
>
> *First I started at a health center near my house, then I was sent to take blood and urine in another unit, giving no results. Later, I was referred to the hospital in Marituba, I repeated the tests that also did not attest anything. They sent me to the University. Conclusion: The time elapsed between the suspicion and the diagnosis took more than three years, since the appointment for consultations took three to six months in the first units, without mentioning the time to perform the exams. Here in the university was faster.* (P6).

The delay in diagnosis is due to the lack of training of health professionals, even dermatologists in the basic health network, for the early diagnosis of the disease(15). It is important to emphasize the importance of early diagnosis through health education for the population and the continuing education of professionals at all levels of health care, which may have an impact on the reduction of waiting time and the path to diagnosis(1).

Leprosy can have a dramatic effect on the quality of life of the diagnosed patients, especially when the treatment is delayed and there is damage to the nerves. The sequel of neural damage are the main concerns of health care providers(17). As for the course between diagnosis and the beginning of treatment, it was possible to notice that most of the patients (45%) started treatment by orientation of the nurses and physicians of the unit in the same day they received the diagnosis, 40% started treatment up to one week after, 10% up to one month and only 5% started more than one month after diagnosis, that is, mishaps decreased between diagnosis and treatment:

> *I did everything in the private hospital, when I received the result the same day I took it to the doctor and he indicated me that unit, and that same day I already received the first dose of the medicine.* (P13).
>
> *About five days, a week ... All I know is that it does not take long.* (P7).
>
> *I think it was about a month. Because I was walking to do the treatment. I wanted to treat myself in Marituba because I had a specialized center. I went to this center many times, but I could not do the treatment there. That made me seek the treatment here.* (P1).

When the diagnosis is made, the patient will not be slow to start treatment. Most start the same day. Therefore, the challenge is not in the treatment, but in the search for an early diagnosis(7). The diagnosis of leprosy should be primarily clinical and epidemiological, performed through anamnesis directed to the signs and symptoms of the disease, general examination and dermatoneurological examination to detect lesions or areas of skin with altered sensitivity and/or impairment of peripheral nerves, sensory and/or motor and/or autonomic, as well as the existence of other cases, domiciliary or not, and epidemiological linkage(1):

> *I was diagnosed by the dermatologist, she looked at the stain and asked for a biopsy in November, it was already March and it was not ready yet. The doctor said that I had leprosy, regardless of the outcome of the biopsy and that I would start treatment. Imagine if I had expected this result? (P9).*

After the beginning of the treatment in the Unit, the patients classified the service provided as very good and good and also reported the differentiated service in the unit. On the other hand, there were reports of financial difficulties to buy the auxiliary medications, prescribed by the doctor:

> *The service is very good, the professionals gave me confidence and guide about the treatment very well.* (P2).
>
> *Here I was well attended until today unless there is someone in front of you and you have to wait your turn. Claudia and André always listened to me well. André, the day I arrived here, was immediately interested in my case.* (P16).
>
> *The dermatologist indicated to me this Unit, because here the treatment is much better when compared to the other Units.* (P13).

> *I have to buy another medicine, the Biogama, it costs R$ 84,00 and I need two boxes. I have to work hard and buy them.* (P16).

Understanding how the patients perceive the care received from the professionals of the Health Unit is of the utmost importance, since the higher the degree of satisfaction with the assistance received, the greater will be the degree of adherence to the treatment. Patients who had a good reception established a bond with the professional healed most of their doubts and adhered to the treatment(18).

Conclusion

The results of the study allowed to conclude that the therapeutic itinerary of leprosy patients is delongated, nebulous and conflicting in the search for a diagnosis. The trajectory begins in units close to their residences. Because they can not always elucidate diagnosis in such places, they seek other units and/or other specialists, even if far from their homes, in the desire to treat and recover their health. However, successions of diagnostic errors, tests, and procedures delay the end of their distress and contribute to the advancement of the evolutionary process of the disease in up to three years, contradicting MOH guidelines.

Some patients and their relatives face significant expenses to obtain the diagnosis and treatment of leprosy with payments of professionals and laboratory tests in the private network, motivated by the fact that the service in these places is fast.

Although this study does not reflect the reality of all patients in the search for diagnosis and treatment, because it is about to a single health unit, the knowledge that emerges may lead to reflections among professionals, managers and other scholars with an interest in this subject to learn about other realities of the Brazilian territory, enabling the development of strategies that respect and value the user as a citizen.

Collaborations

1. design, project, analysis and interpretation of data: Daiane Freitas Carneiro, Mila Michele Batista da Silva, Mariana Pinheiro, Iací Proença Palmeira, Everson Vando Melo Matos, and Angela Maria Rodrigues Ferreira;
2. article writing, critical essay review of intellectual content: Daiane Freitas Carneiro, Mila Michele Batista da Silva, Mariana Pinheiro, Iací Proença Palmeira, Everson Vando Melo Matos and Angela Maria Rodrigues Ferreira;
3. final approval of the version to be published: Daiane Freitas Carneiro, Mila Michele Batista da Silva, Mariana Pinheiro, Iací Proença Palmeira, Everson Vando Melo Matos and Angela Maria Rodrigues Ferreira.

References

1. Brasil. Ministério da Saúde. Secretaria de Vigilância em Saúde. Departamento de Vigilância das Doenças Transmissíveis. Diretrizes para vigilância, atenção e eliminação da hanseníase como problema de saúde pública: manual técnico-operacional. Brasília; 2016.
2. Witas HW, Donoghue HD, Kubiak D, Lewandowska M, Gładykowska-Rzeczycka JJ. Molecular studies on ancient M. tuberculosis and M. leprae: methods of pathogen and host DNA analysis. Eur J Clin Microbiol Infect Dis. 2015;34(9):1733-49.
3. Li J, Yang L, Wang Y, Liu H, Liu J, Cross H. How to improve early case detection in low endemic areas with pockets of leprosy: a study of newly detected leprosy patients in Guizhou Province, People's Republic of China. Lepr Rev. 2016;87(1):23-31.
4. Aquino CMF, Rocha EPAA, Guerra MCG, Lavor Coriolano MW, Vasconcelos EMR, Alencar EN. Peregrinação (Via Crucis) até o diagnóstico da hanseníase. Rev Enferm UERJ. 2015;23(2):185-90.
5. Gaschignard J, Grant AV, Thuc NV, Orlova M, Cobat A, Huong NT, et al. Pauci-and multibacillary leprosy: two distinct, genetically neglected diseases. PLoS Negl Trop Dis. 2016 May;10(5):e0004345.

6. Fundato CT, Petrilli AS, Dias CG, Gutiérrez MGR. Itinerário terapêutico de adolescentes e adultos jovens com osteossarcoma. Rev Bras Cancerol. 2012;58(2):197-208.
7. Martins PV, Bernstein Iriart JA. Itinerários terapêuticos de pacientes com diagnóstico de hanseníase em Salvador, Bahia. Physis. 2014;24(1):273-89.
8. Bardin L. Análise de conteúdo. Lisboa: Edições 70; 2011.
9. Lins AUFA. Representações sociais e hanseníase em São Domingos do Capim: um estudo de caso na Amazónia. Physis. 2010;20(1):171-94.
10. Bruschi KR, Labrêa MGA, Eidt LM. Avaliação do estado nutricional e do consumo alimentar de pacientes com hanseníase do ambulatório de dermatologia sanitária. Hansen Int [Internet]. 2011 [cited 2016 July 22];36(2):53-61. Available from: http://periodicos.ses.sp.bvs.br/scielo.php?script=sci_arttext&pid=S1982-51612011000200007&lng=es&nrm=iso&tlng=pt
11. Oliveira LR, Nascimento AR, Nascimento MMP, Pereira AP, Lemos ICS, Kerntopf MR. Limitação de atividades e participação social entre usuários de um grupo de autocuidado em hanseníase. Rev Interdisc. 2016;9(1):171-81.
12. Silva RCP, Lopes A, Guisard CLMP, Peixoto ES, Metello HN, Ito LS, et al. História de vida e trabalho de pessoas atingidas pela hanseníase em serviços de saúde do estado de São Paulo. Hansen Int. 2008;33(1):9-18.
13. Silveira MGB, Coelho AR, Rodrigues SM, Soares MM, Camillo GN. Portador de hanseníase: impacto psicológico do diagnóstico. Psicol Soc. 2014;26(2):517-27.
14. Palmeira IP, Queiroz ABA, Ferreira MA. Marcas em si: vivenciando a dor do (auto) preconceito. Rev Bras Enferm. 2013;66(6):89-900.
15. Baialardi KS. O estigma da hanseníase: relato de uma experiência em grupo com pessoas portadoras. Hansen Int. 2007;32(1):27-36.
16. Bahmanyar ER, Smith WC, Brennan P, Cummings R, Duthie M, Richardus JH, et al. Leprosy diagnostic test development as a prerequisite towards elimination: requirements from the user's perspective. PLoS Negl Trop Dis. 2016;10(2):e0004331.
17. Pradhan S, Kumar P. Cultural practice and beliefs hampering the treatment of leprosy – area of concern. Lepr Rev. 2016;87(1):124-8.
18. Silva RCPD, Lopes A, Guisard CLMP, Peixoto ES, Metello HN, Ito LS, et al. História de vida e trabalho de pessoas atingidas pela hanseníase em serviços de saúde do estado de São Paulo. Hansen Int [Internet]. 2008 [cited 2016 July 22];33(1):9-18. Available from: http://periodicos.ses.sp.bvs.br/scielo.php?script=sci_arttext&pid=S1982-51612008000100002&lng=pt&nrm=iso&tlng=pt

Received: August 19, 2016

Approved: May 19, 2017

Published: July 5, 2017