EXPERIENCE AND FEELINGS OF WOMEN WITH LEPROSY

ABSTRACT
Objective: to get to know the experience and feelings of women with leprosy. Method: qualitative, descriptive and exploratory study, with 15 women. The data were produced through a semi-structured interview, with open and closed questions, and a script with guiding questions. The data were analyzed by the Content Analysis technique. Results: five categories were defined after the analysis: << Living with leprosy >>, << Life changes as a result of leprosy >>, << Leprosy and social relations >> << Support and search for confrontation>>, << Feelings and future prospects >>. Conclusion: the results showed that leprosy leaves profound marks on women's lives such as fear, insecurity, social exclusion, and therefore, needing humanized care, by health professionals, and the support of people living with them, to cope with the disease.

Descriptors: Leprosy; Prejudice; Women’s Health.

RESUMO
Objetivo: conhecer a vivência e os sentimentos de mulheres com hanseníase. Método: estudo qualitativo, descritivo e exploratório, realizado com 15 mulheres. Os dados foram produzidos por meio de entrevista semiestruturada, com perguntas abertas e fechadas, e um roteiro com questões norteadoras. Os dados foram analisados pela técnica de Análise de Conteúdo. Resultados: cinco categorias foram definidas após o processo de análise: << Convivendo com a hanseníase >>, <<Mudanças de vida em decorrência da hanseníase>>, <<A hanseníase e as relações sociais >>, << Apoio e busca de enfrentamento >>, << Sentimentos e perspectivas futuras >>. Conclusão: os resultados mostraram que a hanseníase deixa marcas profundas na vida das mulheres como medo, insegurança, exclusão social, necessitando, portanto, da assistência humanizada, por parte dos profissionais de saúde, e do apoio das pessoas do seu convívio, para o enfrentamento da doença.

Descritores: Hanseníase; Preconceito; Saúde de la Mujer.

ORIGINAL ARTICLE

EXPERIENCE AND FEELINGS OF WOMEN WITH LEPROSY

VIVENCIA E SENTIMENTOS DE MULHERES PORTADORAS DE HANSENÍASE

VIVENCIA Y SENTIMIENTOS DE MUJERES PORTADORAS DE LEpra

ABSTRACT
Objective: to get to know the experience and feelings of women with leprosy. Method: qualitative, descriptive and exploratory study, with 15 women. The data were produced through a semi-structured interview, with open and closed questions, and a script with guiding questions. The data were analyzed by the Content Analysis technique. Results: five categories were defined after the analysis: << Living with leprosy >>, << Life changes as a result of leprosy >>, << Leprosy and social relations >> << Support and search for confrontation>>, << Feelings and future prospects >>. Conclusion: the results showed that leprosy leaves profound marks on women's lives such as fear, insecurity, social exclusion, and therefore, needing humanized care, by health professionals, and the support of people living with them, to cope with the disease.

Descriptors: Leprosy; Prejudice; Women’s Health.

RESUMO
Objetivo: conocer la vivencia y los sentimientos de mujeres con lepra. Método: estudio cualitativo, descritivo e exploratorio, realizado con 15 mujeres. Los datos fueron producidos por medio de entrevista semiestruturada, con preguntas abiertas e fechadas, y un roteiro con cuestiones norteadoras. Los datos fueron analizados por la técnica de Análisis de Contenido. Resultados: cinco categorías fueron definidas después del proceso de análisis: << Conviviendo con la lepra >>, << Cambios de vida en consecuencia de la lepra>>, << La lepra y las relaciones sociales >>, << Apoyo y búsqueda de enfrentamiento >>, << Sentimientos y perspectivas futuras >>. Conclusión: los resultados mostraron que la lepra deja marcas profundas en la vida de las mujeres como miedo, inseguridad, exclusión social, necesitando, por lo tanto, de la asistencia humanizada, por parte de los profesionales de la salud, y del apoyo de las personas de su convivio, para el enfrentamiento de la enfermedad. Descritores: Lepra; Prejuicio; Salud de la Mujer.
Leprosy is an infectious disease, of insidious evolution, whose clinical manifestations have predominance in the skin and peripheral nerves caused by Mycobacterium leprae, or Hansen’s bacillus, which is an intracellular parasite. The main source of infection is the human, which is recognized as the sole source of infection (reservoir) and the route of elimination of the bacillus by the leprosy patient. The incubation period is long. It is estimated to be between two and seven years, with an average between three and five years.

It is a disease that represents a great challenge to public health due to the innumerable changes it causes in the life of the patients, among them, the high incapacitating power, that reaches the age group economically active of the population, generating damages of greater proportion to the individual, its family and economic aspects of the country.

It is considered an endemic disease throughout the national territory and the regions that present the highest incidence and prevalence rates are North, Northeast and Midwest. In Maranhão, 3,872 new cases were diagnosed in 2009. Of these, 1,629 cases were in women, equivalent to 42%, and 241 women had a degree of disability equivalent to 7.7%. In São Luís, in that year, 606 new cases were diagnosed, of which 278 were females, equivalent to 45%.

With regard to the health-disease process, men and women experience, in different ways, all the changes that come from this process. There is also the way in which the impact caused by leprosy is present in both genders. The woman’s body undergoes significant changes that impair the quality of life, leading to a decrease in her productive condition, as well as limitations in social life and psychological problems.

In societies, the body has been highly valued, especially, for aspects that call attention, such as aesthetics, sexuality and gender social relations, which are closely linked. The problems arising from leprosy are not only limited to dermatological and neurological issues, but the diagnosis of the disease generates psychological instability not only due to the aforementioned complications, but also due to the possibility of alterations in body image, with a direct impact on people’s self-esteem affected. Fear of not being accepted by others is one of the most striking and feared traits of those facing the disease.

Therefore, approaching the woman with leprosy requires a prior understanding of the history of the disease, as well as an understanding of the psychosocial aspects involved. Leprosy has its past marked by dehumanization and stigmatization that, even though it has been worked over the years, remains today.

In the treatment process, the patient’s feelings and experiences must be respected and valued, seeking an understanding of the biopsychosocial aspects of the patients. The moment of diagnosis is very delicate, both for the health professional, and for the patient. The first must convey his knowledge about the disease and welcome the anguish, fears and insecurities and go beyond simply listening to what the patient has to say. Already the person affected by leprosy has to deal with the new situation, which implies ignorance of the disease and uncertainties regarding the future.

Despite the significant advances, the stigma of the disease is still observed, due to the presence of physical, emotional and social deficiencies, leading to discrimination and social exclusion. Therefore, it is necessary an organized effort, of the whole basic health network, in the prevention and treatment, contributing to the improvement of the assistance provided to the patient and his/her relatives, seeking to interrupt the epidemiological chain.

Understanding the daily life of women with leprosy is fundamental for the adoption of improvement strategies for the quality of care. In this context, the study aimed to know the experience and the feelings of women with leprosy.

Article elaborated from the dissertation “The experience and feelings of women with leprosy” presented to the Post-Graduate Program in Nursing, Federal University of Maranhão/UFMA. São Luís (MA), Brazil. 2014.

A qualitative, descriptive and exploratory study of 15 women with leprosy, assisted at a Health Center, in the district of Fátima, São Luís (MA), Brazil. The qualitative research responds to very particular questions, since it works the universe of meanings, motives, aspirations, beliefs, values and attitudes, which corresponds to a deeper space of relationships, processes and phenomena that cannot be reduced to operation of variables.
The subjects were women older than 18 years, with a confirmed diagnosis of leprosy and a drug treatment for the disease. The collected data was performed from June to August 2014.

For data collection, a form with open questions related to age, diagnosis time, clinical form, treatment, schooling and a semi-structured script with guiding questions about feelings and experiences was used. The interviews were recorded in a private setting, according to the availability of the women.

The data was submitted to content analysis, through systematic procedures that seek to determine the comprehension of the speech. There are four modalities of content analysis: expression analysis, relationship analysis, thematic analysis and enunciation analysis. When searching for the exposed meanings of the qualitative material, the thematic analysis was the option of this study, because it was classified by means of a word, a phrase. Make a thematic analysis “discover the nuclei of meaning” that make up the communication and whose presence or frequency of appearance can mean something for the chosen analytical objective.13

Operationally, the thematic analysis unfolded in three stages: the first phase consisted of choosing the documents to be analyzed. The second phase was based, essentially, on the operation of coding the collected material, by means of floating and exhaustive reading of the material. The third and last phase, sought the treatment of the results obtained and their interpretation.

In compliance with Resolution CNS/MS, No. 466/12, the study was evaluated by the Research Ethics Committee of the Municipal Health Secretariat of São Luís - MA, and approved with Opinion No. 2013.01.14.05-58.

RESULTS AND DISCUSSION

The women were between 18 and 71 years old, and the predominant operational classification was multibacillary, with most of the clinical form being dimorphic. The average time of treatment was from seven to 12 months and the level of schooling was high school. Their original names were preserved, in order to keep the privacy of their accounts maintained. In this way, the women were identified with a fictitious name, each one being called, with names of flowers.

After analyzing the data, the following categories were highlighted: <<Living with leprosy>>; <<Future feelings and perspectives >>; <Living with leprosy>. When questioned about what it is like to live with leprosy, women have revealed feelings from the moment of diagnosis and daily life in coping with the disease.

It’s complicated, because, although I know it’s a curable disease, it’s a disease that you know everyone repudiates [...] people will not accept. (Amaryllis)

It was very difficult, I was very shocked, it seemed like, I had lost the ground under my feet, I did not know what I was going to face. (Lotus)

It was very difficult, because I had no information, the information I had was that horrible thing, I dropped my fingers, everything [...] but thank God, I found out soon, I had a very good doctor [...] there I did my right treatment (Acacia);

...very difficult, because, even where I worked, I felt so I was kind a rejection. I cried a lot, because I have a grandson, I have a son. (Almond flower)

The stigma of the disease, characterized over the years, still represents a barrier to the social coexistence of these women, who seek isolation as fear of being excluded from their family and social environment. Palmeira et al.9 report that the prejudice / stigma as one of the most present reactions in the daily life of the patient and is related to the lack of information about the disease, because the patient, due to lack of knowledge about the disease, creates some resistance, generating prejudice from himself. Interpersonal relationship is another difficulty mentioned by the patients, although it is extremely important for coping with the disease, but, in many cases, it is undone by the patient himself due to the prejudice he creates in relation to his image.15

When considering that the knowledge of the disease is of fundamental importance for the bearer, it is emphasized that the actions of health education, should be a link between the people involved in the disease, facilitating the orientation process among health professionals and health professionals. leprosy.16

Change of life as a result of leprosy

As for the changes in life, women stressed that low self-esteem was a feeling that brought with it the perception of inferiority and rejection by society and, with that, the changes in daily life are remarkable. Some women reported that, after the diagnosis of leprosy, their life suffered many changes. Because it is a disabling disease, some people
with leprosy have manifested that the disease causes them pain in the body, preventing them from performing daily tasks and imposing limitations, leading to changes in their lives:

[...] before I got sick, I could go out in the sun, I wanted to leave the house and now [...] (Lotus)

[...] before the illness, I felt much better so, self-esteem was better, I liked to dress better. (Hydrangea)

Today I feel tired, weak, without having strength [...] I no longer have that spirit that I had, I worry about taking something and breaking [...] what differentiates [...] is the inability to locomove, hold (Orchid); I do not have that intimacy with friends any more than before, because I have no idea who I got and I do not want them to know. (Iris)

The personal and social stigma, caused by the illness, causes many sufferers not to reveal to the family, believing that they would be discriminated against. Support, especially from family, is important and essential for coping with the disease and encouraging its condition. 17

Failure to accept changes in body image, which occur suddenly, in women with leprosy, causes estrangement of themselves in women. These women do not have the pleasure of before with their own body, repudiating the same and limiting them of the social life that they had before. 18

Leprosy causes great damage to people's daily lives and interpersonal relationships, causing suffering that surpasses physical damage, causing great social and psychological impact. This quality impairment is, mainly, associated with more severe forms of the disease, such as multibacillary, leprosy reaction and physical disabilities. 19

✧ Leprosy and social relations

Regarding the experience in their social relations, most of the women pointed out that affective relations, work relations and leisure commitment were hampered by the prejudice of society in the face of leprosy:

I felt that many were looking at me, but they did not want to have the contact that was before [...] I got closer they were moving away. (Magnolia)

[...] I basically insulated myself in the house, even people have a prejudice against us. (Fennel)

The father of my children [...] left me at the time because I was in this situation [...] I think it was the worst time for me, because when I needed him most, he abandoned me. (Lotus)

The woman with leprosy herself shows a sense of prejudice, a lack of acceptance of the disease, and deprivation of living with other people. It occurs that the woman, in this condition, has her own prejudices regarding the disease, making rejection also happen on her part, isolating herself from her social group and, thus, assuming a posture of flagellate. 20

Due to the changes of organic and psychological order, the fullness of sexual activity, for both genders, can be affected. Relationships with relatives and healthy people can also be compromised as a result of leprosy. 20

Leprosy generates damage to the daily life of the people, interpersonal relationships are affected and all these changes cause suffering that surpasses pain and malaise related to physical damage, which generates a great social and psychological impact. 19, 21

Prejudice is a reality in the lives of the people, not only by the population, but also by the bearer himself, because he conceals his condition with fear of people's reaction, and, so, they often seek isolation, concluding that social prejudice shows itself more resistant than the disease. 21

The concealment of the disease occurs, mainly, because of the fear of the patients of experiencing situations of exclusion. This attitude may motivate social isolation as a defense and protection against suffering. 23

✧ Support as a search for coping

When questioned about what they considered to be fundamental for coping with the disease and the need for strengthening to face daily life, it was observed that women, in general, emphasized the importance of family support, faith in God in the cure of leprosy and the orientations of health professionals:

[...] the best support, for myself, was my family (Azaleia); I seek God's support, the only one I can seek is God's. (Lotus)

[...] I first sought God's support, I am evangelical, I very much believe that God can heal. (Camelia)

I went to a psychologist, right here at the post and it helped me a lot [...] later it was the doctor. (Acacia)

The doctor explained everything to me, the girls there in the hospital that I already knew all told me [...] it will happen, this [...] (Perfect love)

English/Portuguese
J Nurs UFPE on line., Recife, 11(Suppl. 9):3551-7, Sept., 2017 3554
The family is active in the fight against leprosy, having, in health education, the necessary tool to increase the participation of family members in this process. The family develops attitudes of help and encourages the patient to contribute to their improvement and, thus, participating in their healing.24 As leprosy is still mixed with prejudices and fears about the old “leprosy” stigmatized since biblical times, there is reflection on the ways in which patients seek forms of understanding and help by religion.25

Leprosy does not go unnoticed in people’s lives, it leaves its mark (physical or emotional), either for a limited time, during treatment, or for a longer period, as in the case of physical sequelae. So, the support of health professionals, providing an integral attention, creating spaces of listening, where the bearers where they can express their beliefs, doubts and to talk about the disease and about their life, is fundamental.23

Feeling about future prospects

When questioned about how they projected their future perspectives, some women expressed feelings of discouragement and others mentioned overcoming, believing in healing, as noted in their lines:

[... ] It is painful, we have to accept even, if we don’t accept it, it is worse. (Amaryllis)

Sometimes, I keep thinking like this [...] I’m going to get well [...] and if I do not stay, there are days when I look in the mirror and I do not recognize myself anymore. (Hortência)

[...] the feeling is a bit sad, it affects you too much (Almond flower); in the beginning, I had days that I was very sad, I cried too much [...] but, thank God, I was facing everything, I was not born with Hansen [...] I know you have treatment. (Lotus)

[...] I faced a lot of fighting, it was very difficult for me to face [...] I know you have a treatment, I believe. (Orchid)

The challenge is very great, both for the leprosy patient, and for the health professionals who provide care. This support extends to other people in the community, which makes this support, a task for the group of people who participate in the life of this individual.10

Studies point to the importance of achieving broad recognition of the health needs of people with leprosy, considering the biopsychic and socio-cultural aspects, highlighted above, which involve their daily lives, thus allowing the identification of vulnerabilities and risks, in order to better subsidize the care of this clientele.26-7

Leprosy has been posed as an incurable and disabling disease in many societies and cultures. Claiming that having treatment and cure is, sometimes, not enough. In this way, the social conception of the pathology can be modified, when there are no physical disabilities and the information is more socialized, for carriers, relatives and society. Therefore, it is necessary an educational work, by the health team, in a shared way, to strengthen the coping of the disease.27

CONCLUSION

This study allowed to know the experience and feelings of women with leprosy. The results showed great impact lived by these women, facing the diagnosis and coping of the disease, and their life routine changed. The reported feelings reveal sadness, fear, pain, prejudice, overcoming, and faith. Therefore, the woman with leprosy needs to be received in a humanized way, to feel strengthened and supported in her coping with the disease. It is necessary to emphasize that educational health actions represent a tool in the involvement of the families of these women, whose support has proved essential and also for the breakdown of stigmas that have been created so long ago and that still persist today, harming the early diagnosis, the continuity of treatment and the quality of life of these patients.

REFERENCES


5. Maranhão (Estado), Secretaria de Estado da Saúde, Setor de Epidemiologia. Programa de
Dias ACNS, Almeida RAAS, Coutinho NPS et al.


10.1590/S0365-731820080001900. Doi:


