



Journal of Nursing

Revista de Enfermagem

UFPE On Line

ISSN: 1981-8963

ORIGINAL ARTICLE

SELF-CARE ACTIONS OF PEOPLE WITH LEPROSY AÇÕES DE AUTOCUIDADO DE PESSOAS COM HANSENÍASE ACCIONES DE AUTOCUIDADO DE PERSONAS CON LEPRÁ

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ABSTRACT

Objective: to identify self-care actions taken by people with leprosy. **Method:** descriptive and exploratory study, with a qualitative nature, conducted at the University Hospital Onofre Lopes, in Natal, Rio Grande do Norte, Brazil. The sample consisted of 14 individuals affected by leprosy. Data were obtained by means of an identification questionnaire and a semi-structured interview; they were interpreted in the light of the content analysis technique. This study was approved by the Research Ethics Committee of the Federal University of Rio Grande do Norte (UFRN), under the CAAE 17468213.0.0000.5537. **Results:** the interviews generated 3 thematic axes: 1) The complications/sequelae of leprosy known by people with this disease; 2) The self-care actions taken by people with leprosy; and 3) The possible contributions of a self-care group for people with leprosy. **Conclusion:** the self-care actions were minimally reported by people with leprosy, focusing on eye lubrication, sunscreen use, skin hydration, and wearing shoes. **Descriptors:** Leprosy; Self-Care; Nursing.

RESUMO

Objetivo: identificar as ações de autocuidado de pessoas com hanseníase. **Método:** estudo descritivo e exploratório, de caráter qualitativo, realizado no Hospital Universitário Onofre Lopes, em Natal (RN). A amostra foi composta por 14 indivíduos acometidos pela hanseníase. Os dados foram obtidos por meio de questionário de identificação e de entrevista semiestruturada; eles foram interpretados à luz da técnica de análise de conteúdo. Este estudo foi aprovado pelo Comitê de Ética em Pesquisa da Universidade Federal do Rio Grande do Norte (UFRN), sob o CAAE n. 17468213.0.0000.5537. **Resultados:** as entrevistas originaram 3 eixos temáticos: 1) As complicações/sequelas da hanseníase conhecidas pelos portadores da doença; 2) As ações de autocuidado adotadas pelos portadores de hanseníase; e 3) As possíveis contribuições de um grupo de autocuidado para os portadores de hanseníase. **Conclusão:** as ações de autocuidado foram minimamente relatadas pelos portadores de hanseníase, concentrando-se na lubrificação dos olhos, no uso de protetor solar, na hidratação da pele e no uso de calçados. **Descritores:** Hanseníase; Autocuidado; Enfermagem.

RESUMEN

Objetivo: identificar las acciones de autocuidado de personas con lepra. **Método:** estudio descriptivo y exploratorio, con carácter cualitativo, realizado en el Hospital Universitario Onofre Lopes, en Natal, Rio Grande do Norte, Brasil. La muestra consistió en 14 individuos afectados por la lepra. Los datos fueron obtenidos a través de un cuestionario de identificación y de una entrevista semi-estructurada; ellos fueron interpretados a la luz de la técnica de análisis de contenido. Este estudio fue aprobado por el Comité de Ética en Investigación de la Universidad Federal de Rio Grande do Norte (UFRN), bajo el CAAE 17468213.0.0000.5537. **Resultados:** las entrevistas generaron 3 ejes temáticos: 1) Las complicaciones/secuelas de la lepra conocidas por las personas con esta enfermedad; 2) Las acciones de autocuidado adoptadas por las personas con lepra; y 3) Las posibles contribuciones de un grupo de autocuidado para las personas con lepra. **Conclusión:** las acciones de autocuidado fueron minimamente reportadas por las personas con lepra, centrándose en la lubricación de los ojos, el uso de protector solar, la hidratación de la piel, y el uso de calzados. **Descriptores:** Lepra; Autocuidado; Enfermería.

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INTRODUCTION

Leprosy is a chronic infectious disease with ancient references that still today remains among the major public health problems in the world, due to its high magnitude and high disabling power.¹ The number of cases is alarming in Brazil, mainly because of the incidence among individuals under 15 years, something which indicates high local endemicity. The country ranks second in the overall ranking of cases discovered annually in the world, second only to India.^{2,3} In 2012, almost 29 thousand Brazilians underwent treatment for this problem, including 1,936 individuals under 15 years.³

The number of new cases of this disease has declined in recent years around the world mainly through multidrug therapy, but the reduction in Brazilian statistics is discreet and there is an urgent need for intersectoral actions by the three levels of government focused on prevention and treatment of this disease, as well as on monitoring and rehabilitation of sequelae.^{2,3} The disease still reaches significant proportions within our territory, it has a heterogeneous behavior and reproduces socioeconomic inequalities observed between the various regions of the country. It concentrates at higher levels in the North, Central-West, and Northeast regions, which get together 53.5% of cases detected among only 17.5% of the Brazilian population.³

The disease has high morbidity associated with reactional states and neural damage, which can cause physical disabilities and permanent deformities, significantly affecting patients' quality of life, although it is easy to treat and cure. Its high disabling potential derives from the predilection of *Mycobacterium leprae*, an intracellular bacillus, to affect skin and peripheral nerve cells, combined to its immunogenic power. Thus, it brings on dermatologic and neurological damage, which can lead to osteoarticular deformities and sequelae with a disfiguring, mutilating, and disabling nature, which in most cases trigger multidimensional disorders, including those that arise from stigma, family abandonment, and social exclusion.³

Estimates indicate that there are around 2 to 3 million people worldwide with some degree of physical impairment due to leprosy, despite there is a lack of publications on disability. In Brazil, it is believed that about 23% of individuals with this condition have some kind of physical limitation after hospital discharge.^{4,5} The overall goal of the National Leprosy Control Programme (PNCH) is early

diagnosis aiming at the prevention of disabilities; its manuals provide guidelines for patient care, such as: regular neurological assessment; disability grade classification; application of basic techniques for prevention, control, and treatment.

The assistance of health services is aimed at individuals undergoing multiple chemotherapy treatment, however, the response to compromised subjects after pharmacological discharge is inadequate. An interconnected approach is needed, including physical and psychological care, as well as participation in self-care groups.⁶ The latter constitute spaces where health education activities emerge as a pillar of all measures to control and minimize the damage of leprosy. Through education, the nurse informs the person with leprosy on the way how to recognize and prevent changes on her/his face, hands, and feet, as well as to treat skin lesions. Thus, the patient becomes co-responsible for her/his treatment, she/he deliberately initiates and executes self-care activities in order to maintain life, health, and well-being, i.e. she/he promotes her/his own health.⁷

Given the above, the guiding question of this study is: "Which are the self-care actions taken by leprosy patients?". In order to answer to it, we adopted the following objective:

- To identify self-care actions taken by leprosy patients.

METHODOLOGY

Article developed from the dissertation << **Leprosy: the implication of health education for self-care** >>, submitted to the Center for Health Sciences of the Federal University of Rio Grande do Norte. Natal, Rio Grande do Norte, Brazil. 2014.

This is a field study, descriptive and exploratory, with a qualitative nature, conducted at the dermatology outpatient sector of the University Hospital Onofre Lopes (HUOL), an additional unit of the Federal University of Rio Grande do Norte (UFRN), located in Natal, Rio Grande do Norte, Brazil. This hospital provides specialized care in dermatology, thus assisting people with leprosy referred from all towns within the state.

The target population of this study consisted of 18 people with leprosy undergoing treatment at the dermatology outpatient sector of this hospital. The sample had only 14 individuals because 1 subject refused to participate in the study and 3 patients were not present within the collection period. The eligibility criterion

considered: a) being a current or former leprosy patient; b) undergoing treatment for leprosy or neuritis due to this disease; c) being interested in participating in the study; d) signing the free and informed consent term. We excluded from the sample: a) patients with associated cognitive disorders; and b) patients with unconfirmed diagnosis of leprosy.

Data collection took place within the period from September 23 to November 4, 2013. Users were approached at the time patients arrived at the dermatology outpatient sector to receive a supervised dose of multiple chemotherapy (MCT), with the aid of the nursing team, at the room provided by PNCH.

After the first contact and the required information, users and researchers went to a room, available and previously reserved to conduct the interview. At this location, the subjects were informed about the research objectives, the interview steps, and the recording procedure. The interviews were initiated after reading and signing of the free and informed consent term and the authorization term for voice recording.

This step consisted of two moments: first, the identification questionnaire was filled up, through which data were firstly collected according to respondent's information and, subsequently, they were supplemented with information on characteristics of the disease from medical records; second, we conducted the semi-structured interview, consisting of 6 questions, which were recorded by using an electronic device.

The questions were grouped into 2 thematic axes: the first addressed user's knowledge on their disease, such as: *What do you know about your illness? How is your treatment? This disease can cause some problem/complication? What do you do to avoid these problems/complications?* The second sought to know user's opinion about nursing care through the questions: *What advice do you receive or did receive during the nursing consultation? What do you think of your assistance in the health service? Would you like to talk about their illness, treatment, and the way how to prevent sequelae with other people who have this disease in a group?*

Each day of data collection, the recordings were transcribed, typed, and reserved for later analysis and notes in the field diary, along with the organization of questionnaires into a folder, according to the order in which the interviews were conducted and recorded. Subsequently, data were analyzed using Bardin's content analysis technique.⁸

This study complied with the ethical and legal principles that rule scientific research involving human beings, as recommended by the Resolution 466/12, from the National Health Council (CNS), and it was approved by the Research Ethics Committee of UFRN, under the Opinion 387.769 and the CAAE 17468213.0.0000.5537.

Respondents' anonymity was guaranteed by exchanging their names by other usual names among the Brazilian society, randomly chosen, so that they are not identified with any particular group or character.

RESULTS

We interviewed 14 patients, out of which 9 were women and 5 men. They were grouped according to age into intervals of 15 years, the age group between 31 and 45 years was the most prevalent, gathering 8 patients. The average age was 43 years. There was a predominance of low education level, with a concentration of 5 individuals with complete Primary School. Regarding family income, most of the 8 patients with leprosy declared they survive with a maximum income of 1 minimum wage. Regarding the operational classification, 7 subjects were classified as paucibacillary and the other 7 as multibacillary. Physical disabilities were absent in 8 patients and the others showed disability grade I.

The interviews underwent Bardin's content analysis⁹, with pre-analysis, material exploration, and categorization. Three meaning units or thematic themes emerged: Thematic theme 1: Leprosy complications/sequelae known by people with the disease; Thematic theme 2: Self-care actions taken by people with leprosy; Thematic theme 3: Possible contributions of a self-care group for people with leprosy.

♦ Thematic theme 1: Leprosy complications/sequelae known by people with the disease

Subjects' responses on problems and complications of leprosy were superficial, they seemed to lack confidence when reporting the possible complications of the disease through short answers and, generally, focused on a particular aspect of illness.

The reports, transcribed below, show subjects' knowledge on some complications, such as: loss of movements, decreased sensitivity, possible loss of limbs, skin lesions, and ocular complications. None of the respondents reported complications with the nose or leprosy reactions.

This disease can cause problems and complications. In case of late treatment, it can bring complications like loss of limb movement. (José)

You may also have, lose sensitivity. You can hurt yourself... You can hurt yourself and feel no pain. (Júlia)

It can lead us to lose a foot, a finger, a hand, a leg. (Osvaldo)

When I realized the disease, I was already in the middle, with a small spot. (João)

My eyesight got worse because I am blind girl. I have cataract and she [the physician] said that corticosteroids affect it [...].(Maria)

◆ **Thematic theme 2: Self-care actions taken by people with leprosy**

Respondents, by talking of actions they took to prevent complications of leprosy, pointed out care for the skin, eyes, hands, feet, with the use of medicines and food, as exemplified below:

Avoid the sun when it is most intense... use sunscreen... moisturize the skin. (Osvaldo)

The eye drops, because it dries the eyes a lot. (José)

You have to always be doing physical therapy, she said to pick up a ball and keep squeezing it in my hand, because sometimes my hand falls asleep. (Júlia)

Do not walk barefoot. (Carla)

I just comply with the medication. (Francisca)

Feeding must be on time. (Mateus)

[...] do not drink alcoholic beverages. (Marcos)

◆ **Thematic theme 3: Possible contributions of a self-care group for people with leprosy**

The self-care group is characterized as a proposal by the Ministry of Health to control leprosy, from a perspective of health education, but also of emotional support to fight stigma and prejudice.¹⁰ In this context, we asked: *Would you like to talk about your illness, treatment, and the way how to prevent sequelae with other people with the disease in a group?*

The subjects recognized the importance of self-care group as a significant information vehicle, a channel for listening and health education, able to promote adherence to treatment and fight prejudice the prejudice tied to this disease.

We want to know more, you know. Because when we know, we will be more careful. We will be more careful. I went through many exams with physicians because I did not know. (Mateus)

I think the government has to adopt a more insightful policy. [...] As I have certain

research resources, I rushed into treatment and it was practically a mild form. (Marcos)

Because [she/he] provides more advice, explains more things. We have more information. [...] A conversation in which the person explains that this is not a big deal, as many people tell. We know that prejudice exists, but we have to try breaking down these barriers. (Maria)

The more people have information, the better. It facilitates treatment adherence. You know, the more information, the better. (José)

Redefinition and resilience were found in two speeches, in which subjects expressed the wish and hope for their cure, but they also showed to be interested in helping the other to experience her/his disease process.

Because what I went through, I wanted to report it to other people, tell what was good... (Joana)

I am interested because I want to win and I feel good by seeing the patient as my niece and another patient there who had won. (João)

DISCUSSION

Leprosy is among a group of 17 diseases named by the World Health Organization (WHO) neglected tropical diseases (NTDs), which are diverse from the medical point of view, but they constitute a group for meeting the following characteristics: they are related to poverty and social disadvantage situations; they affect populations with low visibility and weak political voice; they stigmatize and discriminate; they are comparatively neglected in research and development; they are not widely spread over large territorial extensions on a quick basis; they can be controlled, prevented, and possibly eliminated by employing effective and feasible solutions; and they tend to coexist in tropical environments.⁹⁻¹¹

Corroborating this aspect from other studies that addressed the characterization of leprosy patients, we may reinforce that the subjects of this study, in general, are included into this social disadvantage group, because they have a low education level and their income is 1 minimum wage.¹¹⁻¹³

Leprosy remains as one of the major public health problems in Brazil, although it is a highly treatable disease, due to its high prevalence, chronic and silent evolution, high capacity to cause disabling or disfiguring lesions, and ease of proliferation of infectious foci. It causes lesions to the skin and peripheral nerves and can cause complications or sequelae, significantly compromising the

quality of life of affected individuals, when they are not treated or diagnosed early.¹²⁻¹⁴

The main mechanisms causing leprosy deformities and disabilities are neurogenic (loss of nerve function) and inflammatory (immune system response). Among the neurogenic causes, there are: primary (sensory, motor, and autonomic loss) and secondary (retractions, traumatic lesions, and post-traumatic infections). The most common complications occur on the face, eyes (partial or total lagophthalmos, trichiasis, corneal opacity, absence of corneal sensitivity, madarosis), nose, hands, and feet (rigid or movable claws, skin dryness, hypotrophy, ulcer, bone resorption). Regarding the inflammatory causes, there are leprosy reactions, complications arising from the reactions in the immune system over the course of disease and observed as episodes of acute and subacute inflammation have a strong relation to the installation of deformities.^{15,16}

The research subjects apparently showed superficiality when speaking of the complications of leprosy. They provided short and even erroneous answers, for instance, the report by Osvaldo, who mentions “loss of feet, hands, and leg”. From this perspective, we ask, *is still strong the social imagery regarding the disease, the image of a smelly leprosy patient, who will lose parts of her/his body?*

A study on the perception of users of a referral center regarding prejudice of leprosy resumes, nowadays, the prejudice experienced by patients when they realize that some friends and neighbors turned away when they heard of the disease; when in a job interview, when referring that they underwent treatment for leprosy, soon people’s behavior changed and they said the job vacancy had already been filled.¹⁷

Leprosy has a terrible image on people’s history and memory, as a contagious, mutilating, and incurable disease, and the fact that patients and their relatives should be isolated. The main cause of stigma and prejudice is related to lack of knowledge about the disease, its treatment, preventive actions regarding disability, and cure.¹⁷ Deconstruction of archaic beliefs about leprosy is needed, so that we have new ways of acting against leprosy.²¹

The disability grades, established by WHO, are numerically classified as 0, 1, and 2, based on the assessment of the eyes, hands, and feet affected by the disease. Grade 0 corresponds to absence of damage to the eyes, hands, and feet. Grade 1 indicates

decreased sensitivity, without visible damage or deformities on the assessed areas. Grade 2 represents the presence of deformities due to leprosy.^{13,15}

Actions for preventing disabilities or self-care actions in leprosy aim to prevent possible deformities and disabilities, seeking to interrupt the spread of functional and social losses, as well as the stigma tied to this disease. The explanations to patients about this disease vary, in general, about self-care towards the eyes, hands, and feet, such as hygiene, hydration, lubrication, stretching, exercises, guidance on the adaptation of instruments, objects, and footwear.^{15,18}

A study assessing the physical and functional status of the eyes, hands, and feet among leprosy patients through self-care guidelines written in the form of a manual, identified that information was very important in improving patients’ symptoms, especially regarding muscle function of hands and feet, and skin rashes. We also considered the differences in disease progression for each person and their relation to self-care activities taken.¹⁵

It is believed that self-care depends on the patient and her/his relationship with the health care team, which must support the development of individual’s autonomy. It is consensus in the literature that health care professionals take a great importance in the transfer of guidelines on self-care concerning patients’ motivation, appreciation of self-confidence and learning of each individual.^{13,15,18,19}

From this perspective, the creation of self-care groups or interaction strategies between people with the same illness experience is characterized as a means for health education, a place for sharing knowledge, where the guidelines may be more comprehensive and meaningful to the group, helping to dispel myths about this disease.^{6,20}

CONCLUSION

We identified short and, in some cases, wrong answers. Self-care actions were minimally reported, focusing on the lubrication of the eyes, use of sunscreen, skin hydration, and wearing shoes. We also observed in patients’ discourse the historical image of disease reflected on the idea of “body parts falling apart”, something which favors the inference that prejudice and stigma of this disease are still alive and affect ill individuals.

The limitations of this study are related to the dynamics of subjects’ embracement at the

outpatient sector, which takes place on a monthly basis and when various activities are taken, besides the supervised administration of medication. This dynamics, according to authors' perception, also characterizes a limiting factor for the creation of self-care groups and the improvement of self-care guidelines.

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Submission: 2014/02/11

Accepted: 2014/06/07

Publishing: 2014/08/01

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