

## KNOWLEDGE ON PREVENTION OF DISABILITIES IN A HANSENIASIS SELF-CARE GROUP

### CONHECIMENTO SOBRE PREVENÇÃO DE INCAPACIDADES EM UM GRUPO DE AUTOCUIDADO EM HANSENIASE

### CONOCIMIENTO SOBRE PREVENCIÓN DE DISCAPACIDAD EN UN GRUPO DE CUIDADO PERSONAL EN LEPROSIA

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#### ABSTRACT

The purpose of this study was to assess the knowledge acquired on prevention of disabilities in the control of Hanseniasis by the participants in a self-care group in a reference hospital. This was a qualitative study, performed in a reference hospital in infectious diseases in Natal-RN, gathering 16 members of a self-care group in Hanseniasis. The data were collected from September to November of 2012, through an open question and adopting the method of content analysis of Bardin to analyze and interpret the obtained answers. The following categories emerged from the findings: care in the prevention of ulcers and dressing; prevention of falls; and socio-economic rehabilitation. The results allowed the observation that the users' participation in group meetings contributed significantly to the acquisition of knowledge about self-care practices.

**Keywords:** Leprosy; Self Care; Nursing; Patient Education as Topic.

#### RESUMO

O objetivo deste artigo é avaliar o conhecimento adquirido sobre prevenção de incapacidades no controle da Hanseníase pelos participantes de um grupo de autocuidado em um hospital de referência. Trata-se de estudo de natureza qualitativa, realizado em um hospital de referência em doenças infecto-contagiosas de Natal-RN, reunindo 16 membros de um grupo de autocuidado em Hanseníase. Os dados foram coletados nos meses de setembro a novembro de 2012 por meio de uma questão aberta e adotou-se o método de análise de conteúdo de Bardin para analisar e interpretar as respostas obtidas. Dos achados emergiram as categorias: cuidados na prevenção de úlceras e no curativo; prevenção de quedas e reabilitação socioeconômica. Os resultados permitiram a constatação de que a participação dos usuários nas reuniões do grupo contribuiu significativamente para a aquisição do conhecimento sobre práticas de autocuidado.

**Palavras-chave:** Hanseníase; Autocuidado; Enfermagem; Educação de Pacientes como Assunto.

#### RESUMEN

El propósito de este artículo es evaluar el conocimiento adquirido sobre prevención de discapacidad en el control de la lepra por los participantes de un grupo de cuidado personal de un hospital de referencia. Se trata de un estudio cualitativo realizado en un hospital de referencia de enfermedades infecciosas de Natal / RN, con 16 miembros de un grupo de cuidado personal en lepra. Los datos se recogieron entre septiembre y noviembre de 2012, a través de un tema abierto; se adoptó el método de análisis de contenido de Bardin para analizar e interpretar las respuestas. Surgieron las siguientes categorías: Cuidados en la prevención de úlceras y en los curativos; prevención de caídas y rehabilitación socioeconómica. Los resultados permitieron constatar que la participación de los usuarios en las reuniones del grupo contribuyó significativamente a la adquisición de conocimientos sobre prácticas de cuidado personal.

**Palabras clave:** Lepra; Autocuidado; Enfermería; Educación del Paciente como Asunto.

## INTRODUCTION

Hanseniasis, the current term for what was previously known as leprosy, is one of the oldest and most referred diseases throughout history. Secularly considered contagious, disabling, and stigmatized by society, it was characterized by prejudice attitudes and rejection of the sick and their families.<sup>1,2</sup>

In the past, the coping strategies for the disease were based on compulsory isolation and social exclusion. Currently, new conducts related to the elimination of prejudice, social reintegration, and improvement in quality of life are required by the World Health Organization (WHO) taking into account humanitarian issues and the rights of persons affected by hanseniasis.<sup>3</sup>

Because it is caused by a bacillus that mainly affects peripheral nerves, skin, and mucous membranes, the neural tropism of *Mycobacterium leprae* is responsible for the crippling potential of the disease, which, if left untreated or belatedly treated, generates deformities and disabilities in patients.<sup>4</sup> The degree of disability can be determined from the neurological evaluation of eyes, hands, and feet, and has its result expressed in values ranging from 0 to II.<sup>4</sup>

Such neural damages are manifested through pain and or thickening of peripheral nerves, decreased and/or loss of sensibility, decreased and/or loss of strength in the muscles innervated by these nerves, which leads to the differential diagnosis from other dermatitis.<sup>5</sup>

Hanseniasis controlling activities aimed at the discovery of cases, multidrug treatment of patients to cure the individual and interrupt the chain of bacillus transmission, implementation of prevention activities, and treatment of physical disabilities with the physical and social rehabilitation of the patient.<sup>6,7</sup>

Hanseniasis is endemic in Brazil, with an average of 47,000 new cases per year, representing the second highest absolute number of cases in the world. Estimates suggest that approximately 2 to 3 million people worldwide have some degree of disability as the result of this disease.<sup>5</sup>

Despite efforts for the elimination of hanseniasis in Brazil, approximately 23.3% of new cases diagnosed annually have disability grades I and II<sup>4</sup> and such installed physical disabilities lead to decreased capacity for work, limited social life, and psychological problems.<sup>4</sup>

Activities of prevention and treatment of physical disabilities must be part of the treatment of hanseniasis and every healthcare professional must be attentive to diagnose and treat early any hint of neural injury to prevent future injuries as well as encourage patients to practice self-care.<sup>8</sup>

The conceptual model of self-care from Dorothea Orem fits the purposes of education in health based on the premise that patients can take care of themselves and the capacities

for such are the skills that are developed throughout the life of people, especially when there is a health problem.<sup>9</sup>

Orem's theory is based on the reasoning that people can take care of themselves, however, when they cannot, the nurse offers help. The practice of self-care in hanseniasis is a way to prevent disabilities and consists of simple care activities that the user performs in his domicile, being duly guided by the health team from health education.<sup>10</sup>

Thus, health education is a method of teaching and learning that aims at health promotion.<sup>11</sup> The Organization of groups of self-care in hanseniasis stands out as essential, understanding this action within the humanization of care and the integration of health networks and users with the goal of improving integral attention to the health of persons with hanseniasis.<sup>12</sup>

Self-care groups contribute to learning, provide subsidies for the patient's self-care building the competence and conscience to identify behaviors that need to be changed or corrected, always reinforcing the importance of exchanging experiences and knowledge among members.<sup>13</sup>

The importance of health education in prevention of disabilities related to self-care in hanseniasis is observed in this reality that permeates hanseniasis. In this perspective, the following is questioned: to what extent the participation in a self-care group in hanseniasis contributes to increasing knowledge about the prevention of disabilities?

Based on that question, the study has the following objective: to evaluate the acquired knowledge on prevention of disabilities in the control of hanseniasis by participants of a self-care group in a reference hospital.

## MATERIAL AND METHOD

This was a descriptive study with a qualitative approach, performed between September and November of 2012, in a hospital that is a reference center for infectious diseases in Rio Grande do Norte.

The Dermatology clinic of that hospital was selected for the study for being a reference to the State in the treatment of hanseniasis and for sustaining a self-care group in hanseniasis for five years with a multidisciplinary team to assist its patients.

The self-care group in this hospital meets since 2008 and is coordinated by one physiotherapist, one occupational therapist, and one social worker. It is reported that it is extremely gratifying to observe the formation of friendships, respect, and improvement in the quality of life of its members, which feature positive change both physically and emotionally.

The study population consisted of 20 users, hanseniasis patients or ex-patients, which integrated the self-care group during the year of 2012. The sample based on the inclusion and

exclusion criteria was composed of 16 users from both genders (three are in treatment and 13 are cured). The age range was between 28 and 81 years old.

The inclusion criteria were meeting attendance during the period of the study implementation and users' consent to participate in the study. The exclusion criteria were the no-show in the group meeting at the time of data collection and age under 18 years old.

The necessary interaction for the achievement of this study came about through two educational meetings and one workshop of social practice. These were developed from our inclusion in the self-care group and following its program at intervals of one month between each meeting. The first meeting was about the care of skin ulcers, coordinated by the researcher; the second meeting was about falls, conducted by the social worker; and the workshop was about socio-economic rehabilitation, presented by two economists invited by the group.

The data was obtained through an open question: "what have you learned today about self-care?" This form of data collection aimed to allow participants the freedom and spontaneity needed for the enrichment of the investigation. Data collection was carried out in the self-care group itself, after each meeting, in the presence of all users, and through the use of an audio recorder previously authorized by the participants. The information collected was subsequently transcribed without changes in the speeches' contents.

This work meets the precepts standards and guidelines established by the resolution 196/96 from the National Health Council (CNS/MS), which regulates research involving human beings in Brazil. The research project was submitted to the analysis of the Committee on Ethics in Research Involving Humans from the Federal University of Rio Grande do Norte and approved under the opinion n° 147/2008.

Study participants were informed about the objectives of the study; anonymity and the right to withdraw participation at any time were guaranteed. All participants agreed to sign an informed consent form before study start.

Testimonies were randomly numbered from 01 to 16 to identify subjects in the study and preserve anonymity.

The results were organized in empirical categories and analyzed based on the content analysis technique of Bardin, which is defined as a set of communication analysis techniques to obtain indicators that allow the inference of knowledge relating to conditions of production/reception of messages through systematic procedures and objective description of contents in messages, and based on reports from participants in the assumptions of health education and selected literature.<sup>14</sup>

The following categories were elected after the analysis of contents in the users' reports: care in the prevention of ulcers and dressing; prevention of falls; and socio-economic rehabilitation.

## RESULTS AND DISCUSSION

### CHARACTERIZATION OF STUDY SUBJECTS

Tables 1 and 2 show the data concerning sample characterization.

Table 1 - Sample characterization, Natal, 2012

Characterization	Total	
Gender	Male	9 (56,25%)
	Female	7 (43,75%)
Profession	Farmer	4 (25,0%)
	Retired	4 (25,0%)
	Merchant	3 (18,75%)
	Fisherman	1 (6,25%)
	GSA*	1 (6,25%)
	Home worker	1 (6,25%)
	Construction	1 (6,25%)
	Unknown	1 (6,25%)
	From	Countryside in RN
Natal/RN		7 (43,75%)

\* General Services Assistant.

Table 2 - Clinical characteristics of the sample, Natal, 2012

Clinical characteristics			Total
Operational classification	Paucibacillary	Undetermined	0 (0,0%)
		Tuberculoid	2 (12,5%)
	Multibacillary	Dimorphic	10 (62,5%)
Degree of incapacity	During the diagnosis	Vichowian	4 (25,0%)
		0	2 (12,5%)
		I	5 (31,25%)
Treatment situation	In treatment	II	9 (56,25%)
		Cured	3 (18,75%)
			13 (81,25%)

The analysis of the collected data reveals that there was a predominance of the number of male participants; however hanseniasis affects both men and women. It can be found, in any studied population, a greater or smaller number of men, at the time of the study, and that there are certain regions of the world where the prevalence of women is greater.<sup>15</sup>

A total of 90% of the sample have incomplete high school; schooling levels were compatible with the profession developed by participants. Health professionals must suit to the education level of patients when developing educational activities to increase information retention.<sup>16</sup>

The majority of individuals presented the multibacillary form of hanseniasis and disability grade II, making this data rel-

evant to the epidemiology of the disease because the dimorphic and Vichowian forms are responsible for maintaining the chain of transmission and may indicate late diagnosis.<sup>16</sup>

When the diagnosis and appropriate treatment are carried out immediately, the bacillus is not transmitted and physical disabilities can be prevented. In this perspective, the evaluation of the degree of physical incapacity becomes a relevant strategy adopted in the control of Hansen's disease as a tool to monitor the effectiveness of the program.<sup>16,17</sup>

Periodic neurological evaluation is relevant because of its crippling power in addition to the development of activities focused on self-care to improve the evolution of treatment as the patient becomes active in self-care.<sup>15</sup>

The self-care group in Hansen's disease in question has, among its assistance activities, educational strategies aimed at providing the necessary knowledge to the life of its members. Knowledge about the disease is essential for the prevention of complications and practice of self-care, as noted from the interviews and presented in categories as follows.

## CARE IN THE PREVENTION OF ULCERS AND DRESSING

The nerve lesion caused by the Hansen's bacillus determines sensory and motor changes that lead to the installation of varying degrees of disabilities. Skin ulcers are among serious and socially relevant disabilities.<sup>18</sup>

Disability prevention activities need to be performed, in particular those that are suitable and can be performed in the patients' homes. In relation to the prevention of ulcers, self-inspection, inspection of footwear, and use of special insoles and adapted shoes must be stimulated.<sup>5</sup>

The findings of this study showed that the group, after the educational activity, realizes the need for self-care to prevent the appearance of ulcers as verified in the following report: "we have to look at the body every day, wear the appropriate shoes, this avoids having the deformity" (p06).

Most ulcers in patients with Hansen's disease are located in the plantar region, mainly distributed in areas that support weight while they walk or stand.<sup>19</sup>

In Hansen's disease, when there is injury to the peripheral nerve trunk, there is sensory involvement, autonomous and motor in the territory of nerve involvement, resulting in loss of all forms of sensitivity.<sup>4</sup> The perception and understanding of this lack of sensitivity causes the Hansen's disease patient to practice self-care as a form of prevention as exposed below: "Hansen's disease leaves the feet and hands numbed, then we have to care to not create wounds. You can't walk with shoes for long periods, it hurts." (p01)

Despite the distribution of free special shoes in the group, there were still members who did not use them, opting for the

use of open sandals and tight shoes. It is observed in the literature that many Hansen's disease patients do not use any type of adapted footwear, suggesting negligence on disability prevention and self-care on the part of patients.<sup>19</sup> Therefore, the distribution of free special footwear does not guarantee its proper use by those who receive them.

Another knowledge cited by the participants about ulcers was the dressings' care, especially regarding hygiene: "Hygiene and cleaning care, we have to make the right dressings, use the right material. Moisturize your skin, do not let it dry. If it does, it will be harmed." (p08)

A study in the Amazon showed that the participants were using bandages out of a variety of materials and without any guidance. After the evaluation of wounds by nurses and health education guidelines, a reduction from 426 to 189 was observed in the total number of ulcers in six months.<sup>20</sup>

It is known that self-care also encompasses skin hydration and lubrication, care with nails and calluses, and the use of the correct material when replacing dressings.<sup>5</sup>

Through the reports exposed, members of the group acquired knowledge about the self-care of ulcers relating them to the prevention and dressings performed correctly.

## PREVENTION OF FALLS

The involvement of the peripheral nervous system before, during, and even after the end of treatment is responsible for most of the disabilities and deformities associated with Hansen's disease. It may involve ocular complications, paresis, paralysis, and muscular atrophy, which influences the risk of falls.<sup>3</sup>

The prevention of falls was focused on meetings as a health promoting activity with the adoption of measures and precautions to prevent risk factors that contribute to such an outcome. It was found that the main information stored by participants over falls consisted basically in prevention at home and on public roads, as the following statements:

*When I'm going to the bathroom, I should not go in the dark because I do not see very well because of my illness, I'm afraid of falling, I learned safety in the bathroom (p09).*

*Do not cross the street running because when I'm passing, I run a little in time to fall. And I have numbness in the foot and can fall (p05).*

A study on 12,617 medical assistances due to falls showed that the higher incidence of falls is in the residence, followed by on public roads.<sup>21</sup>

The speeches show the need that the participants have in practicing self-care in relation to falls because many have dis-

abilities resulting from the illness, such as eye complications and paresias in the lower limbs: "Beware of stairs, using handrails, climbing slowly, no hurry. Do not leave wet floors, carpets, these things slip." (p11)

The research stressed that a safe home environment that contributes to the prevention of falls and therefore, the occurrence of fractures should follow these guidelines: maintain floors free of slippery substances such as waxes; avoid dark environments; avoid uneven floors; prefer ramps instead of stairs; avoid carpets; arrange furniture to leave free passages.<sup>22</sup>

## SOCIO-ECONOMIC REHABILITATION

The stigma is the main cause of socio-economic prejudice that people affected by Hanseniasis experience; it reduces opportunities to find work because of physical disability. This means that overcoming disabilities is an essential step for the reintegration into society.<sup>23</sup>

In the meantime, we emphasize that the socio-economic rehabilitation, by means of different interventions, helps to restore the social condition based on increased motivation, information, and training.<sup>24</sup>

*What I learned here I will use, this is great advice. I sell popsicles and adjusted the profits. The profit was very little, this helped me (p16).*

*It's not because I have a sequel that I will remain still, I'll do my part too (p03).*

With socio-economic rehabilitation, people are helped to resume their places in the community. Opportunities are created to help them find jobs, contributing to the livelihood of their families and living off of their own resources with dignity and as financially independent community members:<sup>24</sup> "I liked the course, I'm loving it, I will use it in my life. I want to raise chickens. I'm already organizing here with another man in the course"(p12).

The cure of Hanseniasis is complete when people are able to enjoy health and socioeconomic conditions that enable them to live with dignity.

## FINAL CONSIDERATIONS

Health education actions aimed to improve the quality of life of people by stimulating reflection about attitudes that favor healthier living. In addition, they enable individuals to share experiences and knowledge, which tends to increase the skills needed to cope with their health conditions.

The results obtained in this research revealed the importance of this type of activity through the participation in group

meetings that contribute significantly to the acquisition of knowledge about self-care practices.

The importance of professional nurses is highlighted in the development of activities aimed at self-care for patients who have already completed or are still undergoing treatment, coupled with the continued assessment of new and old cases to avoid or reduce physical disabilities that arise from *Mycobacterium leprae* infection.

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