

Practices for self-care in Hansen's disease: face, hands and feet



Práticas de autocuidado em hanseníase: face, mãos e pés

Prácticas de autocuidado en hanseniasis: cara, manos y pies

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ABSTRACT

Objective: To analyze the self-care practices on the face, hands and feet carried out by people affected by Hansen's disease.

Methodology: A qualitative study, carried out in reference units for Hansen's disease in Pernambuco, between May 2014 and April 2015, with 24 people. Data was collected through the semi-structured interview and content analysis was carried out.

Results: Two categories emerged: Knowledge and execution of self-care practices in Leprosy and Singularities and challenges for self-care. The study found that respondents are familiar with information about face, hand and foot care, but report difficulties such as low income to acquire material for self-care, lack of time, and some lack of interest. Most of them already presented a degree of incapacity.

Conclusions: The training of professionals who work on the empowerment of people facing the disease, guidelines on prevention of disabilities and access to inputs for carrying out self-care are necessary.

Keywords: Leprosy. Self-care. Secondary prevention. Tertiary prevention.

RESUMO

Objetivo: Analisar as práticas de autocuidado em face, mãos e pés realizadas por pessoas atingidas pela hanseníase.

Metodologia: Estudo qualitativo, realizado em unidades de referência para hanseníase em Pernambuco, entre maio de 2014 e abril de 2015, com 24 pessoas. Os dados foram coletados por meio da entrevista semiestruturada e realizada a análise de conteúdo.

Resultados: Emergiram duas categorias: Conhecimento e realização de práticas de autocuidado em Hanseníase e Singularidades e desafios do autocuidado. O estudo apontou que os entrevistados conhecem as informações sobre os cuidados com a face, mãos e pés, mas relatam dificuldades como baixa renda para adquirir material para o autocuidado, falta de tempo, e alguns falta de interesse. A maior parte já apresentava grau de incapacidade.

Conclusões: É necessário a capacitação de profissionais que atuem no empoderamento das pessoas frente à doença e orientações sobre prevenção de incapacidades e acesso a insumos para realizar o autocuidado.

Palavras-chave: Hanseníase. Autocuidado. Prevenção secundária. Prevenção terciária. Enfermagem.

RESUMEN

Objetivo: Analizar las prácticas de autocuidado en cara, manos y pies realizadas por personas afectadas por la hanseniasis.

Metodología: Estudio cualitativo, realizado en unidades de referencia para hanseniasis en Pernambuco, entre mayo de 2014 y abril de 2015, con 24 personas. Los datos fueron recolectados por medio de la entrevista semiestruturada y realizada el análisis de contenido.

Resultados: emergieron dos categorías: Conocimiento y realización de prácticas de autocuidado en Hanseniasis y Singularidades y desafíos del autocuidado. El estudio apuntó que los entrevistados conocen las informaciones sobre los cuidados con la cara, manos y pies, pero relatan dificultades como bajas rentas para adquirir material para el autocuidado, falta de tiempo, y algunos falta de interés. La mayor parte ya presentaba grado de incapacidad.

Conclusiones: Es necesario la capacitación de profesionales que actúen en el empoderamiento de las personas frente a la enfermedad y orientaciones sobre prevención de discapacidades y acceso a insumos para realizar el autocuidado.

Palabras clave: Lepra. Autocuidado. Prevención secundaria. Prevención terciaria.

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■ INTRODUCTION

Hansen's disease is an infectious, chronic and slow-developing disease, caused by the *Mycobacterium leprae*, whose manifestation takes place in cutaneous cells and peripheral nerves. From 2012 to 2016, 151,764 new cases of Hansen's disease were diagnosed in Brazil, which is equivalent to a mean detection rate of 14.97 new cases for every 100 thousand people. Despite the reduction presented by epidemiological indexes, the goal of completely eradicating Hansen's disease from Brazil is yet to be reached⁽¹⁻³⁾.

When Hansen's disease is not adequately treated, it can lead to physical disabilities, which may even turn into deformities. This clinical framework results in great suffering, which is even greater than pain, since it is associated to psychic and sociocultural impacts⁽¹⁻³⁾.

Inabilities resulting from Hansen's disease not only are stigmatized, as they also directly interfere in the emotional, social and productive stability of the individual. Therefore, all actions towards preventing and treating these disabilities and deformities are essential for the improvement of the quality of life of people with the disease⁽⁴⁾.

The nurse and all other members of the health team have important roles in the creation of knowledge about many things related to Hansen's disease, such as the prevention of disabilities, health promotion, diagnostic research, treatment, monitoring through instruments, self-care and family guidance, and epidemiological vigilance and control, all of which aim at offering an integral care to the patients⁽⁵⁻⁶⁾.

In this context, one of the main functions of nursing in caring for people who have been suffering from Hansen's disease is the promotion of individual self-care actions, offering a base for the patients to support their lives and health, recover from the disease or injury and adapt to its consequences. Therefore, when patients perform self-care actions, the structural and functional integrity of the person is maintained, contributing for the development and recovery of health⁽⁵⁻⁶⁾.

In Pernambuco, from 2013 to 2016, 3,000 new cases of the disease were registered. In 28% of them the level of physical disability was of the 1st or 2nd degree, which could be prevented through early and correct diagnoses, and through the offering of planned integral care to these individuals⁽⁷⁾. This worrying framework highlights the need to reinforce strategies to control or prevent disabilities.

To this end, the practice of self-care is an essential strategy in the treatment of the disease and in the prevention of disabilities. It consists of procedures, techniques and exercises which help preventing disabilities or avoiding

their worsening, all of which can be performed at home or at work. The knowledge about the disease and its treatment is a right of people with Hansen's disease⁽¹⁾.

To guide this study, the following issues were brought forth: How do Hansen's disease patients practice self-care? What are the challenges in the execution of these practices? Considering that, the following objective was proposed: to analyze the self-care practices for face, hands and feet, executed by Hansen's disease patients being treated in health units, references for the treatment of the disease.

■ METHODOLOGY

This is a qualitative, descriptive and exploratory research. Such a critical and reflexive perspective was chosen as a way to understand the social phenomenon and its associations in the health field⁽⁸⁾.

The study was conducted in health care units which were references for Hansen's disease treatment in Pernambuco. The units chosen were located in Sanitary Districts in the city of Recife which had high endemicity of the disease: the Integrated Health Center Amauri de Medeiros (CISAM), the Clementino Fraga Polyclinic and the Albert Sabin Polyclinic.

The participants of the study were male and female 18 year-old or older Hansen's disease patients undergoing treatment, who lived in the state of Pernambuco and had been through more than one consultation in the aforementioned units. Patients who were in the waiting room of the selected health units were invited to participate.

Data collection took place from May 2014 to April 2015. Semi-structured interviews were conducted individually, and recorded in digital media, with the permission of the participants. The interview involved issues regarding the guidance about self-care received for Hands/Feet/Eyes/Nose in the consultations, and what was easy or difficult about them. Data collection was terminated when data saturation was reached for the phenomenon being investigated.

Data for the characterization of the participants and the establishment of their clinical history was collected from the health records, including general physical exams, dermatological-neurological exams, as well as diagnostic and treatment.

Interviews were submitted to content analysis through a pre-analysis, material exploration and categorization⁽⁹⁾. The subjects of the study who agreed to participate read and signed two copies of the Free and Informed Consent Form, according to ethical principles and to Resolution 466/2012 from the National Council of Health⁽¹⁰⁾.

This article is a product of the End of Course Paper⁽¹¹⁾ ***"Práticas de autocuidado das pessoas atingidas pela***

hanseníase: singularidades e desafios", submitted and approved by the Research Ethics Committee of the Hospital Complex HUOC-PROCAPE in 2014, under protocol: 875.460 and CAAE: 24821313.4.0000.5192.

To preserve the anonymity of participants, they were identified by the word "Interviewee", followed by a number indicating the order.

■ RESULTS AND DISCUSSION

Twenty-four patients from three reference units in the secondary level of attention for Hansen's disease treatment, in Recife, Pernambuco, participated in the study. Most interviewees were male (seventeen *versus* seven women). Their age varied from 20 to 76 years of age.

Considering the clinical types of the disease, it was tuberculoid for seven interviewees, borderline for eight, and lepromatous for two. The records of seven patients did not indicate the type. Regarding the disability levels, twelve interviewees had disabilities of the 1st degree, four of the 2nd, six of zero degree, and two of them had unspecified disability degrees.

It stands out that most interviewees already had a degree of disability, according to the data. This might have happened due to late diagnostic related to the lack of knowledge of the population regarding the symptoms of Hansen's disease; to the lack of training of health professionals; to the symptoms Hansen's disease have in common with other diseases; or even to an insidious evolution of the disease, leading to permanent physical disabilities. Therefore, the difficulties that the patients have to face start with the search for a diagnostic, eventually becoming aware of it, going through treatment, and maintaining it after being cured, since the same actions executed for the cure can be continued to treat the sequelae left behind by the disease⁽²⁾.

The analysis of the interviews originated two units of meaning or thematic categories: Knowledge and execution of self-care practices in Hansen's disease; Singularities and challenges to self-care in Hansen's disease.

Knowledge and execution of self-care practices in Hansen's disease

Hansen's disease is a potentially disabling disease. For this prognosis to be avoided or minimized, patients need to develop attitudes and abilities that favor the protection of their physical, emotional and social integrity^(1,3). Therefore, this competence involves self-care practices guided by health professionals and those that are conducted by patients, considering self-care with the main body areas

affected by peripheral nerve lesions, according to their own view.

Problems in the face are known to take place only in people diagnosed with the multibacillary types of the disease. Therefore, any effort to prevent and treat the physical disabilities and deformities must be valued, since it not only avoids harm, as it also contributes to minimize the risks of suffering from low self-esteem and social and family stigma⁽¹²⁾.

When questioned about the guidance they received in the consultation regarding how to care for their face and skin, some of the interviewees reported having received information on the use of body moisturizers, sunscreens, and avoiding exposure to the sun during the treatment, as indicated by the following statements:

I can't stay in the sun, I spent some time in the sun and got black. (Interviewee 5)

[...] In the skin, I was [advised] to use sunscreen when I go out, not to stay on the sun [...] (Interviewee 6)

It is essential to clarify to the patients that changes in the color of their skin are associated to the use of the clofazimine, a medication whose bacteriostatic action prevents the *M. leprae* from multiplying while also performing an important anti-inflammatory function^(1,3). The skin of the patient may present a reddish pigmentation, which is reversible, starting in the third month of drug polytherapy (DPT), reaching its greatest intensity before the end of the first year. After the treatment is interrupted, the pigmentation of the skin starts to change, and the skin goes back to its original color one year after the suspension of the DPT⁽¹³⁾. Another adverse reaction is the xeroderma, which may lead to ichthyotic lesions. One of the interviewees identified the need for skin moisturizing:

I arrived with dry skin... then she [nurse] said: you have to moisturize! But I didn't think it was because of the treatment. (Interviewee 24)

It should be highlighted that Interviewee 24 did not identify dryness in his skin and that this symptom could be related to the disease, which emphasizes the need for an adequate monitoring of the treatment evolution. Therefore, it is necessary to advise, during consultations, about the need to moisturize and lubricate hands and feet using body moisturizers and the immersion of limbs in buckets or basins with water in adequate temperatures for 10 minutes⁽¹²⁾. Moisturizing and lubricating the skin are actions for dry and hyper-keratotic skin, to compensate for the

compromised sebaceous and sweat functions, improving the conditions of the skin and preparing it for the exercises suggested for the prevention of disabilities⁽¹⁴⁾.

Other necessary guidance involve the daily use of accessories, such as caps, sunglasses, as well as ophthalmic monitoring and the use of lubricating eye drops. These measures were reported by the interviewees, as can be noted below:

For the eyes she gave some guidance, that I went to the ophthalmologist, be careful with them, right, I always wear sunglasses. (Interviewee 14)

Always wear a cap, right, avoiding the sun so I don't have like tired eyes and the sun with the reflection, right, but since I wear glasses that deals with the reflexes. (Interviewee 18)

It could be noted that the professionals highlighted for the patients that they should care for their eyes. The recommendation is to monitor the eyes daily to verify whether they present trichiasis (ciliary inversion) or dryness, advising the patients to use the eye drops indicated by the adequate professional. If the patient has lagophthalmos (opened eyes during sleep), they must use a blindfold at night. They are also recommended to avoid scratching or rubbing the eyes, and not to try and remove motes from their eyes with cloths or other objects, also avoiding to dry their eyes with t-shirt or blouse sleeves⁽¹²⁾.

One must also be attentive for possible eye lesions that can be the result of direct *M. leprae* invasions, due to type 1 and 2 reactions. Type 1 reaction leads to the compromising of the facial nerve, consequently leading to lagophthalmos, while type 2 leads to iritis and iridocyclitis, often resulting in secondary cataract and glaucoma. The reactions are immunologic phenomena related to the antigens of *M. leprae*, released during drug therapy and, therefore, intimately connected to the surfacing of eye lesions⁽¹⁵⁾. Regarding the face, patients reported the use of sunglasses and caps, as indicated below:

For the eyes I like wearing glasses, we have to know that we have this and anything can hurt us... if the sun is too hot [...] (Interviewee 9)

Regarding respiratory pathways, specifically the nose, few interviewees reported having received guidance regarding self-care, and none mentioned caring for this organ in their daily routines, as can be observed in the following statements:

Being careful, because sometimes you can scratch your nose and it bleeds and you didn't even noticed like happened to me before, so you really have to avoid that. (Interviewee 18)

She told me to keep the nose clean and be a little more discrete when sneezing (Interviewee 21)

The care that should be recommended regarding the nose is hygienic, such as cleaning it three or four times a day and avoiding removing crusts from the inside with the finger or any other object that might injure its interior; also, they should avoid blowing their nose hard⁽¹²⁾.

Regarding changes or losses of sensitivity in upper and lower limbs, patients must avoid situations that expose their hands to the risk of being hurt, burned, cut or pierced, according to the statements below:

Hotness, was what she [nurse] mentioned the most, but I got burned anyway, I got burned very often, every time I went there I hid my hands so she wouldn't see. (Interviewee 19)

The statement above shows that the patient is aware of the risk, but is finding it difficult to minimize it. Therefore, the adherence from the patients to the practices of caring for their own bodies still demands, in addition to knowledge, the internalization of concepts that may favor the understanding of body image changes that can be caused by Hansen's disease. Additionally, it can help the patients to recognize their pain, anguish, hope and perspectives, thus adding new concepts to the educational actions in self-care for people who had Hansen's disease⁽¹⁶⁾.

The non-adherence to self-care by Hansen's disease patients, among other reasons, is due to the disruption of their body image and to the stigma from the social representations of their "leprous", incapacitated and deformed body⁽¹⁶⁾.

Considering that, it is paramount that health professionals periodically monitor the patients, perform domiciliary visits to evaluate the housing conditions and organize daily life activities, also offering therapeutic advice for the adaptation of utensils used in the patients' daily lives.

Hansen's disease patients, with peripheral neurological lesions, may present diminution or loss of the protective sensitivity of their limbs, that is, the loss of the perception of pressure and strength, as well as those of heat and touch. Devoid of these perceptions, the individual might suffer burns during daily activities, when, for instance, handling hot utensils. They may even get hurt in routine activities, such as holding a hoe's handle or a doorknob, for instance.

Putting long wooden handles in pans, forks and spoons, using gloves or pliers for these domestic utensils, among many other possible adaptations, are ways to avoid accidents and prevent deformities⁽¹⁾. Only one interviewee stated to have been advised to wear gloves.

To use gloves so I could get the pan because every time I burned my hand. (Interviewee 5)

Concerning the advises received about caring for their feet, interviewees mentioned the use of oils and moisturizers, daily verifications, the use of closed footwear, orthopedic sandals and boots. They were also recommended to take some preventive actions, such as avoiding walking on bare foot and caring to avoid cracks on the skin, as mentioned below:

To avoid cuts, injury to the feet, because it feels numb, with the sequelae I got I can't feel my feet, for instance I hit it 3 months ago and didn't feel it. (Interviewee 16)

It is essential to highlight for the patients how important it is to inspect, clean and moisturize daily the skin of the feet, to prevent blisters, calluses and cracks, while also removing any calluses with water sandpaper after bath, always wear footwear and loose cotton socks when walking. Other essential attitudes are the use of closed footwear made of cloth or soft leather, soft insoles with no prominences in the area that stays in contact with the feet, examining the insides of the shoe before wearing it and after, to see if any object that could hurt the feet is inside^(12,14). Considering the advise received about this, the following report is representative:

[...] I always try to moisturize, look the feet always below them, because I usually don't feel my fingers, so I always look and use the moisturizer in my feet [...] and I keep looking... to see if I didn't get hurt without noticing, that's it. (Interviewee 6)

One of the main complications in the feet of the users is the presence of foot ulcers, caused by the loss of the protective sensitivity or by numbness in the region due to lesions in the tibial nerve. Plantar "cracks" or fissures are very common, and frequently are pathways for infectious agents⁽¹⁾. Self-care practices are essential to prevent and treat plantar complications.

A study conducted in Natal-RN highlighted that a group, after an educational activity, was made aware of how necessary self-care was to prevent ulcers from appearing⁽¹⁷⁾, since

most ulcers in Hansen's disease patients are in the plantar region, and are distributed mainly in the areas which have to support weight while the patients stand or walk⁽¹⁸⁾.

In this study, eight interviewees reported to not have performed any self-care practice. During an investigation conducted in the Teaching Health Center of the Medicine School of Botucatu, reports were observed regarding the perception of self-care, and subjects were found to have restrictions regarding this practice due to difficulties to autonomously understand the need for self-care, and often because they were not aware of the severity of the disease⁽¹⁹⁾.

It was also revealed that patients were not entirely carrying out the preventive actions recommended, and therefore, were not receiving the benefits from the self-care. That corroborates the reports of the patients themselves, many of whom stated to have been advised about self-care, but among whom just a few performed it in its entirety, as the statements of these interviewees show:

Maybe I can do it, but I don't... I'll be honest, I don't do it. (Interviewee 8)

Well... if I dedicate and watch myself I can do it, sometimes it's a matter of time. (Interviewee 10)

Considering the context exposed, it is possible to see that the theme "Self-care practices" is seldom addressed during the follow-up of patients being treated, during times when it is still necessary to address it. Therefore, interviewees were shown not to understand the importance of these advises to avoid disabilities and have a better quality of life. Being aware that immediate results cannot be expected, patients must rigorously implement the self-care practices about which they are advised, in order to avoid future complications.

Singularities and challenges in the self-care for Hansen's disease

When asked about what was easy and what was difficult about performing the self-care practices, some patients stated that they do not have the time to insert them in their daily activities, which can be observed in the following statements:

During the day I can't because I start work very early, I have to care for the children and I don't have time to care for myself, and that's the type of time I want to have, to care for my health, for my problem, so it doesn't get worse. (Interviewee 16)

I was never used to moisturize. I never cared for it. I think I don't have the time either. House, dog, child, food... I think I forget myself. (Interviewee 24)

They also reported difficulties in wearing gloves, caring for their feet, cleaning their nose, touching objects to write; others reported not having any trouble.

I have a hard time wearing the glove because I think I put it in every finger and then when I look two fingers are in the same finger-hole [...] It's difficult for me to hold things, coins, I can't write, my writing also got too ugly. (Interviewee 5)

Doing these practices is no trouble at all... if its for my good there's no problem. I don't wear sunglasses cause I'm not used to them, I don't like it. (Interviewee 23)

The interviewees who reported having received self-care guidance highlighted that there are restrictions and difficulties that they cannot express. That shows that they acquired little to no knowledge regarding the magnitude and severity of Hansen's disease.

About the disease? I don't even know because she didn't explain. She said it was a skin condition and that was it, she ordered medication, and every month I come and get it. (Interviewee 20)

That it causes skin patches if you don't care for it and that can be harmful right... so the treatment is caring for yourself. (Interviewee 9)

It was also found that the knowledge about the problems with Hansen's disease is also very restricted regarding its signs and symptoms. That is possibly due to the constant informative campaigns focused on the "white or reddish spots" created by the Ministry of Health and the Municipal State Secretariats, due to the need for early diagnostic.

Therefore, the aspects related to the types of transmission and treatment of the disease are still not well clarified and need to be better divulged for the general population in different media, since understanding the transmission chains and the prevention of disabilities for the conduction of an adequate treatment can consolidate the adherence of the patients and strengthen integral health care programs targeted at people with the disease.

On the other hand, fragmented, mechanical and linear health care actions condition the individual to repeat older patterns, creating a dependence from health professionals.

Thus, they become unaware of their responsibilities, as they believe their actions do not influence reality, which has a negative effect on actions that lead to self-care⁽¹⁹⁾.

The Ministry of Health prescribes that guidebooks with Hansen's disease self-care guidance should be made available for the professionals, but these workers must be encouraged to work from a multi-professional perspective, being trained to address the disease in all its aspects, focusing, after diagnostic is confirmed, in the execution of self-care actions. Such guidance must be given in the first consultation and reiterated in every supervised dose.

Through Nursing Consultations, the professional can identify the health needs of the patient and guarantee that prescriptions and guidance are given in an individualized manner. The prescriptions are not only targeted at dealing with needs identified during the physical exam. They also are useful for guiding the patient regarding self-care. The treatment is long, which means that adverse reactions may surface, not to mention the unwanted physical disabilities, and that reiterates the need for the co-participation of the client in the process⁽²⁰⁻²¹⁾.

Considering all that has been discussed, it was possible to notice that the main challenges reported by the interviewed patients in the conduction of the self-care practices were the lack of time, which would be due to the accumulation of daily activities, and difficulties in handling objects. These facts are justified by the lack of knowledge the patients have about the disease and the importance of self-care. Such difficulties also indicate that the professionals do not understand the magnitude and importance of their own advice for the prevention and treatment of disabilities during consultations.

■ FINAL CONSIDERATIONS

The study "Práticas de autocuidado em hanseníase: face, mãos e pés" points out that self-care practices conducted for the face, hands and feet of people with Hansen's disease are guided and encouraged by the health professionals that monitor these patients. It can be noticed that the challenges the interviewees go through are related to physical, environmental, emotional and social factors, such as the lack of interest or time, low family income, and difficulties caused by already installed disabilities.

One of the main contributions of this field research was the fact that it allows for the recognition of limitations in the reality of the patient with Hansen's disease, from the perspective of self-care and knowledge about it. Considering this, strategies that act towards empowering people to deal with the disease, advances in the guidance

for the prevention of disabilities, and the access to inputs for the execution of self-care are necessary, as they enable the transformation of reality for a more autonomous way of life.

It is necessary to discuss the prevention of disabilities in the education and training of health professionals, as well as to encourage actions to implement, in the services that care for patients who have the disease, actions that promote the insertion of self-care practices in their daily routines.

In this setting, the nurse is one of the professionals who integrate the multiprofessional team who acts since diagnostic, through treatment, and after discharge. One of the limitations of this study was not including the nurses and other professionals as participants, which meant the study was restricted to the point of view of the users, regarding the guidance they received. It would be pertinent, in future studies, to analyze the activities performed by the health professionals to offer guidance to the patients and find what are the challenges they face during them.

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