

ORIGINAL ARTICLE

SELF-CARE IN INDIVIDUALS WITH LEPROSY: EVALUATING PRACTICES IN THE SECONDARY HEALTH CARE NETWORK*

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ABSTRACT

Objective: To evaluate self-care practices for face, hands and feet of individuals with leprosy treated in the secondary health care network.

Method: Quantitative, descriptive-exploratory, cross-sectional study carried out in a reference hospital. Population of 127 people and sample with 74. Data collection performed using two structured instruments and analyzed by the Spearman and chi-square tests.

Results: The self-care practices for the feet were better performed compared to the other dimensions. There was a significant correlation in the practices for hands/feet and face/hands. The associations were significant for operational classification/practices for feet, facial impairment/practices for face and impairment of lower limbs/practices for feet.

Conclusion: The study is attentive to the proposed objective and concludes that self-care practices need to be better known and applied, since their effectiveness is recognized in the scientific community, as it is an evidence-based strategy.

DESCRIPTORS: Nursing; Secondary Health Care; Health education; *Mycobacterium leprae*; Health Promotion.

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ARTIGO ORIGINAL / ARTÍCULO ORIGINAL I

AUTOCUIDADO EM INDIVÍDUOS COM HANSENÍASE: AVALIAÇÃO DE PRÁTICAS NA REDE DE ATENÇÃO SECUNDÁRIA À SAÚDE

RESUMO

Objetivo: avaliar as práticas de autocuidado com face, mãos e pés de indivíduos com hanseníase atendidos na rede de atenção secundária à saúde.

Método: estudo quantitativo, descritivo-exploratório, transversal, realizado em hospital de referência. População de 127 pessoas e amostra com 74. Coleta de dados realizada por meio de dois instrumentos estruturados e analisados pelos testes de Spearman e qui-quadrado. Resultados: as práticas de autocuidado para os pés se mostraram melhor executadas em comparação às demais dimensões. Houve correlação significante nas práticas para mãos/pés e face/mãos. As associações foram significantes para classificação operacional/práticas para pés, comprometimento facial/práticas para face e comprometimento de membros inferiores/práticas para pés.

Conclusão: o estudo atente ao objetivo proposto e conclui que as práticas de autocuidado precisam ser melhor conhecidas e aplicadas, uma vez que tem sua eficácia reconhecida no meio científico, tratando-se de uma estratégia baseada em evidências.

DESCRITORES: Enfermagem; Atenção Secundária à Saúde; Educação em Saúde; Mycobacterium leprae; Promoção da Saúde.

AUTOCUIDADO EN SUJETOS CON HANSENÍASIS: EVALUACIÓN DE PRÁTICAS EM LA RED DE ATENCIÓN SECUNDARIA DE SALUD

RESUMEN

Objetivo: evaluar las prácticas de autocuidado en el rostro, manos y pies de personas con lepra tratadas en la red de atención secundaria de salud.

Método: estudio cuantitativo, descriptivo-exploratorio, transversal, realizado en un hospital de referencia. Población de 127 personas y muestra de 74. Recolección de datos realizada con dos instrumentos estructurados y analizados por Spearman y pruebas de chi-cuadrado. Resultados: las prácticas de autocuidado de los pies se realizaron mejor si comparadas con las otras dimensiones. Hubo una correlación significativa en las prácticas con manos / pies y rostro / manos. Las asociaciones fueron significativas para la clasificación operativa / prácticas para los pies, deterioro facial / prácticas para el rostro y deterioro de extremidades inferiores / prácticas para los pies.

Conclusión: el estudio alcanza el objetivo propuesto y concluye que las prácticas de autocuidado deben conocerse y aplicarse más, una vez que se ha reconocido su eficacia en el medio científico, dado que se trata de una estrategia basada en evidencias.

DESCRIPTORES: Enfermería; Atención Secundaria de la salud; Educación en Salud; Mycobacterium leprae; Promoción de Salud.

INTRODUCTION

To talk about leprosy is to refer to an important disease that apparently always existed, given its millenary origin, but which until then presents itself to underdeveloped national and international communities as a public health problem. From Asia to South America, it is vast the range of people who are infected with Mycobacterium leprae and who develop the pathology in its clinical forms⁽¹⁾.

However, the most negative impact of leprosy translates into disabilities, which may vary from discrete forms to severe deformities that affect mainly the triad "face, hands and feet" in its most aggressive prognosis, adding harm such as fear and stigma in life of the sick⁽²⁾. Furthermore, considering that leprosy affects people in the socioeconomically active age, the sequelae also compromise their dynamic and functional participation in their daily lives⁽³⁻⁵⁾.

Contrary to physical disabilities, the World Health Organization (WHO), as well as the Brazilian Ministry of Health (MH), proposes the use of operational and epidemiological indicators that consider the number of patients evaluated and physical incapacity grades (PIG) 1 and 2 to measure the quality of health care. They also emphasize the adoption of preventive strategies recommended by relevant studies, such as self-care, through affordable and easy-to-perform techniques⁽⁶⁻⁷⁾.

The MH conceptualizes self-care as "procedures, techniques and exercises that the patient can perform at home and in other environments" (6). However, pioneeringly, the self-care is based on Orem's nursing theory, which centralizes on the individual as the protagonist of their own care. In the impossibility of carrying it out, the nurse assists the individual, starting up from the nurse competence to guide and help. In addition, self-care enables self-perception, empowerment and independent care, as well as involving surveillance and body care (8-9).

However, the self-care dynamics is not restricted to practice and assistance when necessary. It also involves the perception of the individual with leprosy about their health status, their limitations and potential, their desire to prevent themselves against disabilities, as well as for the professional who assists them, bringing the responsibility to be aware of their client's psychosocial situation without separating the body from the mind and guiding it whenever necessary⁽¹⁰⁾.

Starting from this context, it is necessary to foster the need to intervene from the first consultation, using the health education process to enable self-care practices, and thus promote health, prevent injuries and rehabilitate individuals. Such actions should be encouraged and oriented, as they are considered simple to perform and important for the therapeutic process, dependent on the knowledge, harmony and communication between the caregiver and patient⁽¹¹⁻¹²⁾.

Secondary health care made up of outpatient and hospital services is continuous to primary care in the model of health care networks, acting in the intervention for more severe cases of leprosy, in the treatment of disabilities and in support for the performance of self-care practices, without neglecting the prevention and promotion of individual health^(6,13).

Therefore, the importance of assessing behavior in self-care practices is recognized, since it is essential to reduce the negative consequences of the disease, providing well-being and health. So, this research inquires: How are the self-care practices for the face, hands and feet of individuals with leprosy being carried out?

Searching for answers to this question, the research aimed to evaluate the self-care practices for the face, hands and feet of individuals with leprosy treated in the secondary health care network.

METHOD

This is a cross-sectional, descriptive-exploratory study, with a quantitative approach, with the setting of the dermatology outpatient clinic in a reference hospital for leprosy in Paraíba.

The study population was established from the registration records of the referred clinic, for the month of January 2017 (the year in which the data collection was performed), where 127 individuals were monitored. Based on this data, the inclusion criteria were established: Over 18 years old, use of multidrug treatment from the 2nd dose. Individuals with impaired self-reported or perceived cognition were excluded.

The sample size to obtain representativeness was reached from the sample calculation of formula $n = (N \times n_0) / (N + n^0)$, like this:

 n^{0} - first approximation for the sample size (number of cases registered in the research scenario = 127);

e - tolerable sample error= 0.05;

N - population size (119 new cases of leprosy registered in the metropolitan region of João Pessoa/Paraíba, for the year 2016⁽¹⁴⁾.

n - sample size = 62 individuals.

As it is a probabilistic sample of flow by convenience, 74 subjects were interviewed, considering the period delimited for the study, from January to March 2017.

Data collection was carried out using two structured instruments, the first containing sociodemographic data (gender, age, education level, marital status, average family income, religion), and clinical-epidemiological (treatment dose, operational classification, status bacilloscopy, clinical form, degree of physical disability in the diagnosis, neural impairment).

The second instrument used consists of 46 questions related to self-care of leprosy patients, being divided into three dimensions: 13 questions for face, 11 for hands and 22 for feet. Each question of the instrument admits an answer, which score can vary from 1 to 5. Thus, it is understood that 1 corresponds to "Never", 2 "once or twice a week", 3 "I don't know/indefinite frequency", 4 "three to four times a week" and 5 to "Always". However, some questions have a negative connotation, inverting the score downwards for the answer classification. As for the dimensions, they admit different partial scores, namely: 13 - 65 points for face, 11 - 55 points for hands and 22 - 110 points for feet. To evaluate self-care practices, the arithmetic mean of the score for each dimension was calculated, classifying the subjects' self-care practice as "unsatisfactory" (average of 1.0 - 2.5 points), "needs to improve" (average of 2.6 - 3.5 points) and "satisfactory" (average of 3.6 - 5.0 points).

It should be noted that the instrument was built as part of the doctoral thesis of a component of the Study and Research Group on Wounds at the Federal University of Paraíba, and was subsequently submitted to the validation process.

The data were analyzed descriptively and inferentially by the Spearman test in order to measure the correlation on the classification of dimensions as ordinal variables, and Chisquare by the Friedman test in order to determine the association among clinical variables and self-care practices. Statistical significance was considered p-value ≤ 0.05 .

The project was approved by the Ethics and Research Committee of the Health Sciences Center of the Federal University of Paraíba, under protocol n° 0785/16 and according to the Presentation Certificate for Ethical Appraisal number 62360816.3.0000.5188. All

ethical observances contemplated in Resolution No. 466/12 of the National Health Council were obeyed⁽¹⁵⁾.

RESULTS

A representative sample of 74 interviewed subjects was obtained, with sociodemographic predominance of men 58.1%; age between 18 and 82 years old (mean 43.4; SD \pm 15.09); married or in a stable relationship 51.4%; level of elementary school education 59.5%; family income less than or equal to a minimum wage 56.8%; Catholic religion 62.2%; 50.0% brown individuals; and 67.6% own residence.

Regarding the clinical-epidemiological variables, 86.5% were multibacillary; positive smear microscopy 55.4%; dimorphic clinical form 47.3%; PIG diagnosis zero 52.7%; without facial impairment 93.2% and upper limbs (Upper Limbs) 68.9%; with lower limb involvement (Lower Limbs) 48.6%.

Addressing the purpose of this study, the classifications of self-care practices for the face, hands and feet are described in Table 1.

Table 1 - Distribution of the classification of self-care practices in the three dimensions in their absolute and percentage frequencies. João Pessoa, Brazil, 2018

Classification	F	Face		Hands		Feet	
	N	%	N	%	N	%	
Satisfactory	1	1.4	8	10.8	17	23.0	
Needs improving	54	73.0	44	59.5	57	77.0	
Unsatisfactory	19	25.6	22	29.7	-	-	

Considering the satisfactory classification, these results show that self-care practices for the feet are better performed compared to the others, followed by practices for hands and finally for the face.

To understand the correlation between the study variables, Table 2 shows the correlation coefficients between the dimensions and their significance indexes.

Table 2 - Distribution of the correlation of dimensions using the Spearman test with their correlation coefficients and p-values. João Pessoa, Brazil, 2018

Correlations	Coefficient of Correlation*	p-value
Face and Hands	0.250	0.032**
Face and Feet	0.210	0.073
Hands and Feet	0.270	0.020**

^{*}Spearmann correlation test. **Statistically significant values (p<0.05).

These results reflect the weak, but significant, directly proportional correlation between the face-hand and hand-foot dimensions.

To verify the association of intervening variables with the process of worsening of the clinical picture in leprosy, an inference of statistical association was made between those and self-care practices, as shown in Table 3.

Table 3 - Distribution of the association test between variables using the Friedman test, with its Chi-square and p-values. João Pessoa, Brazil, 2018

Associations	Chi-Square Value	p-value
Operational Classification x Face Practices	3.240	0.072
Operational Classification x Hand Practice	1.059	0.303
Operational Classification x Foot Practice	23.000	0.01**
Facial Compromise x Face Practices	14.727	0.01**
Commitment of Upper Limbs x Hand Practice	0.000	1.000
Compromise of Lower Limbs X Foot Practice	31.837	0.01**

^{*}Friedman Association Test. **Statistically significant values (p<0.05).

DISCUSSION

Epidemiological studies recently published in the literature describe samples with sociodemographic and clinical characteristics similar to this study, such as sex, race, education level, clinical form and operational classification, corroborating the variables described and showing the epidemiological profile currently prevalent⁽¹⁶⁻¹⁸⁾.

Considering the practices of self-care, the individuals evaluated in the group "Need to improve", although they have flaws regarding the frequency of execution, are still considered partially positive, since they perform in a moderate way (average of 2.6 - 3.5 points, or that is, it corresponds to an average of three times a week). Practices classified as "Unsatisfactory" have a negative aspect for the subjects, whereas they are performed sporadically, or are not even performed at all. For this last group, it is necessary to identify preliminary problems inherent to self-care and interventions that affect and encourage it. This process can be guided by health education conducted by professionals in the area and by the understanding and initiative of the subjects⁽¹⁹⁾.

Self-perception, knowledge about the severity of the disease and the possible effects on the human body, personal empowerment and confidence in its potentialities are determining factors for the formation of the foundation and pillars of emotional and motivational support, and then embrace the regular practices of self-care, in favor of the health and well-being^(8,10).

Other strategies can strengthen both the professional-client bond and the integration of self-care actions. Self-care groups can meet the needs related to health education for individuals with leprosy⁽⁸⁾. This method provides participants with the opportunity to exchange mutual knowledge, share experiences and knowledge, and learn from others about the disabling dangers of leprosy and how to prevent them through self-care.

In addition to the isolated analysis of their daily practices, and considering the clinical profile of the individuals, it is observed that the involvement of the lower limbs (48.6%) it was the highest among the three dimensions, converging with the predominant classification "needs to improve", a consequence of the partially satisfactory performance of the self-care practice. Some ideas can act as hypotheses in this case, such as risk awareness developed from the already installed impairment that affect sensitivity and locomotion, awakening in subjects the need for self-care for disease control.

Regarding the dimension of the Lower Limbs, an Asian study that addressed self-care in plantar ulcers brings results that denote negativity in this type of care⁽²⁰⁾. Following the findings, a Brazilian study on self-care practices shows results that reflect the deficient care of individuals with leprosy to the feet⁽²¹⁾. Both corroborate the results of this study, while, although better performance of actions with Lower Limbs is observed, most participants still point percentages far from the desired - Satisfactory practice (23%).

Hands and face presented unsatisfactory indexes of execution of practices compared to the feet. The low index of facial involvement (6.8%) to face their unsatisfactory practices (25.6%) reinforces the idea that self-care is not being performed in an attempt to prevent disabilities, because it might be understood that the fact of not presenting involvement may also be interpreted as unnecessary to perform care. In addition, during data collection, the subjects expressed having no knowledge about face practices.

A similar process can be evidenced in relation to the hands dimension, in which there was also a lower frequency of the Upper Limbs involvement (31.1%) and a higher classification of unsatisfactory practices (29.7%). In this case, however, the concern is greater, given that compared to the face dimension, the percentage of affected individuals is increased.

Thus, the evidence indicates that risk awareness from the knowledge deficit is affected, leading to weaknesses in disability prevention practices for hands and face. A study points to the low perception of leprosy risk that reflects deficiency in self-care⁽²²⁾. This result becomes a threat to physical and psychological integrity and personal image, even more considering that disabilities can appear at any stage of the disease, requiring self-care as soon as possible⁽²³⁻²⁴⁾.

It is noteworthy, in complementarity to the above information, that the clinical characterization of individuals represents mostly multibacillary and dimorphy classification in the sample. The axioms between these results present a conjuncture in which the affected individual presents the severe form of the disease, with high potential for neural involvement and, therefore, more conducive to the development of deformities and disabilities. Also in this context, the dimorphic form is pathologically characterized by its diversity of signs and symptoms, being considered of strong magnitude due to immunopathological instability.

Regarding statistical correlations, it is observed that the subjects treat self-care of the face x hands and hands x feet as sets or similar. Current studies on disabilities in leprosy show an early predominance of lower limb involvement in their samples⁽²⁵⁻²⁶⁾. Thus, there may be the possibility of the face and hand dimensions being considered separated from the foot dimension, because the subjects do not associate the injuries among the dimensions.

On the other hand, the weak correlation between Upper Limbs and Lower Limbs seems to be related to simultaneous executions and use of adjuvant components (moisturizers, lubricants, water sandpaper, among others) similar, according to the guidelines of the MS manual dealing with disabilities and self-care⁽²⁷⁾.

It is also believed that some of this care is performed routinely, regardless of pathological involvement. In addition, the present study presents the highest rates of satisfactory practice of hands and feet, although poor, unlike for the face, also corroborating the investigated correlation. A qualitative study helps to strengthen the idea that the dimensions for hands and feet converge in their representations and interpretations for the

body image of the individuals with leprosy, especially for those with installed disabilities⁽²²⁾.

In addition to correlating the dimensions, it is interesting to test associations between sociodemographic and clinical variables and self-care practices in the three dimensions, as it is understood that these can influence the performance of self-care activities and express valuable meanings.

The associations between operational classification and lower limb involvement converge to self-care practices in the feet. In other words, the predominant multibacillary in the sample is characterized not only by the greater number of bodily injuries, but also by the greater bacillary load in the body⁽²⁾. Consequently, limb involvement becomes even greater in this directly proportional relationship, due to neural damage, thus facilitating physical disability, similar to another study⁽²⁸⁾.

Having said that, and considering the statistical association between self-care practices in feet and their involvement together with multibacillary, it can be inferred that awareness about the risk of diseases leads to the significant tendency of self-care execution by the subjects, whether satisfactory or partially satisfactory⁽¹⁰⁾.

As for facial impairment and self-care practices, the variables have a dependent association, that is, the sample understands that for there to be practices, involvement is necessary. As there is no considerable presence of facial involvement in the sample, satisfactory practices were minimal (1.4%), thus, it is understood that if the subjects do not present facial sequelae, they do not take care of prevention.

Facial disabilities are remarkable and can affect self-esteem and social presentation, as well as quality of sleep and vision. In addition, they may manifest in the form of lagophthalmos, trichiasis, among others, in addition to changes in nasal morphology and facial muscles. Therefore, leprosy brings with it all the negative burden of disease that incapacitates, deforms and can leave sequelae, especially for the face, which is considered the identity and personal presentation⁽²⁹⁾.

It is worth remembering that the development of physical disabilities may, in addition to measuring the magnitude of the pathology, be an indication that the diagnosis was probably late or that the clinical form was inadequately defined⁽³⁰⁾.

Unfortunately, there are many issues that lead people with leprosy not to perform self-care in the correct way and frequency. It was observed during the collections that this is due to the lack of knowledge about the risks that leprosy can entail, or by the lack of time and material resources, by the weak stimulation from family members, friends or even from the health professionals.

Therefore, it is seen the need to reinforce its importance, to open proposals for educational interventions in self-care, and to understand the human being, their limitations, wills and perceptions, elements that can influence adherence to self-care and their effective practice.

On the other hand, for practices that need to improve, surveillance, reaffirmation of self-care responsibility and health education are necessary, as well as for practices that are already satisfactory so that they continue to be classified in this quality. In this context, this study brings with it the description of some nuances that can be verified within this theme that involves the dependence of circumstances, conditions and other issues pertinent to the individual with leprosy.

The study presented limitations regarding the intimate and in-depth understanding of the subjects and their peculiarities regarding the execution of self-care practices and what can influence them. In particular, we emphasize the opportunity for new qualitative studies, in order to fill gaps found here, to answer and reformulate hypotheses.

CONCLUSION

The research points out sociodemographic and clinical description of subjects affected by leprosy that similar to the scientific literature. When analyzing self-care practices for the face, hands and feet dimensions, a better response from the participants was observed for actions directed at the lower limbs, followed by the superiors and, finally, by the face. Even so, the results indicate that the practices do not have the quality and/or frequencies necessary to be considered satisfactory.

Below the regularity of self-care, the data showed correlation and associations between these and the presence of commitment to the analyzed dimension (except for the Upper Limbs), so that it seems necessary to perceive the involvement of the face or feet so that the actions self-care are carried out.

In view of the above, the study attends to the proposed objective, and, therefore, it is concluded that self-care practices need to be better known and applied, since they have their effectiveness recognized in the scientific community, being an evidence-based strategy. In addition to knowledge, it is necessary to encourage their adherence and to investigate factors that may become intervening in the adoption process by individuals.

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