ORIGINAL ARTICLE

REVISTA ENFERMAGEM ATUAL IN DERME

DIFFICULTIES FACED BY NURSES IN THE MANAGEMENT OF LEPROSY PATIENTS

DIFICULDADES ENFRENTADAS PELOS ENFERMEIROS NO MANEJO DOS PACIENTES COM HANSENÍASE

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ABSTRACT

Objective: know the difficulties faced by nurses in the management of patients with leprosy. Method: exploratory, descriptive and qualitative study. The sample is composed of nine nurses who work in the Family Health Strategy, in an endemic region of southern Ceará, Brazil. Data collection was performed using a semi-structured interview script, from august to september 2015, with subsequent analysis of thematic content. Results: based on the results obtained, three categories emerged: difficulties listed in the performance of the dermato-neurological examination by nurses of the family health strategy; complications in the care of patients with leprosy; early detection versus continuing education. Final Considerations: the study revealed the difficulties faced, such as the lack of instruments to perform dermato-neurological tests; stigma and prejudice manifests by the population; early detection with domain failures; permanent education poorly structured to meet the demands of professionals. The importance of more investment in innovation research in the management of leprosy is highlighted.

Keywords: Leprosy; Nursing; Nurse-Patient Relations; Family Health Strategy; Primary Health Care.

RESUMO

Objetivo: conhecer as dificuldades enfrentadas pelos enfermeiros no manejo dos pacientes com hanseníase. Método: estudo exploratório, de caráter descritivo e qualitativo. A amostra é composta por nove enfermeiros que atuam na Estratégia Saúde da Família, em região endêmica do sul do Ceará, Brasil. A coleta de dados foi realizada com um roteiro de entrevista semiestruturada, nos meses de agosto a setembro de 2015, com posterior análise de conteúdo temático. Resultados: embasando-se nos resultados obtidos emergiram três categorias: dificuldades elencadas na realização do exame dermatoneurológico pelos enfermeiros da estratégia saúde da família; intercorrências no atendimento ao paciente com hanseníase; detecção precoce versus educação permanente. Considerações finais: o estudo revelou as dificuldades enfrentadas como a falta de instrumentos para realizar os testes dermatoneurológicos; estigma e preconceito manifestos pela população; detecção precoce com falhas de domínio; educação permanente pouco estruturada para atender a demanda dos profissionais. Ressalta-se a importância de mais investimento em pesquisas de inovação no manejo da hanseníase.

Palavras-Chave: Hanseníase; Enfermagem; Relações Enfermeiro-Paciente; Estratégia Saúde da Família; Atenção Primária à Saúde.

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INTRODUCTION

Leprosy, an infectious disease caused by Mycobacterium leprae, is considered a neglected disease. Brazil integrates the global list of 22 countries with a high burden of the disease, occupying the 2nd place with the most reported cases in the world, only behind India (WHO)1. When analyzed by regions, the geographic distribution of the disease in the country presents uneven patterns, with a high concentration of new cases in the Midwest, North and Northeast regions when compared to the South and Southeast regions2. In the Americas, 20,957 new cases of leprosy were detected, with a detection rate of 3.08/100,000 inhabitants, with 28,660 new cases reported in Brazil, representing 93% of the disease case records in 2018. Ceará identified 1,691 new cases of leprosy leprosy in 2018, with a detection rate of 18.63 new cases per 100,000 inhabitants, considered high by the WHO parameters3.

From 2008 to 2019, 23,622 new cases of the disease were reported in the state of Ceará, with 1,292 in children under 15 years of age. There was a significant reduction in the overall leprosy detection rate (43.6%), from 30.5/100,000 inhabitants in 2008 to 17.2/100,000 inhabitants in 20193.4. These data indicate the need to continue with an effective and programmed performance of health professionals, especially nurses in primary health care in endemic areas. However, difficulties are reported by professionals who are protagonists in actions for a more effective coping, possible through early detection and control of the disease.

Primary Health Care in Brazil is anchored in the performance of the Family Health Strategy, which has a fundamental role in the control of leprosy, developing actions and activities to achieve it, in addition to being essential for the reorientation of the care model and for the consolidation of guidelines of the Unified Health System5. The importance of the work of the professionals who make up this Strategy is highlighted, especially physicians and nurses, who must be attentive to carry out actions that break the chain of disease transmission, favoring the early detection of signs and symptoms and strengthening the coverage of contact exams6.

Regarding the signs and symptoms, the clinical consequences of leprosy do not only affect the skin, its manifestations range from hypochromic, brownish or reddish spots, with changes in sensitivity, to the involvement of superficial skin nerves and peripheral nerve trunks (located on the face , neck, middle third of the arm and below the elbow and knees), eyes and internal organs (mucosa, testicles, bones, spleen, liver, etc.), which can lead to lifelong disabilities and unavoidable disabilities for the affected person7.

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Disease control is centered on early detection of clinical manifestations, on correctly instituted treatment, and on the identification of susceptible contacts. A sensitive indicator of disease transmission is diagnosis in children8. All these actions can be performed in primary health care by nurses. Therefore, the nurse has an essential role in monitoring the disease when providing care to patients with suspected or confirmed diagnosis of the disease, however, the maintenance of endemic situations of the disease in some regions raises questions about the effectiveness of the action of these professionals. As a result, it is intended to answer the following question: what are the difficulties faced by nurses in the management of patients with leprosy?

Knowing the reality of those who deal with the daily challenge of the disease can better support professional practice and decision-making in the difficulties to face this problem. Given the above, the research aims to understand the difficulties faced by nurses in the management of patients with leprosy. This content will contribute to the development of nursing care with more information for professionals who work or will work in the care of patients affected by leprosy, who monitor and work to control the progress of this disease.

METHOD

The exploratory study, with a qualitative descriptive approach, was carried out with nurses in Primary Health Care (PHC) from a small town in the endemic region of Cariri, southern Ceará, Brazil.

The study setting consisted of nine teams from the Family Health Strategy (ESF), two from the urban area and seven from the rural area, which correspond to the local front responsible for the activities of the Leprosy Control Program at the PHC level. The research participants were nine nurses who work in the FHS in that municipality. The following inclusion criteria were adopted: having followed up at least one patient with leprosy until discharge due to cure and being a nurse in the ESF for more than a year. The exclusion criteria adopted were: absence of notified cases of leprosy in the territory covered by the team where the nurse works and having temporary ties. Data collection was carried out from August to September 2015.

The instrument adopted was a semi-structured interview script, using a digital recorder and subsequently transcribing and typing the speeches. Before the interview, the individual authorization of the Informed Consent Term (TCLE) was read and signed. It is important to clarify that, to ensure the identity of the participants, codes such as the

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letter E (Nurse) and identification numbers 1, 2... 9. were used.

Thematic content analysis technique was used, which is divided into three stages: pre-analysis, which corresponds to the choice of material to be used; exploration of the material, which consists of the encoding operation; treatment of the results obtained and interpretation, which highlights the information obtained, proposes inferences and performs interpretations provided for in its theoretical framework9.

In the analysis of the thematic content of the data, three categories emerged, namely: difficulties listed in the performance of the dermato-neurological examination by the nurses of the ESF; complications in the care of patients with leprosy; early detection versus continuing education. The project was submitted to the Research Ethics Committee of the Universidade Regional do Cariri, obtaining a favorable opinion (protocol nº 705.008).

RESULTS AND DISCUSSION

The study consisted of nine nurses from the ESF. Regarding the profile of the interviewees, the age group was between 24 and 34 years old, configuring young adults in action. Regarding gender, it was possible to observe that 90% were female. The working time was greater than two years of experience in ESF for all respondents. Regarding the degree, 100% of the participants had a latu sensu postgraduate degree, but the area of specialization was varied, with only one respondent having specialized training in family health. Next, excerpts from the interviews that cover the three categories and the discussion with the relevant literature are presented.

Difficulties listed in the performance of the dermato-neurological examination by the FHS nurses

The ESF is developed in basic units that operate in their area of concentration that cover the entire territory to which they belong. Such units must have a physical structure and adequate resources for the development of activities inherent to the services offered without prejudice to the service, in order to offer accessible and quality care.

Still, these units must be provided with a reserved and silent place with specific materials that help professionals in carrying out their activities according to their area. Regarding the care of patients with leprosy, examples of such materials are: unflavored dental floss with wax; Snellen's table; ruler; clinical flashlight; pens of various colors; test tubes; cotton swab; pin; monofilaments/esthesiometers. These materials are used to perform the dermato-neurological examination, which consists of

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evaluating corneal sensitivity, visual acuity and thermal, painful and tactile sensitivities10.

The absence of these materials hinders the clinical diagnosis processes carried out by the physician and the monitoring carried out by the team. In the case of nursing, the nurse assesses and records the degree of physical disability in medical records and forms, in the diagnosis and monitoring of patients with leprosy, as well as performing the dermato-neurological examination in all household contacts of new cases.

Conquering the trust of leprosy patients is the role of everyone on the team, who must strive to strengthen the bond. Nurses, in particular, use the moment of the nursing consultation to make this approach wisely. The use of techniques by the interviewees has improved this contact through special strategies, individualized knowledge, availability of time and some specific materials. WHO, when it launched the Global Strategy 2016-2020, had as one of its focuses strategic operational recommendations aimed at reducing physical disabilities developed by late detection of leprosy1.

When nurses were asked about the performance of disability prevention, the answers referred to the absence of specific materials for the dermato-neurological examination. Still, it was possible to identify, according to the reports, how essential is the availability of a quiet place and with specific equipment for the care of patients with leprosy.

> [...] one of the challenges encountered is the performance of sensitivity tests, as the units do not have the esthesiometer, which is one of the material resources that is not available [...] (E2)

> [...] the challenges faced are related to the instruments to perform the physical examination and the monofilaments that the basic unit does not have, in addition to the test tubes to perform the thermal sensitivity tests, or any other material that can be used for this purpose [...] (E4)

It was possible to notice that the lack of material prevents the complete and accurate performance of all items of the sensitivity tests. This assessment plays an important role right after medical diagnosis and throughout the treatment period, paying attention to an effective follow-up to prevent peripheral nerve injuries10. Early detection of nervous function disorders allows for timely intervention by the medical team in order to avoid a progressive and permanent loss of functionality of the affected nerve. The disabling power of leprosy has economic, social and psychological consequences. It should be noted that the disabling disease interferes with the individual's productive capacity, quality of life and social life,

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contributing to psychological trauma and economic losses.

The test performed to test skin sensitivity with Semmes-Weinstein monofilaments has been shown to be easy to perform and reliable in terms of results. The routine clinical use of the esthesiometer makes the test more accurate, monitors the evolution of peripheral nerve damage and quantifies the degree of sensory loss as a result of leprosy5.

With regard to communicable diseases, leprosy is one of the biggest causes of peripheral neuropathy and disabilities worldwide10. And it is worth noting that this is one of the main causes of disability that could be avoided worldwide11.

In this context, the performance of the dermato-neurological exam simply performs a current and standardized neurological assessment of sensitivity tests, muscle strength and palpation of peripheral nerves, allowing monitored follow-up, recording and data exchange12. The availability of a form for a pre-determined script and periodicity, such as at diagnosis, when presenting complaints, during treatment at intervals of at most one year and at discharge due to cure13.

Intercurrences in the care of patients with leprosy

Leprosy is curable and has free treatment by SUS. The treatment comprises specific therapy to eliminate the bacillus from the affected patient's body, avoiding immunological complications and disabling physical deformities. The responsible health team works by developing actions for health promotion, disease prevention and psychosocial rehabilitation. In addition, mandatory notification to the responsible health authority must be carried out and all treatment progress informed14.

The therapeutic journey of leprosy has a long period, which can last for several months. During this period of treatment, complications may arise, arising from the medication, the patient's immune status and the disease itself. The process of falling ill for leprosy patients encompasses complex aspects such as lack of knowledge or old and prejudiced ideas related to social, cultural, biological and emotional issues15.

Another aggravating factor of the disease is represented by the occurrence of reactive outbreaks during the treatment, in which inflammatory episodes are interspersed in the chronic course of leprosy, which can be more aggressive or not. Individuals are subject to the occurrence of reaction conditions before, during or after the treatment of the disease, affecting approximately 25 to 30% of individuals16. The interferences reported later by the participants were varied, and it is important to note their common occurrence in the routine of those who work with this type of patient.

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> [...] other people have type I and II leprosy reactions, concomitant with the appearance of new lesions, decreased muscle strength, changes in the sensitivity of the legs, these are complications that interfere with a good prognosis of the disease (E1).

> What occurs more are complaints related to side effects due to medication and infrequently adverse events. Ah! There was a patient who developed a condition with Lúcio's phenomenon according to the medical report (E6).

> [...] most of the time what we see is a type I reaction. So, the patient receives the treatment and we are able to control this patient [...] (E3).

When the treatment of reactional episodes is started early and carried out properly, neural damage is reduced by up to 60%, it is essential, therefore, that health professionals have experience and subsidies that facilitate identification, diagnosis and treatment of these reactional conditions, preventing the occurrence of physical disabilities16. Still, the very enriching account citing a rare reactional state known as the Lúcio phenomenon shows how essential this discussion is. In 2021, a case study published in The New England Journal of Medicine pointed out that the development of severe necrotizing skin lesions in leprosy patients was characterized as Lucio's phenomenon, which is an uncommon clinical condition17.

> [...] sometimes the patient uses alcohol, and because the treatment is prolonged, he does not have much adherence to the treatment, so the professional has to keep stimulating directly, always interacting with the team to create a bond and get a return frequent issue of [...] complications only when he does not go to the unit, recording the absence; in the issue of absentees, the health agent goes to the patient's home to find out why he did not attend the unit (E5).

> The search for absentees as well as for contacts is another difficulty, as they often do not show up [...] lack of transport to pick up patients and supervision of the dose of bedridden patients (E2).

All leprosy patients have gone through the communicating stage, therefore, they are considered of extreme epidemiological importance in terms of endemic disease and become a susceptible risk group from the point of view of the chain of the infectious process18. Furthermore, follow-up must be carried out on an outpatient basis in the public service network, where the patient must attend for medical and nursing consultations, receive the supervised dose of the MDT treatment and carry out the Prevention of Disabilities assessment18.

It is important to recognize that neuropathies underlie the development of disabilities. Hence, early diagnosis and immediate treatment are very important to prevent the process of nerve damage, in addition to being the most essential intervention in preventing and limiting disabilities. However, deformities and

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deficiencies occur in the chronic phase of the disease, due to weakness and wear of the muscles innervated by the affected nerves, such as claw hand due to the ulnar nerve or foot drop due to peroneal nerve injury; other occurrences are unnoticed burns, blisters, or trophic ulcers; in the case of trophic ulcers, they can occur on the sole of the foot, hands and fingers due to the loss of the sensation of pain; absorption of fingers and toes seen in the final stages of the disease19.

Another relevant issue is the vulnerability in which patients and their contacts are inserted in the great social reality of Brazil. In a study carried out in Rondonópolis-MT, Brazil, it was found that most contacts have low income and, despite good sanitation conditions in their homes, most of them have a rudimentary septic tank, showing a high level of social vulnerability20.

Early detection versus continuing education

Leprosy is known to be a disease that has its diagnosis based on the clinic. However, the clinical diagnosis or even the identification of signs and symptoms results from the theoretical and practical experience arising from the professional's experience with patients, with an emphasis on continuing education courses and practices developed in training and conferences.

Professional nurses often feel the need for a referral center where the patient could have a service of medium and high complexity that is fundamental throughout the treatment.

> Although people say that leprosy is an easy disease to be diagnosed and easy to be treated, I don't agree with that! It is very complex, sometimes, when performing the physical examination on the patient, we come across a spot with characteristics of the disease, but it ends up not really confirming, difficult to diagnose because they have to take into account the cultural level of the patient, sometimes, they go so anxious, thinking it's leprosy that they feel themselves, they say they don't feel it (E5).

> We do not have a reference center to refer leprosy patients who are more severe and need more specific follow-up (E1).

> [...] and also the referral of patients in the event of leprosy reaction, as we do not have a referral center (E2).

Reference centers have an image of fundamental and potential generators of new knowledge in order to improve the living conditions of patients, as they develop care, research and extension actions21. In Ceará, there is a national reference center, located in Fortaleza, but the distance to the investigated endemic region prevents more complex cases from being referred.

This reality corresponds to a national orientation of the last two decades, as the country has made great efforts to introduce the assessment and prevention of physical

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disabilities, together with the decentralization of leprosy control activities in PHC, always aiming at early diagnosis22.

Furthermore, the National Program for the Control of Leprosy has been modifying its profile based on the adherence to new technological measures in health and the incorporation of guidelines disseminated worldwide21. Although, theoretically, leprosy control actions are implemented throughout the network of public health services, passive detection of cases is still reported as an evident difficulty23.

The elimination and control of leprosy in the country, as an essential public health issue, direct all strategic actions to increase early detection and discharge for cure of diagnosed cases5.

Another important factor is permanent education, recently considered the method most used by managers to keep professionals updated and trained on the themes inherent to their area of expertise, with a focus on solving health problems. The aforementioned permanent education is used for learning processes at work with a focus on the program's success as an institutionalized technical item, using it as a basic tool for the good performance of any care professional23. The following reports show the absence of this routine:

> Leprosy is a topic that at the moment in relation to the current city I have not taken any courses yet, but as I have worked in other cities and also in the time of the academy, I took several courses to approach the leprosy patient and treatment, but offered by the city I didn't do any. I was invited by the municipality's coordination to participate in a course that will take place soon and I have already confirmed my presence (E1).

> Regarding the practical and scientific part, I also think that the issue of training is relevant, continuing education is always like renewing knowledge by learning techniques because sometimes there is a training course, but one person or another never goes, everyone so some end up benefiting and others not; there with regard to leprosy I was never any type of training. Then I have difficulty in that sense, but the good thing here is that we, the physiotherapist, that we can refer to this part of physical examination reactions, he does it. Then it decreases in this sense (E4).

The performance of roles such as the nurse's capacity for clinical judgment and decision-making depend on their theoretical knowledge, experience and continuous improvement24. Thus, the ESF teams must be trained according to the needs of the service and inserted in the context of the principles of the Unified Health System25.

A study pointed out that the role assumed by the professional nurse in the involvement of prevention and control actions carried out by the health team in the ESF provided an increase in diagnosed and treated cases26.

It is noteworthy that, for the professionals interviewed, it is of fundamental importance to strengthen permanent

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education, being very useful to provide quality patient care. However, the program works by releasing few professionals to participate in training, generating a feeling of dissatisfaction for those not covered. This reality has partially changed with the offer of online courses, especially by the state government, as a way to fill the identified need. However, the absence of practical modules and the discussion of realities specific to each municipality can be harmful to the continued training of these professionals.

FINAL CONSIDERATIONS

In view of the results obtained in this study, it was possible to know the difficulties faced by the FHS nurses regarding the management of patients with leprosy. Among them, it is worth highlighting the lack of specific materials for the performance of dermato-neurological tests that support early detection. Therefore, it is worth pointing out a management deficiency in the non-compliance with the priority in the control of leprosy in not providing basic instruments for adequate care and efficient.

Still, the prejudice and stigma of leprosy are present today and need investment in time and educational technologies aimed at the population. The population's lack of knowledge about leprosy becomes an aggravating factor, which contributes to reinforce these two aspects.

Early detection is accepted as a way to break the chain of transmission faster and prevent physical disabilities. However, despite leprosy being a medically diagnosed disease based on the clinic presented by the patient, its capture by signs and symptoms requires a practical experience developed with the disease by professionals to reach a level of safety for an effective approach.

Continuing education is an auxiliary tool, always present, used to update and improve the knowledge of FHS professionals, and is also an alternative to fill gaps with regard to the knowledge of professionals about leprosy.

In this context, the study contributed by pointing out the difficulties that impede the improvement of knowledge about the management of leprosy by nurses working in the ESF. As a limitation of the study, the sample selected in a single endemic municipality can be cited, which prevents the generalization of the findings. Furthermore, there is an evident need for more studies with professionals from different regions of the country with endemic conditions to reinforce the nurses' discourses regarding coping with difficulties as well as the strengthening of leprosy control actions.

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