

Knowledge and practice of the nurse about leprosy: actions of control and elimination

Conhecimento e prática dos enfermeiros sobre hanseníase: ações de controle e eliminação Conocimiento y práctica de enfermeros acerca de hanseniasis: acciones de control y eliminación

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How to cite this article:

Rodrigues FF, Calou CGP, Leandro TA, Antezana FJ, Pinheiro AKB, Silva VM, Alves MDS. Knowledge and practice of the nurse about leprosy: actions of control and elimination. Rev Bras Enferm. 2015;68(2):271-7. DOI: http://dx.doi.org/10.1590/0034-7167.2015680216i

Submitted: 11-04-2014 **Approved:** 03-12-2015

ABSTRACT

Objective: to assess the knowledge and practice of primary health care nurses about control and elimination actions of leprosy. **Method:** evaluation study with qualitative approach, using the Discourse of the Collective Subject, data were collected through semi-structured interviews conducted with 16 nurses. **Results:** the data collected revealed that health professionals have sufficient knowledge about the National Policy on Control and Elimination of Leprosy (NPCEL) and that the main actions preconized were applied, however, notification of suspected or confirmed cases and social reintegration of the patient were not mentioned. **Conclusion:** keeping patients in treatment, overload of work, lack of interdisciplinarity and treatment performed at other locations outside of the community were difficulties reported by professionals. Nurses know the actions addressed at assistance of leprosy patients, however, the study points to the need for a practice which is more aligned to what advocates NPCEL. **Key words:** Leprosy; Primary Heath Care; Nurses.

RESUMO

Objetivo: avaliar o conhecimento e a prática de enfermeiros da atenção primária de saúde quanto às ações de controle e eliminação da hanseníase. **Método:** estudo avaliativo, com abordagem qualitativa, utilizando o Discurso do Sujeito Coletivo, cujos dados foram obtidos por meio de entrevista semiestruturada, realizada com 16 enfermeiros. **Resultados:** os dados coletados revelaram que os profissionais de saúde possuem conhecimento suficiente sobre a Política Nacional de Controle e Eliminação da Hanseníase (PNCEH) e que as principais ações preconizadas foram executadas, porém, a notificação de casos suspeitos ou confirmados e a reinserção social do doente não foram citadas. **Conclusão:** manter os doentes em tratamento, sobrecarga de trabalho, falta de interdisciplinaridade e tratamento realizado em outros locais fora da comunidade foram dificuldades relatadas pelos profissionais. Os enfermeiros conhecem as ações direcionadas à assistência ao hanseniano, entretanto, o estudo aponta para a necessidade de uma prática mais alinhada ao que preconiza a PNECH.

Descritores: Hanseníase; Atenção Primária à Saúde; Enfermeiros/Enfermeiras.

RESUMEN

Objetivo: evaluar el conocimiento y la práctica de los enfermeros que trabajan en la atención primaria de salud como las acciones de control y eliminación de la hanseniasis. Método: es un estudio evaluativo con enfoque cualitativo, utilizando el Discurso del Sujeto Colectivo, cuyos datos fueron recolectados a través de entrevistas semi-estructuradas con 16 enfermeros. **Resultados:** los datos obtenidos revelaron que los profesionales de la salud tienen el conocimiento suficiente sobre la Política Nacional de Control y Erradicación de la Hanseniasis (PNCEH) y que las principales acciones recomendadas se han implementado, pero la notificación de los casos sospechosos o confirmados y reinserción social del paciente no fue mencionado. **Conclusión:** mantener a los pacientes en tratamiento, exceso de trabajo, falta de interdisciplinariedad y tratamiento realizado en otros lugares fuera de la comunidad fueron problemas reportados por el personal de salud. Los enfermeros conocen las acciones destinadas a ayudar a los pacientes con hanseniasis, sin embargo, el estudio apunta la necesidad de una practica más direccionado a lo que defiende la PNECH. **Palabras claves:** Lepra; Atención Primaria de Salud; Enfermeros/Emfermeras.

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INTRODUCTION

The Family Health Strategy (FHS) emphasizes the practices of health promotion and disease prevention, seeking for good resolvability of the most common problems of people at lower costs, giving priority to several specific areas, such as control of hypertension and diabetes, tuberculosis control, prevention of cervical cancer, and others. Among these, we can highlight the control of leprosy, a disease that has increasingly emerged as a public health problem and a challenge for health professionals and managers for its high prevalence and the negative impact that causes in population health⁽¹⁾.

Leprosy is a communicable disease caused by *Mycobacterium leprae*, an obligate intracellular bacterium that has tropism for skin and peripheral nerves, which causes changes in sensitivity of the areas affected by the presence of the bacillus⁽²⁾. This neural tropism, "is responsible for the potential disabling of the disease that, without intervention, generates deformities and disabilities, especially in the eyes, hands and feet". These problems will have a negative effect also on the psychological aspect of the patient, considering this as a cause of prejudice and social exclusion suffered by affected people⁽³⁾.

However, physical disabilities can be prevented or reduced if the affected people are early identified and diagnosed, treated with appropriate technique and monitored by basic health care services⁽⁴⁾. We emphasize the importance of having a multidisciplinary team able to act effectively in the treatment and control of leprosy, performing all actions established to face the problem, through a systematic and individualized follow-up throughout the course of the disease, including actions taken after patient's discharge.

Given the severity of the disease and the many problems caused by it, Brazil launched the National Program for Control and Elimination of Leprosy (NPCEL), which aims to develop a set of actions that aim to guide the different levels of complexity of health service in relation to the disease, strengthening epidemiological surveillance of leprosy, especially in primary care, and developing health promotion actions based on health education⁽⁵⁾.

The integration of leprosy control programs in basic health services is currently considered the best strategy to eliminate the disease, for early diagnosis and improved quality of care for leprosy affected, facilitating access to treatment, prevention of disabilities, and reducing the stigma and social exclusion⁽⁶⁾.

Despite the efforts that have been conducted over the years and the many strategies implemented in endemic countries, leprosy is still a public health problem, affecting approximately 1.5 million people worldwide⁽⁷⁾. In six countries the disease is considered endemic: India, Brazil, Madagascar, Mozambique, Nepal and Tanzania, with prevalence rates higher than 3.4 per 10.000 inhabitants. The total number of cases registered in these countries represents 83% of the overall prevalence⁽⁸⁾.

In 2012, Brazil diagnosed 33,303 new cases of leprosy⁽⁹⁾. In the world, it is in second place in absolute numbers of cases⁽¹⁰⁾. The national epidemiological panorama of leprosy is considered heterogeneous, since there are differences between the prevalence of various regions of the country, which is an indicator of disease transmissibility⁽¹¹⁾. In countries with epidemiological characteristics similar to Brazil, it is necessary to intensify leprosy surveillance, mainly aimed at greater effectiveness in diagnosis and completion of treatment.

Nursing is essential and fundamental in health care of the population and is part of a collective process of work within the FHS in leprosy control, acting directly in disease control actions, with affected people either individually, families or community⁽¹²⁾.

The nursing consultation is an activity provided by the nurse to the user, in which health problems are identified and also other diseases; nursing actions are prescribed and implemented for the purpose of promotion, protection, recovery and rehabilitation of the patient. In addition, it favors the individuals health, improves adherence to treatment, accelerates the recovery of the patient, reduces the cost of care, allows the diagnosis of their needs, allows resolute and qualified care, and directs the nursing actions provided⁽¹³⁾.

As a member of the multidisciplinary team in primary care, the nurse must assist the leprosy patient from the time of diagnosis to post-discharge follow-up, with an individualized and systematic care, enabling better client interaction, better adherence to treatment, promoting self-care and reduction of the resulting physical disabilities caused by the disease⁽¹⁴⁾. Additionally, nurses should also encourage client participation in the program, providing opportunities and stimulating the exchange of experiences and the discussion of the problems, and the values implicit in his/her life and his/her family.

Given the recognized importance of actions that nurses must carry regarding the patients affected by leprosy, we decided to identify the line between the actions established by the Brazilian Ministry of Health and the actions taken by these professionals in primary care of a city in the state of Ceara.

This work becomes relevant because we recognize that nursing should consider leprosy in its uniqueness, complexity and socio-cultural integration, seeking to promote health, prevention and treatment of the disease, and reduction of individual and collective harm, and the elimination of all forms of prejudice that may be affecting their quality of life.

Therefore, nurses as an integrating part of the team and historically an educator in their health actions, may contribute to the reflection on the possibilities of reorientation of care practices in this area, aiming to provide quality of care, focused on clients and their real needs.

This study aimed to assess the knowledge and practice of nurses in primary health care concerning control and elimination measures of leprosy.

METHODS

This is an evaluation study with qualitative approach, conducted from May to July 2011, in15 Basic Health Units (BHU) in a city in the semi-arid northeastern region of Brazil, with 16 FHS teams. The city has 21 Family Health teams, and over 20 BHU. The choice of this city is due to its partnership with the *Universidade Regional do Cariri*, characterized, thus as a field of research. It also has a high prevalence of new cases of leprosy⁽¹⁵⁾.

The study subjects were 16 nurses working in the FHS of the selected city. The inclusion criteria for the study were: nurses who have performing treatment in at least one client with leprosy in the BHU where they worked or have already cared for a client with leprosy at some point in their working lives. Two nurses did not fulfil the established inclusion criteria, two nurses were on leave for health treatment and one nurse was on holiday.

For data collection, we used a semi-structured interview instrument. It consisted of objective and subjective questions, clearly directed, highlighting the problem to be addressed. The first part of the instrument was designed to obtain professional data, such as: year of completion of undergraduate studies, whether they have specialization certificates, masters or doctorate degrees, if the nurse had any training on control and prevention of leprosy, how long they had worked for the FHS and how long specifically at the BHU.

The subjective data was composed by the following questions: Do you know the leprosy control program proposed by the Brazilian Ministry of Health? What are the main actions that must be performed by nurses in primary care, recommended by the control and elimination program of leprosy? Which of these actions do you perform at the BHU? What are the main difficulties or facilities that you can find for the implementation of the actions proposed by the control and elimination program of leprosy?

For better applicability, a pilot test or pre-test were conducted with the research instrument used in the study, seeking to correct possible errors and to validate the interview. The pilot

test was applied to four nurses from the rural area of the city.

For organization and analysis of the results, we used as technique the Discourse of the Collective Subject (DCS). This is a methodology of results presentation from qualitative research that aims to express the thoughts of a community, as if this collective thought was emitted by a single discourse. The DCS is a tabulation and organization technique of qualitative data which basically consists in analyzing the verbal material collected in research that have statements as the raw material, extracting from each of the core ideas and their corresponding key expressions⁽¹⁶⁾.

The DCS is a process divided into several stages, in which, based on the statements, comprising the responses obtained in interviews, are followed by three basic steps: at first moment all discourses are transcribed together with their questions, analyzed one by one. Then we can identify Key Expressions (KE), which are pieces, excerpts or even verbatim transcripts of the discourse, which reveal the essence of the statement, which usually answers the question; the second stage, from KE, the Central ideas (CI) are extracted, which can be a name or sentence that describes more concise and accurate the sense of each analyzed statements; Finally, with the sum of KE and CIs that have similar or complementary sense are built the DCSs, referring to synthetic discourses written in the first person of singular, with the purpose of the "I" speak for a collectivity⁽¹⁷⁾.

The study met the rules governing research with human beings, according to Resolution 196/96 of the National Health Council of the Brazilian Ministry of Health. A consent form was presented for the research subjects, their anonymity was also ensured. The project was approved by the Research Ethics Committee, with protocol No. 06/2011.

RESULTS

The characterization of the nurses investigated became relevant because it provides an understanding of the care practices recommended by NPCEL.

As for the time of completion of undergraduate studies, eleven nurses reported having finished it between one and three years, three professionals reported having between four to six years of nurse experience, only one nurse reported having between seven and nine years of nurse experience and the number of professionals with ten or more years was one. The length of work of these professionals in primary care was the same as the academic background.

With regard to training in the prevention and control of leprosy, six nurses reported some type of training offered by the city Department of Health. We also asked whether they had conducted some training for FHS team. Of the participants, ten said they had never conducted any educational activity directed to that purpose. Nurses who had attended the activity performed only with the community health agents.

Referring to the specialization certificate, only one professional did not have it and was not taking any specialization course; other professionals were specialists in different areas of health, such as Public Health, Intensive Care Unit, Family Health Strategy, Occupational Health, Audit and Nephrology. None of the participants had or was enrolled in a master's or doctorate.

Completed the first moment of data analysis, followed by the analysis of the discourse of the collective subject stages, which emerged on the basis of the answers given to questions involving knowledge about NPCEL, the main activities performed by nurses and the facilities or difficulties encountered in practice of these professionals.

Discourse of collective subject analysis 1 - DCS 1

Box 1 - Cl 1: Knows the leprosy control program proposed by the Brazilian Ministry of Health, addressing goals and objectives

DCS 1: I have to identify the disease as early as possible to prevent it from spreading. Every time a patient comes to the clinic, whether for a routine visit or for anything else, I observe it. After identification, I have to classify and immediately treat him/her to break the chain of transmission of the disease. I have to block the patient and the communicant. When I identify a case, I always suspect that there are several others. So, I always have to search in the community. But I find much difficulty with my team. Sometimes I think I'm working alone, I need the whole team to make a commitment. It is not enough just me making the search for new cases. I think that's why there are still many cases of leprosy and we cannot eliminate it. It is still very common in Brazil.

Considering the discourse of the collective, it was found that knowledge of the program was adequate with the main goals set by the Brazilian Ministry of Health, which are early diagnosis, elimination of the disease through the well established treatment, and other actions concerning the pursuit of communicating and preventive practice in the community. However, a major goal was not mentioned by the participants, which is the importance of early diagnosis in children under 15 years old.

Discourse of collective subject analysis 2 – DCS 2

Box 2 - Cl 2: Key actions recommended by the National Program of Leprosy Control must be performed by nurses in primary care and which of these are carried in their units

DCS 2: I think the Ministry of Health basically calls for the active search for new cases with early identification, administration of the supervised dose and evaluation of contacts. These are the main actions established by the program. I always do health education in my area, it is the main action of the program, I do it a lot, even in the waiting room. I also give talks in the community, trying to raise awareness and educating the population. I think the active search is one of the most important actions to immediately capture this patient, therefore, the main function of the entire team. Observing the risk of population early diagnosis is essential. I'm always alert to any signs. Once I identify, the treatment immediately begins, then the patient has to come each month to the clinic to take the supervised dose. Then, I go to the home visit and do the assessment of people who live in the house, parents, children, everybody. I observe if all people have the scar of BCG vaccine. When the patient comes to the consultation, we examine the nerves to see if it has lost some movement. It is very important because if I do not look, they might never regain their movements.

With regard to nursing actions recommended by the program, it was found that the active search and early identification, supervised dose, evaluation of contacts, health education and home visits were the main actions established by the Brazilian Ministry of Health and the most mentioned by nurses who participated in the research.

Discourse of collective subject analysis 3 – DCS 3

Box 3 - Cl 3: Main difficulties or facilities encountered in implementing the actions proposed by the National Program of Control and Elimination of Leprosy

DCS 3: Patients who I monitor prefer to be treated in the hospital or by private doctors, than being attended at the clinic since it is a very busy place. So, I have to do everything without anyone knowing, because there is still a lot of prejudice. Another problem is that when they start the medication, and considering this is a long treatment, and realize improvements they tend to stop it. They are still not sensitive to continue the treatment and lack information. Moreover, today everything is very focused only on the nurse, I have to take care of all the FHS programs, and I can't. The paperwork takes a lot of my time. Another downside is lack of commitment by the other team members, which ultimately aggravates the problem; however, something that facilitates my work is the respect and the bond created with my patients. This relationship ensures a positive response about my work in the community.

Regarding the answers presented, the various discourses reported: the difficulty that nurses have to keep patients on treatment for the recommended time, work overload, especially the paperwork, lack of interdisciplinarity in assisting affected people by leprosy and prejudice experienced by patients.

DISCUSSION

Given the proposed changes with the advent of the Unified Health System and the Family Health Strategy, nurse have played a significant role in the process and their professional profile can be a determinant factor in the care provided.

Most of this research nurses were at a time of transition between the theory learned in universities and professional practice, and it may require a support during care practice. Therefore, it is important that the newly undergraduate nurses are trained and familiarized with all stages of the work process, in order to get the most out of all the theoretical knowledge that has been provided to them in academic life, and thus, knowing how to reconcile theory and practice in their field.

It is necessary, therefore, investment in human resources qualification policies for the needs of professionals working in the FHS teams, whose guiding conception would seek to strengthen the teaching-service integration around health professional training needs included in the program⁽¹⁸⁾. Trained health workers can offer the people a more qualified care.

Educational processes are fundamental in health services, however, such processes, which occur through qualification, training or long term courses may not be punctual, seeking to critically address the problems encountered in professional practice to better understand the determinants of the phenomena⁽¹⁹⁾.

The training of professionals involved in leprosy care is one of the expected results with the development of the National Policy for Control and Elimination of Leprosy established by the Brazilian Ministry of Health in order to support the elimination of the disease as a public health problem in the city⁽²⁰⁾. What should be clear is that these professionals always seek knowledge without necessarily waiting for the initiative of managers who, for the most part, do not prioritize the continuing education of their teams.

In the structure proposed by the FHS, nurses play an important role as team coordinators in addition to acting as an educator. One of their functions is to train all staff so that everyone can work in harmony, thus, ensuring the universality and accessibility in health care, in order to develop more extended actions of surveillance, not only in understanding the epidemiology, but above all, health surveillance.

Due to their work as educators, it is essential that professionals seek to enhance their knowledge. In this study, only one nurse did not have a specialization certificate. It is noticed that the specialists have professional experience and maturity, which favors the implementation process on the quality of care. Thus, nurses are increasingly required so they can, competently, correspond to changes in their work environment⁽²¹⁾. Therefore, it is understood that the professional qualification will be the difference in providing care, promoting the achievement of their role within the team, allowing them a more critical view and greater competence in carrying out their tasks.

During the discourse analysis of the interviewed nurses, it was possible to identify the knowledge and practice of care provided to patients affected by leprosy.

In the DCS 1, the central idea draws attention; the knowledge of the actions recommended by the NPCEL, which showed the importance of early diagnosis and treatment for leprosy patients, included in the disease control actions, the pursuit of contacts and preventive practice in community.

However, a major goal was not mentioned by the participants, which is the importance of early diagnosis in children under 15 years. It should be noted that the non-detection in children under 15 years, aggravates the situation because the disease is usually manifested in childhood, especially in the age group of zero to five years, which indicates high endemicity, lack of information and lack of effective actions to health education. Brazil, as a country with high prevalence of leprosy, facilitates early exposure of children to adults with active bacillus⁽²²⁾.

The DCS 1 excerpt that refers to the feeling of the professional being alone and the lack of commitment on the part of some members of the team should be highlighted. This highlights the fragility of interdisciplinarity and teamwork, conditions necessary for the smooth running of the FHS.

It is essential to clarify patients' doubts through nursing consultations, with regard to various aspects of leprosy in order to understand the clinical manifestations, the importance of adherence to treatment, and control of contacts so that they feel encouraged to self-care, as this is key to improving the patient's quality of life and maintenance of health.

In the DCS 2 the main actions recommended by NPCEL were described and if nurses perform them, leading to the belief that

most actions are performed by these professionals. Early diagnosis, proper treatment as the monitoring of signs of reaction, the immediate treatment of reactions, the examination of contacts and vaccination are priority nursing actions for the elimination of leprosy⁽¹⁾. Home visits are another form of leprosy control, which should be made, when necessary, by the family health team.

Active surveillance plays an important role, since it is a tool that leads to early identification of cases in the community, the increasing number of cases identifies the affected who abandoned treatment and detect the disease at an early stage, helping to ensure reduced disability, social exclusion and stigma⁽²³⁾.

The main actions recommended by NPCEL were addressed by the study participants, however, the reporting of suspected or confirmed cases and the social reintegration of the patient, were not mentioned by the nurses. Failure in reporting is an epidemiological silence, leading to a worrying epidemiological panorama, not to highlight the reality of the disease profile, implying, among other losses, the lack of investment and improvement of public policies for this population.

The social isolation of the leprosy patient intensifies social inequalities experienced by the stigma that the disease brings, disseminated in precarious work and life situations, further strengthening the characteristic prejudice of the disease⁽²⁴⁾. However, nurses need to approach this reality, promoting patient autonomy, with the aim of agreeing on proposals for treatment, implementing self-care in order to minimize the impact of the disease in their lives.

The DCS 3 only highlighted the difficulties faced by nurses in implementing the actions proposed by NPCEL, namely: treatment non-adherence, work overload, lack of interdisciplinarity during care and prejudice of the patients about the disease. This fact may be evidenced by the preference of patients to receive treatment outside the community, showing interest in concealing his/her leprosy condition. It is noteworthy that no facility was mentioned on these actions.

Treatment non-adherence implies a reflection on the risk of transmission of active bacillus cases detected and not treated properly, the risk of developing physical disabilities, and the risk of developing drug-bacillary forms resistant to the current drugs used as best treatment regimen. Authors point out that the socio-cultural aspect of individuals as knowledge, attitudes and practice of leprosy and the access to information, can influence treatment adherence⁽²⁵⁾.

The DCS 3 pointed out as one of the difficulties for carrying out activities aimed at NPCEL, work overload, especially from the paperwork. In a previous study, the authors reported that a difficulty of nursing in the FHS is the work overload by demand and lack of health professionals, which has generated demotivation for the team and job dissatisfaction⁽²⁶⁾. Another study reports that in Family Health Units, nurses develop, on a daily basis, multiple activities in the field of care, management, education and training, broadening their responsibilities, which, associated with the existing difficulties and the interest to provide the smooth running of the service, overload their everyday⁽²⁷⁾.

Another barrier cited by study participants refers to interdisciplinarity in the care of patients suffering from leprosy. Teamwork is essential to the smooth running of the FHS and of all people connected with it. However, teamwork is also presented with great limitations, when it reveals the absence of collective responsibility for the work and the low degree of interaction between the professional categories. Despite the equalitarian discourse, members of the family health teams maintain representations of hierarchy between professionals and non-professionals, higher education level and secondary education level, physician and nurse⁽²⁸⁾.

In Brazil, leprosy remains a major public health problem all over the country. From this perspective, one can see that the nursing professional has played a strategic role for integrality and humanized care at SUS* and in the FHS, and for the organization of services across the health team, contributing to the development of interdisciplinary activities and the fulfillment of the goals established by the various programs included in primary care, including NPCEL.

FINAL CONSIDERATIONS

In the construction of discourses, we found that the collective studied has sufficient knowledge about the program proposed by the Brazilian Ministry of Health. Although they

did not mention two of the major goals set by the program, the professionals showed their capacity to develop the proposed actions. They are also sensitive and aware that the goal of elimination of leprosy is not being fulfilled. This is a positive element because it demonstrates knowledge of the epidemiologic situation of the area and provides a review of its care practices aimed at solving the problem.

We can also see that the main actions recommended by the control and elimination program of leprosy have been addressed in the statements and, according to professionals, also implemented. However, two important actions were not covered by the interviewees, the reporting of suspected or confirmed cases and the social reintegration of the patient. These actions are essential for the control and elimination of the disease. This may have been a result of lack of periodic training by nurses.

Some limitations were found in the study. One was the small sample size, since the study setting was only one city. Additionally, the professional practice was assessed from the perspective of the subject of the study, thus, the real situation was not investigated.

* Unified Health System of Brazil.

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