

120 - FACTORS THAT INTERFERES IN ACTIONS AND CONTROL OF THE LEPROSY IN THE USER'S PERSPECTIVE IN RIO GRANDE DO NORTE

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INTRODUCTION:

Leprosy is a millenarian disease that is still a problem of public health in the world, mainly in developing countries. Among these, Brazil is one that still presents areas of large endemicity, as the regions North, Midwest and Northeast of the country.

The main characteristic of the disease is the commitment of peripheral nerves, which results in a large potential to cause physical disabilities which can evolve to deformities, which ones might result in serious problems, such as: decrease in capacity to work, limitation of social life and psychological problems. They are also responsible for stigma and prejudice against the disease. The bacillus predilection for the skin and peripheral nerves gives peculiar characteristics to this disease which makes the diagnoses be simple. In majority of cases, it can be done just by clinical exam (BRASIL, 2002).

Through the Ministry of Health, Brazil assumed the commitment to eliminate leprosy up to 2005, which was not effected, being reconsidered as a target for 2010. In order to achieve this goal, one of the main strategies used by the Brazilian government was the wide decentralization of Leprosy Control Program (PCH) for municipalities, within the context of the Unique System of Health - SUS (BRAZIL, 2005).

In Rio Grande do Norte, the PCH passed through a restructuring that started in 1996, when the database was computerized and had its information checked by the data from local health units and regional of health. In 1997, the state started receiving support from the British ONG "The Leprosy Relief Association - LRA" which allowed realization of annual training courses for municipalities, effectively starting the process of decentralization of the PCH (NOBRE, 2004).

It is important to emphasize that for the actions of PCH to succeed the path is to integrate actions across the whole SUS network. Studies (MUNHOZ Jr., et al, 1997) performed in the states of Maranhão and Mato Grosso made evaluation of the decentralization program and concluded that there was a quantitative and qualitative improvement in health services with the advance of this process.

OBJECTIVE:

This study aims to identify factors which are interfering in actions from the Leprosy Control Program in the state of Rio Grande do Norte under the perspective of users.

METHODOLOGY:

The study characterizes by an operational research, or Investigation at Health Systems (ISS), of descriptive and quantitative character. The Investigation at health systems have proved to be an extremely useful tool for managers of health in all levels of the system over the last 15 to 20 years at providing necessary data for decision making.

The criterion for inclusion of selected municipalities was that ones with the highest detection rate in the last three years. We emphasize that for this study among the municipalities that had the same detection rate in the last three years, those which had the least number of inhabitants were selected, which means higher detection. The sample consisted of the following countries: Metropolitan Region: Natal, 1st Regional Unit of Public Health (URSAP): Nova Cruz, 2nd URSAP: Mossoró; 3rd URSAP: Macau, 4th URSAP: Caicó; 5th URSAP: Lages Pintadas; 6th URSAP: Pau dos ferros.

The study population consists of sixty-one (61) users of the municipalities that were selected in the active record in 2006. These were identified based on the database of the National System of Notifiable Injuries (SINAN) from State of Rio Grande do Norte.

Data collection was conducted from May to October 2006 at the following locations: the Hospital Reference Giselda Trigueiro, in Natal; ambulatory from the Academical Hospital Onofre Lopes (HUOL), located in Natal; Municipal Hospital Monsenhor Pedro Moura, in Nova Cruz; Health Center of Macau; ambulatory from the Hospital Rafael Fernandes; PAM Bom Jardim, Health Unit of Santo Antônio; in Mossoró, Clinical Center Dr. Gerson Feitosa; PSF Itans; PSF Paul VI; UBS Paraíba; PSF Boa Passagem, in Caicó.

The study followed the parameters of the resolution 196/96 from the National Health Council (CNS), which directs the ethic principles of researches involving human beings. It was assessed by the ethic committee of the Federal University of Rio Grande do Norte being approved by the Protocol nº 023/06. Data analysis of the study was done using the software Microsoft Office Excel, where the data were consolidated and analyzed.

RESULTS:

From the 61 users interviewed, 6.55% are from the Health Center of Macau; 11.47% from Hospital Pedro Moura - Nova Cruz; 32.78% from Hospital Giselda Trigueiro; 4.9% from HUOL in Natal; 8.19% from Caicó; 40.98% from the Health Center Chico Costa; 11.4% from the Hospital Rafael Fernandes; and 16.39% from the Clinical Center Professor Vingt-Un Rosado in Mossoró.

It is noteworthy that in the municipalities of Lajes Pintada and Pau dos Ferros, at the time the research was conducted, there weren't cases in active record. The average age is 45-48 years old, presenting a minimum of 19 and maximum of 99 years old. As for gender, 37.71% are male and 62.29% are female.

In relation to occupation, 81.98% are working and 18.03% are unemployed. Among these, 24.59% are from home; 13.33% are retired; 6.55% are farmers; 3.27% are pensioners; 3.27% are teachers; 3.27% are street sweeper; 3.27% are hodmans; 3.27% are hairdressers; 3.27% are machinists; 16.3% others.

As for the family income, 11.8% earn less than a minimum wage; 70.6% earn from 1 to less than 4 minimum wages; 5.9% earn from 4 to less than 8 minimum wage and 11.8% earn from 8 to less than 12 minimum wages.

Regarding the data of the disease was it was contemplated the time of diagnosis, treatment with polychemotherapy,

prevention of disabilities, leprosy reactions and the presence of disease in relatives. About the time of diagnosis 82.4% found more than a month and 17.6% were diagnosed less than a month.

In relation to treatment with polychemotherapy, 88.2% use it regularly and 11.8% finished regularly. As for the inability installed, 88.2% do not present it and 11.8% do. In item on presented reactions 58.8% had leprosy reactions and 41.2% had no reactions. When questioning about the disease in other family members 88.2% reported not having cases and 11.8% confirmed the disease in the family.

Besides customers' characterization and data about the disease, areas, which evidenced user's opinion about received assistance, were contemplated. In the area of search behavior in health were approached demands of the service, relation between the time the problem was identified and received attendance. In questioning about the looking for other health services before the current one in order to take care of leprosy, 88.2% confirmed not having sought another service and only 11.8% sought other assistance to health.

The search for spontaneous demand was 52.9% and 47.1% by routing. Note that the reference routing occurs mainly in the Hospital Giselda Trigueiro and HUOL.

When questioning about the reasons for them to have spontaneously sought health services, motivations reported had the same percentage (14.3%) and were: nodules and pain in the limbs, contacts and symptoms after BCG, the presence of spots on the face, guidance through the child, receipt of pamphlets about the disease, appearance of spots on the back and the appearance of a numb spot.

In item closest unit from their residence, 52.9% confirmed the existence health unit and 47.1% ignored the existence of health unit. As for the factor time of disease perception or confirmation of diagnosis in years by health professionals, we have found the following results: 28.6% did not confirm the time, for others (1, 2, 3, 7 and 15 years), the percentage was the same: 14.3%. The factor time of disease perception in months and attendance at the health unit to confirm the diagnosis: 25.0% reported the time of 4 months; the remainder was divided equally, with 12.5% for the others (2, 4, 6, 7, 8 and 15 months).

With regard to notice the problem and be attended by the first time in any unit in days: 33.3% reported receiving attendance in 7 days, 16.7% for each of the other options in days: 1, 3 and 15. And 16.7% did not mark the number of days. In months: 16.7% in 1 month, 33.3% in 2 months, 33.3% in 6 months and 16.7% in 7 months.

Regarding how long it took between noticing the disease and being attended in this unit. In days: Quanto ao tempo que demorou entre perceber a doença e ser atendido nessa unidade. In days: 37.5% did not make numerical registry of this time; 1 (12.5%), 4 (12.5%), 7 (12.5%), 14 (12.5%) and 15 (12, 5%). In Months: 1 (40.0%), 6 (20.0%), 7 (20.0%) and 14 (20.0%). In years: 3 (33.3%), 2 (33.3%) and 33.3% did not make numerical registry.

According to the Ministry of Health (BRAZIL, 2001) "the Program of Leprosy Control is operationalized through the implementation of activities of disease control in all health units of the basic network from SUS so that the entire population has access to these activities. The (primary health care), secondary care and tertiary care (specialized units and general hospitals)".

In relation to education in health to users who participated from this research: 62,5% heard about the disease before their diagnosis and 37,5% did not hear before.

From the users who heard about the disease before their diagnosis: 27.3% heard about on TV, and the same percentage for the other options (9.1%): through posters, radio and TV; with the population; on media and posters in health center; in the child diagnosis; at the health center; at the health center, poster and pamphlets; TV and posters.

With these data we refer to the guidelines of the Ministry of Health (BRAZIL, 2001) that tells us: "health education, understood as a transformative practice should be inherent in all efforts to control leprosy, developed by health staff and users including family relationships established between health services and population".

Accessibility in terms of organization and geography was partially contemplated through an understanding of users about the existence of health units near their residence with 52.9%, as well as those who did not know, with 47.1%. Technically, this fact alone shows that the population is unaware of the health services at the community they belong to.

Regarding information to patients were included aspects of origin of information received, knowledge about leprosy reactions and suggestions.

Regarding the information received from health professionals after the diagnosis of disease, 76.5% reported receiving information about the transmission and 23.5% did not receive this information. About leprosy reactions, 82.4% received orientation and 17.6% report not having received.

About the treatment, 88.2% had information and 11.8% did not. About self-care, 70.6% received orientation and 29.4% did not. All of them (100%) received information about the examinations of contacts.

About family relationships, professional and community, 76.5% received orientation and 23.5% did not. About the existence of physical disabilities potential, 70.6% received information and 29.4% did not. From the interviewed 94.1% were aware of possibilities of reactions to drugs and 5.9% did not. As for the time of treatment, 94.1% were informed and 5.9% received no information. On the meaning of cure of the disease, 82.4% received information and 17.6% did not.

In the item information given to patients and their families, the interviewed found: good (13.3%); sufficient (3.3%); satisfactory (13.3%); great (13.3%); excellent (6, 7%); weak (6.7%); had no information on forms of disease, signs and symptoms (6.7%); did not obtain information about the transmission of the disease (6.17%).

In relation to leprosy reactions: 23.1% received no information and 76.9% received guidance about the same. They obtained the information: 55.6% from doctors, 22.2% from nurses, 11.1% through information on the Internet, 11.1% from the multidisciplinary team.

In relation to examination of contacts, it was approached orientation of relatives and strategies used in the search of contacts. In the matter of examinations of family members, 58.8% were examined and 41.7% said they were not. About the orientation for the family to seek health unit with routing, 82.4% confirm had been oriented and 17.6% answered no.

Regarding the team which visit homes to examine family members, 88.2% reported that there are no visits and 11.8% said there are visits. About user's opinion regarding the treatment of leprosy patients compared to other patients, 58.8% said there is no difference, while 29.4% said that there is difference and 11.8% did not know to inform.

It was approached differences in attendance, attendance performed by the same professional, reliability in care and opinion about the training of professionals.

When asked if they were attended always by the same professional, 52.9% said yes, 41.2% answered no and 5.9% do not know. As for the security felt by the users interviewed from the health team which provided services to them, 81.3% trust in professionals' knowledge about leprosy and 18.8% do not.

When asked about the need for additional training to health professionals, 64.7% think that there is no need, 29.4% said yes and 5.9% did not know whether they need. From those who said yes, 100% affirmed to have some training in order for them to be trained to guide patients about the disease.

When questioned about the why of these trainings, interviewed answered: 25% to spread more the disease, 25% to improve knowledge and performance in health actions, 25% because they do not undergo appropriate treatment and 25% because they look for other professionals in search of information.

Regarding the attitude of the teams, the subjects reported that there is no difference between the attendance of leprosy compared with other diseases, once health professionals besides having a higher frequency in the attendance, they provide information about treatment and medicines. Most users claim to be attended by the multidisciplinary team. This organization demonstrates the importance of participation and integration of team members in relation to the execution of actions of programs.

Following it was contemplated the treatment area by demonstrating the existence of drugs, belief in the cure of leprosy and adherence to treatment.

As for the availability of medicine for the treatment in their unit, for Polychemotherapy: 81.3% said yes and 18.8% denied such availability. About prednisone: 66.7% confirm availability and 33.3% say they have no availability.

About thalidomide: 56.3% have it available in the treatment unit and 43.8% do not have this medication in their unit training.

As for the non-availability: 66.7% report having passed 7 days without this medication and 33.3% 14 days. All (100%) did not look for anywhere, they were waiting the problem to be solved.

In item credibility on the cure for the disease when taking the medicines: 82.4% believe yes and 17.6% do not believe in being healed, justifying the denial due to manifestations of reactions (33.3%) or that reactions and disabilities can not be cured (33.3%) or because they believe the disease is slow to appear and also to disappear (33.3%).

Those who believe in healing, they were asked if they use any medicine: 60.6% say they use, 26.7% said they do not use and 13.3% do not know.

When we asked users if any of them thought to stop taking the medication: 76.5% answered no and 23.5% confirmed that yes. For those who said yes, the reasons are: 50% felt malaise and 50% felt stomachache.

The reason that justifies them for stopping the drug was: 33.3% could not stand to see the drugs, 33.3% felt stomachache, and 33.3% felt tremors and headache.

About the return from treatment: 50% returned and 50% did not return. For those who returned: because they were afraid of complications and had seen the community health agent 3 times (50.0%) or because they wanted to get better (50%). All (100%) returned to the same health center.

As regards the Polychemotherapy, the study shows there is enough number, while for the anti-reactional drugs there is change, since the absence of medicine in health care is frequent. This reality goes against what tells us the Ministry of Health (BRAZIL, 2001, p.30) which states "the integral treatment of leprosy cases includes specific chemotherapy treatment, its monitoring in order to identify and treat possible intercurrent and complication of the disease and prevention and treatment of physical disabilities".

In the area of disabilities prevention it was only contemplated the aspect of guidance on how to prevent disabilities. On the receiving of these guidelines: 76.9% say they received it and 23.1% answered no.

The last covered area refers to the stigma, which was identified by users' attitudes on telling people about their disease, its influence on daily life and awareness of discrimination against people. When asked if they told anyone about the disease: 88.2% said yes and 11.8% say they did not tell anyone.

As for the influence of the disease on daily life: 58.8% said there is no influence and 41.2% reported that there is. When answering about how their daily life was affected: 22.2% said they stopped doing home activities, 11.1% are away from work and unable to retire, 11.1% stopped working; 11.1% got discouraged but with hope, 11.1% could not stand working, 11.1% said it interfered in their leisure (sun and alcoholic drinks), for 1.1% it interfered in their job and 11.1% say the spots on the body interfered with prejudice and fear from people at contracting the disease.

In the item: if they noticed differences on their friend's behavior when they started knowing about the diagnosis: 11.8% observed difference and 88.2% felt no difference in treatment. For the family: 82.4% did not notice differences. However, 17.6% felt changes in the treatment of their relatives. As for co-workers: 94.1% noticed no difference and 5.9% felt difference. For those who confirm this change in treatment: 33.3% avoid getting together, separate utensils, separate room at home, 33.3% fear of contamination, 33.3% questions about skin color and why it is ugly.

When questioned about the perceived discrimination: 93.8% say they do not feel and 6.3% said they do. From these, 100% answered: in public transportation and looks of people.

Goffman (1998) affirms that stigma is characterized by society, by attributes considered unusual and unnatural, observed and documented in multiple psychosocial interactions. These features can be "evident and distinct" and/or "not perceptible", allowing individuals to construct their "social identity". In other words, the stigma can be understood as a deviation from the standard of social behavior.

Queiroz and Puntel (1997) affirm that the changing of the term "Leprosy" to "Hansen's disease", due to the reconstruction of the Ministry of Health in mid-1974 has helped to reduce prejudice and stigma surrounding the disease, although partial, that by itself has a limited scope and must be accompanied by educational campaigns.

FINAL CONSIDERATIONS:

After the development of this research we concluded that the proposed objective was achieved when we identified the factors which interfere in the control program of leprosy from the perspective of users from the state of Rio Grande do Norte. These factors are critical points that difficult effectiveness of decentralization of the PCH, as the difficulty of accessibility to health units with resoluteness, the later diagnosis of the disease, the difficulty of reference and cross-reference with clarification on the status of user's disease, lack of leprostatics in municipalities and anti-reactional drugs, disabilities in guidance of health professionals to patients and relatives about the actions of PCH, difficulty with information on the care received in general from health units, attendance in service by only one professional during treatment, professional without mastery on knowledge about actions of HCP, changes in user's daily life, lack of guidance/information about leprosy reactions.

From this identification the state of Rio Grande do Norte will be able to promote policies and strategies of action in order to ensure achievement of full quality actions in the SUS network and the elimination of leprosy.

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FACTORS THAT INTERFERES IN ACTIONS AND CONTROL OF THE LEPROSY IN THE USER'S PERSPECTIVE IN RIO GRANDE DO NORTE

ABSTRACT

This study has an objective identifies the factors that interferes in the actions and control of the leprosy in the state of Rio Grande do Norte under the users perspective. The study is characterized by being an operational research. The population's study was composed by 61 users in active registration in the year of 2006. The data were consolidated and analyzed by the program MICROSOFT OFFICE Excel. After analysis we presented those factors: accessibility difficulty to the units of health with resolution, the belated diagnosis of the disease, the reference difficulty and against-reference, anti-leprosy medications lack in the municipal districts and medications anti-reactionaries, deficiency in the orientations and lack of the professionals of health domain about the actions of PCH.

KEYS-WORDS: leprosy, control program, elimination, nursing.

FACTEURS QUI INTERFÈRENT DANS LES ACTIONS ET CONTROLE DE LA LÈPRE SOUS L'OPTIQUE DES USAGERS DU RIO GRANDE DO NORTE

RÉSUMÉ

Cette étude vise à identifier les facteurs qui interfèrent dans les actions et le contrôle de la lèpre dans l'état du Rio Grande do Norte sous l'optique des usagers. L'étude se caractérise comme une recherche opérationnelle, dont la population fut composée de 61 usagers figurant sur un dossier actif en 2006. Les données furent consolidées et analysées par le logiciel MICROSOFT OFFICE Excel. Après l'analyse, on présente les facteurs suivants: la difficulté d'accès aux centres de santé, le diagnostic retardé de la maladie, la difficulté de référence et contre-référence, le manque de Leprostatics dans les villes et des médicaments anti-réactionnels, la faiblesse des orientations et le manque de connaissance des personnels de santé en ce qui concerne les actions du PCH.

MOTS-CLÉS : Lèpre, programme de contrôle, élimination, soins infirmiers.

FACTORES QUE INTERFIEREN EN ACCIONES Y CONTROL DEL MAL DE HANSEN EN LA PERSPECTIVA DE LOS USUARIOS EN RIO GRANDE DO NORTE

RESUMEN

Este estudio tiene como objetivo identificar los factores que interfieren en las acciones y en el control de la lepra en el estado de Rio Grande do Norte, desde la perspectiva de los usuarios. El estudio se caracteriza por una investigación operativa. La población del estudio consistió en 61 usuarios en el registro activo en 2006. Los datos se agruparon y se analizaron con el software de Microsoft Office Excel. Después del análisis de los datos obtenidos se arriba a estos factores: la dificultad de acceso a los centros de salud con solución, el diagnóstico tardío de la enfermedad, la dificultad de referencia y contra referencia, la falta de leprostatics en los municipios y medicamentos anti-reactiva, las inexactitudes en las directrices y falta de control de profesionales de la salud acerca de las acciones de PCH.

PALABRAS CLAVE: lepra; programa de control; eliminación; enfermería.

FATORES QUE INTERFEREM NAS AÇÕES E CONTROLE DA HANSENÍASE NA PERSPECTIVA DOS USUÁRIOS NO RIO GRANDE DO NORTE

RESUMO

Este estudo tem como objetivo identificar os fatores que interferem nas ações e controle da hanseníase no estado do Rio Grande do Norte sob a perspectiva dos usuários. O estudo caracteriza-se por uma pesquisa operacional. A população de estudo foi composta por 61 usuários em registro ativo no ano de 2006. Os dados foram consolidados e analisados a partir do software MICROSOFT OFFICE Excel. Após análise apresentamos esses fatores: dificuldade de acessibilidade às unidades de saúde com resolutividade, o diagnóstico da doença tardio, a dificuldade de referência e contra-referência, falta de hansenostáticos nos municípios e medicações anti-reacionais, deficiência nas orientações e falta de domínio dos profissionais de saúde sobre as ações do PCH.

PALAVRAS-CHAVES: hanseníase; programa de controle; eliminação; enfermagem.

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