

TRAJECTORY OF LEPROSY CASES AND RELATED FACTORS

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ABSTRACT

The objective of this study was to analyze the trajectory of the cases diagnosed with leprosy and related factors, focusing on the prevention and control actions recommended by the Ministry of Health. Descriptive cross-sectional study. The data were collected through a structured household interviews, using the Open Data Kit collect program. They were exported, processed and analyzed in the Statistical Package for the Social Science (SPSS®) v.24. For the calculation of the late diagnosis, three variables were considered, one of them being sufficient: passing through more than one health service; one more time; or more than six months between the first signs and symptoms until the effective diagnosis. Of the participants: 69.6% at the first symptoms sought the nearest health service; 43.5% sought the Basic Health Unit of reference; 73.9% reported a delay of less than or equal to one month for consultation; 34.8% diagnosed in outpatient referral; 82.6% were diagnosed late; there was no participation in waiting room or educational group with leprosy theme in basic reference health units; 21.7% ram denies access to self-care guidelines. Operational difficulties evidenced by late diagnosis and inadequacy of leprosy prevention and control actions advocated by the Ministry of Health were detected.

Keywords: Leprosy. Epidemiological Monitoring. *Mycobacterium leprae*.

INTRODUCTION

Leprosy is still a public health problem in Brazil, even with guidelines for surveillance, care and elimination as a public health problem. In 2017, presented over 26 thousand new cases and overall detection rate per 100 thousand inhabitants of 12,9, the first time since 2008 that there is an increased number of new cases in the country⁽¹⁻³⁾. It is noteworthy that of the 22 countries of global priority for leprosy, Brazil is among the eight that presented an increase in the number of new cases from 2016 to 2017. Added to this, is the fact that Brazil, along with India and Indonesia, account for 80,2% of new cases in the world in that year⁽¹⁾.

Since the standardization of polychemotherapy (MDT) for the treatment of leprosy by the World Health Organization (WHO) and its recommendation by the Ministry of Health (MS), there was a decrease in the prevalence of the disease, but it was not enough to eliminate it the entire national territory, since it is related to operational difficulties for timely diagnosis and early treatment, as well as presence of hidden

prevalence⁽²⁾.

Late diagnosis and treatment are the main factors that interfere in the control of the disease and perpetuate the transmission chain, since it occurs from the bacilliferous patients who did not start treatment. In addition to these factors, there are chronicity of clinical manifestations, operational difficulty of health services, lack of knowledge about clinical manifestations and stigma still present in society, culminating in prejudice to those affected by the disease^(4,5).

Aiming to know the factors that are associated with late diagnosis and treatment, a study of the trajectory of the leprosy case can be made, and it is possible to identify misconceptions that may occur situations that need to be maintained because they bring positive results^(6,7).

Therefore, the interest of analyzing the trajectory of the cases diagnosed with leprosy, as well as analyzing the related factors, with focus on the actions of prevention and control of leprosy recommended by the Ministry of Health, arose.

METHODOLOGY

*Originating from The Capstone Project with the name "Trajectory of cases diagnosed with leprosy in a municipality of Zona da Mata Mineira" presented to the Nursing School of the Federal University of Juiz de Fora (UFJF) in the year of 2017.

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This is a descriptive cross-sectional study, with people diagnosed with leprosy in the period from 2011 to 2016 from a municipality in Zona da Mata Mineira, chosen because it was the only one in the mesoregion to present cases of leprosy in the years 2015 and 2016 and the one that presented the most cases during the study period.

The study participants were 23 cases of leprosy diagnosed in the period mentioned above, residents in the urban area of the municipality. These were selected from the database Sistema de Informação de Agravos de Notificação – SINAN, provided by the State Department of Health Dermatology of the Minas Gerais State Health Department (CEDS / SES / MG) and services of the municipality.

Data collection was through household interviews in which the selected participants were individually approached, questioned about the interest of participating in the study, proceeding to the application of the structured questionnaire consisting of questions related to the identification of the leprosy case, to the trajectory until the effective diagnosis, and to the organization of the actions of prevention and control of leprosy. The clinical information was extracted from SINAN.

Data collection took place between August and October 2016, by three researchers duly trained in the approach and application of the questionnaire.

The data, after the collection through the Open Data Kit (ODK) collect program, were exported, processed and analyzed in the International Business Machines Corporation (IBM®) Statistical Package for the Social Sciences (SPSS®) Statistics v.24 for Windows. A descriptive analysis of the data was carried out through measures of central tendency and dispersion. Subsequently the data were categorized and grouped.

For the calculation concerning the late diagnosis, two literatures were used, which bring: the user have gone through more than one health service or at least more than once⁽⁸⁾ and as a criterion of minimum time six months, considering the appearance of the first signs / symptoms to the effective diagnosis⁽⁹⁾. The three variables were crossed and all cases that fit into at least one of the possibilities were considered as a late diagnosis.

Participants who agreed to participate freely in the research signed the Free and Informed Consent Form. The research complies with all the determinations described in Resolution 466/2012 of the National Health Council, which determines guidelines and

norms regulating research involving human beings. It was submitted and approved by the Ethics Committee of the Federal University of Juiz de Fora under opinion No. 1,744,517, as well as authorization from the Minas Gerais State Health Department (CEDS / SES / MG).

RESULTS

The mean annual detection rate of new cases of leprosy in the study period was equivalent to 1.77 cases / 100,000 inhabitants, ranging from 2.69 in 2011 to 0.72 in 2016, presenting as the highest value 2.86 in 2012.

Of the total of 23 participants, 52.5% were female, 56.5% were between 46 and 64 years old, ranging in age from 28 to 87 years and 43.5% were married. As for education, 60.9% reported to attend primary school, and only one participant reports currently studying.

Regarding the work, 60.9% were not working, the monthly income variation being between R\$ 880.00 and R\$ 12,000.00. According to the Brazilian Institute of Geography and Statistics (IBGE), the group that predominates is class E, which receives up to two minimum wages (the minimum wage being equal to R\$ 880.00, referring to the year 2016, of data collection).

Of the factors related to the transmission chain, it has been that the majority, 82.6%, did not have or have cases of leprosy in the family. Regarding the presence of intradermal Calmette-Guérin Bacillus scar (BCG-ID), 17.4% presented no scar, 26.1% had one and 56.5% had two.

The majority of the cases had initial multibacillary operational classification (MB) (73.9%) and final as MB (78.3%), and 47.8% had a dimorphic clinical form. The treatment time most presented was 12 to 18 months (60.9%), and MB treatment (78.3%). There was grade 2 disability (G2D) in 17.4% of the participants at the time of diagnosis and in 4.3% in the medical release, with a degree of disability as ignored being 17.4%. The location of disabilities added up to seven reports in eyes, hands and feet. Regarding the leprosy reaction, 65.2% did not present and of the 8 that presented, 3 (37.5%) were type 1 and 3 (37.5%) were unspecified. Referring to relapses in leprosy, 13.0% presented it.

It was found that 73.9% were not aware of the initial symptoms of leprosy, 69.6% sought the health service closest to where they live as soon as they started, 34.8% sought a private practice and 43.5%

Primary Health Care (PHC) unit of reference. Regarding the difficulties of mobility to reach the health service, 87.0% reported that they did not have and the 13.0% who presented some, all said to be by transportation, distance and presence of hills in the route (Table 1).

As for obtaining consultation in the health service,

73.9% reported delay of less than or equal to one month. The number of diagnosed patients in a reference outpatient clinic was 34.8%, being the most frequent when compared to the number of patients diagnosed in a reference PHC unit, 13%, and a private practice, 17.4% (Table 1).

Table 1. Characterization of the factors related to the trajectory until the diagnosis of leprosy cases. Municipality of the Zona da Mata Mineira, Minas Gerais, Brazil, 2017.

Variables	n	%
Did you know the symptoms are related to leprosy?		
Yes	6	26.1
No	17	73.9
When you first noticed the symptoms, did you go to a health service near where you live?		
Yes	16	69.6
No	7	30.4
What was the first health service sought at the onset of symptoms?		
PHC unit	10	43.5
Outpatient clinic	1	4.3
Hospital	2	8.7
Private Office	8	34.8
Others	-	-
Do not know	2	8.7
Did you have mobility difficulties to get to the health service?		
Yes	3	13.0
No	20	87.0
How long did it take to follow an appointment at the health service (in months)?		
≤ 1	17	73.9
2	3	13.0
3	1	4.3
≥ 4	2	8.7
In which health service have you been diagnosed with leprosy?		
PHC unit	3	13.0
Outpatient clinic	8	34.8
Hospital	6	26.1
Private Office	4	17.4
Others	-	-
Do not know	2	8.7

The number of times when it was necessary to seek the health service to have the diagnosis that had the highest frequency was twice or more (69.6%). The time in months of delay for diagnosis varied from one month to 72 months, with a higher frequency in a period of up to six months (73.9%). The number of professionals that the participants passed until the diagnosis ranged from one to ten, with more than one professional (65.2%) being more frequent. From the calculation of the late diagnosis, it was found that 82.6% had at least one characterizing factor.

As for having treated for some other pathology rather than treating leprosy, 30.4% said yes, reporting:

arthritis; allergy; spur; dermatitis; ringworm; tuberculosis; emotional urticaria.

As for having suffered some kind of prejudice, 26.1% said yes, and there were reports of family members, co-workers, friends, PHC unit health professionals of reference and / or others. Others were reported by being bosses or neighbors. Regarding emotional support from the professionals who perform care of the participant, 17.4% gave a negative response.

From the participation of some educational group or waiting room that dealt with leprosy, all the participants reported never having participated.

Regarding the knowledge of some educational action with leprosy theme, 65.2% said they did not have it. And from the guidelines on self-care after diagnosis, 21.7% said they did not have access.

DISCUSSION

The prevalence of leprosy in the period from 2011 to 2016 shows a decrease, even with an increase from the year 2011 to 2012. This results in a reduction in the annual detection rate of new cases of leprosy per 100 thousand inhabitants. However, it cannot be said that the disease is on the way to elimination, since a previous study shows a hidden prevalence among the cities belonging to the Regional Health Superintendence to which it belongs⁽¹⁰⁾, which suggests operational difficulty in the timely diagnosis of the disease.

This study has a close number of male and female participants, but what was found in previous studies points higher number of male cases⁽¹¹⁻¹⁴⁾, in non - endemic areas.

The majority of the participants presented age from 46 to 64 years old, close to what was found in a previous studies, in which the majority were concentrated from 37 to 59⁽¹²⁾ and from 45 to 60 years⁽¹³⁾, suggesting a greater involvement of the age group population near the end of adulthood in regions not considered endemic.

The diagnosis of leprosy is possibly associated with a situation of vulnerability and requires attention⁽¹²⁾, since most of the participants do not currently work and receive up to two minimum monthly family income.

Most of the participants did not have or have cases of leprosy in the family, suggesting possible infection environment than intradomiciliary, but it is necessary caution when analyzing this data, since there are individuals who hide their symptoms, even their diagnosis, as a mechanism of protection and denial, due to the stigma still present today^(12,15-17).

From the presence of BCG-ID scar, it was found that the majority of the participants presented two scars, among which the largest number of cases obtained initial operational classification as MB. Previous studies have shown a decline in the overall detection of leprosy cases when combined immunoprophylaxis with BCG-ID and quimioprophylaxis with rifampicin, ofloxacin and minocycline (ROM)⁽¹⁸⁾. In addition, there is evidence that BCG-ID vaccination would provide greater

protection for MB forms than for PB forms⁽¹⁹⁾. The result of this study corroborates the finding of the previous study, which means that even if there is protection offered by the vaccine against leprosy, it is not possible to generalize this finding⁽²⁰⁾.

The characterization of the clinical data of leprosy cases shows that most participants had initially the operational classification being MB and borderline clinical form, in agreement with previous studies^(11,13,14). The evolution of the disease to such a situation may suggest the difficulty of the health system in the "timely" diagnosis when associated with the presence of individuals with grade 2 disabilities. Once decentralized, leprosy control and elimination actions should be reinforced because they are located at the main entry point of the Unified Health System that is the Primary Care⁽¹⁷⁾, which can not be stated in the municipality of this study.

Reinforcing the hypothesis of operational difficulty is the presence of recurrences at intervals shorter than the usual five-year intervals⁽²⁾, which leads us to reflect on whether there were actual cases of relapse, if the treatment was not effective and specific, if classification error occurred and, therefore, the therapeutic indication failed, or cases of reaction were treated as relapses.

At the time of diagnosis, a majority without disability or grade one disability was recorded, according to the literature⁽¹¹⁻¹⁴⁾. However, the proportion of cases of leprosy with G2 at the time of diagnosis was high, higher than 10 %⁽²⁾, which, together with the high rate of individuals diagnosed as MB, suggests the presence of late diagnosis and operational difficulty⁽⁵⁾.

When comparing the degree of physical incapacity at medical release with the same indicator at diagnosis, it is noted a decrease in the degree and increase in the number of individuals without disability, however it is relevant to point out that there was a high number of people who had the assessment at the ignored high.

When the first symptoms were felt, most of the participants reported that they had sought the health service close to where they lived, even though most of them said they were not aware of the association of what they felt is related to leprosy. The first health services sought at the onset of symptoms were the PHC unit, whether traditional or family health strategy units. In addition, the majority of the participants stated that they did not find difficulty in mobility to reach the health service sought. This result reinforces the importance of the strategy of decentralization of

leprosy control actions to the PHC units⁽¹⁷⁾.

It is recommended that the diagnosis be given already in the first service sought by the users^(2,8,17-20), but it is emphasized that, even if the demand is higher by the PHC units, the private clinics, together with the reference clinics and hospitals, presented higher diagnostic numbers, leading to the belief that primary health care services are referencing individuals with signs and symptoms.

In this context, it is worth mentioning that one of the referral outpatient clinics in the city is located in a hospital institution, leading to reflect if the cases that reported having been diagnosed in hospitals were actually diagnosed in an outpatient clinic and characterizing diagnostic difficulty outside of these centers, which would contribute to the permanence of the transmission chain, since there is an association between delay to obtain consultation the more specialized the service.

Still, regarding the operational difficulty of the municipality, corroborating for this conclusion, there is the fact that there is an expectation report to get consultation in health services (when it should be care by spontaneous demand and / or by active search actions) and necessity of seeking health services twice or more, with a delay of up to six months for effective diagnosis and most having to go through more than one professional.

Important aspect observed in the study and that is directly related to the dissemination of information about the disease, is the psychological impact and stigma still present. Of the 23 participants, 26.1% said they had suffered some kind of prejudice because they had leprosy and 17.4% said they had not received emotional support. This leads to think that there is still stigmatizing factor of the disease, which may be related to an attempt to cover-up diagnostic denial and favor late diagnosis and treatment dropout, adversely affecting the transmission chain interruption^(15,16).

From the characterization of the factors related to the organization of the actions of prevention and control of leprosy, we have, from the result, that the thematic leprosy is little explored in the educational actions in the PHC units of the participants, but that exists, since even if none of participants reported having participated in either waiting room or educational group, involving the theme, 34.8%

reported having knowledge that the subject had been approached in some educational activity.

This picture configures a municipality subject to maintenance of the chain of transmission and installation of disabilities^(4,5), since it is important to implement educational activities in a period prior to diagnosis, as well as related to the prevention of disabilities, both during drug treatment and in post-discharge healing.

CONCLUSION

The main results obtained were: 82.6% of the cases with late diagnosis; 17.4% with G2D at diagnosis; 73.9% with initial operating classification MB; there was no participation in a waiting room or educational group with leprosy theme in basic health units of reference; and 21.7% of cases denied access to self-care guidelines.

It was noticed operational difficulty evidenced by late diagnosis, by the report of users who passed through more than one health professional, users searching for the health service more than once and for having waited for consultation after the first symptoms, as well as presence of users at diagnosis with grade 2 disability and dimorphic clinical classification.

In addition to the above, there is inadequacy of leprosy control actions regarding disability prevention and self-care as recommended by the Ministry of Health, requiring investment in the dissemination of knowledge for leprosy cases, for the general population and for health professionals.

It is necessary to invest in the qualification of the health professionals in the recognition of the first signs of the disease, qualification of the services related to the standardization of the activities such as waiting rooms, health education and self-care groups. From the dissemination of information, it is still possible to impact on the stigmatizing factor of the disease that is still present, in order to sensitize everyone who comes to deal with the disease.

FINANCING

FAPEMIG - Fundação de Amparo à Pesquisa do Estado de Minas Gerais.

TRAJETÓRIA DE CASOS DE HANSENÍASE E FATORES RELACIONADOS

RESUMO

Objetivou-se analisar a trajetória dos casos diagnosticados com hanseníase e os fatores relacionados, com enfoque nas ações de prevenção e controle preconizadas pelo Ministério da Saúde. Estudo transversal de natureza descritiva. Os dados foram coletados através de questionário estruturado em visitas domiciliares, com uso do programa Open Data Kit collect. Foram exportados, tratados e analisados no Statistical Package for the Social Sciences (SPSS®) v. 24. Para o cálculo do diagnóstico tardio considerou-se três variáveis, bastando a presença de uma: passar por mais de um serviço de saúde; mais de uma vez; ou mais de seis meses entre primeiros sinais e sintomas até o diagnóstico efetivo. Dos participantes: 69,6% aos primeiros sintomas procuraram o serviço de saúde mais próximo; 43,5% procuraram a Unidade Básica de Saúde de referência; 73,9% relataram demora menor ou igual a um mês para consulta; 34,8% diagnosticados em ambulatório de referência; 82,6% diagnosticados tardiamente; não houve participação em sala de espera ou grupo educativo com o tema hanseníase em unidades básicas de saúde de referência; 21,7% negaram acesso a orientações ao autocuidado. Percebeu-se dificuldade operacional evidenciada por diagnóstico tardio e inadequação das ações de prevenção e controle da hanseníase preconizadas pelo Ministério da Saúde.

Palavras-chave: Hanseníase. Monitoramento Epidemiológico. *Mycobacterium leprae*.

TRAYECTORIA DE CASOS DE LEPRA Y FACTORES RELACIONADOS

RESUMEN

El objetivo fue analizar la trayectoria de los casos diagnosticados con lepra y los factores relacionados, con enfoque en las acciones de prevención y control preconizados por el Ministerio de la Salud. Estudio transversal de naturaleza descriptiva. Los datos fueron recolectados a través de cuestionario estructurado en visitas domiciliarias, con uso del programa Open Data Kit collect. Fueron exportados, tratados y analizados en el Statistical Package for the Social Sciences (SPSS®) Statistics v. 24. Para el cálculo del diagnóstico tardío se consideraron tres variables, bastando la presencia de una: pasar por más de un servicio de salud; más de una vez; o más de seis meses entre primeros síntomas y señales hasta el diagnóstico efectivo. De los participantes: 69,6% en los primeros síntomas buscaron el servicio de salud más próximo; 43,5% buscaron la Unidad Básica de Salud de referencia; 73,9% relataron demora menor o igual a un mes para consulta; 34,8% diagnosticados en ambulatorio de referencia; 82,6% diagnosticados tardíos; no hubo participación en sala de espera o grupo educativo con el tema lepra en unidades básicas de salud de referencia; 21,7% negaron acceso a orientaciones al autocuidado. Se percibió dificultad operacional evidenciada por diagnóstico tardío e inadecuación de las acciones de prevención y control de la lepra preconizados por el Ministerio de la Salud.

Palabras clave: Lepra. Monitoreo Epidemiológico. *Mycobacterium leprae*.

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