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Leprosy: a millenary, neglected and emerging disease

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Abstract: *Leprosy is one of the oldest diseases of mankind, known for thousands of years, and which still represents a serious public health problem as part of the list of (re) emerging and neglected diseases in the 21st century. Over time, Hansen's disease has been marked by different situations, such as the implementation of strict public policies by government officials and professionals specialized in the area, to the segregation and isolation of patients with prejudice and stigma. This article presents the results of a study that aimed to investigate health care actions in the fight against Hansen's disease. A survey was carried out in the database of the Information System for Notifiable Diseases of the Informatics Department of the Unified Health System (SINAN / DATASUS), in 23 municipalities in the State of Santa Catarina that had cases of Hansen's disease diagnosed and / or being treated, from December 2012 to December 2015. The results demonstrated that there is a need to intensify surveillance actions, with greater effectiveness in the diagnosis and treatment of the disease and an emphasis on monitoring contacts, for the elimination of the disease as a health problem. Public health.*

Key words: *Epidemiology; Public health; Neglected Diseases; Public policy.*

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I. Introduction

In Brazil, in 2004 the National Leprosy Program (PNEH) established a new direction for the leprosy elimination policy, understanding that it was a public health problem. The PNEH established among the work proposals, the partnership with non-governmental organizations and governmental and civil entities, among which the following stand out: the Movement for the Reintegration of People Affected by Leprosy (MORHAN); the Brazilian Society of Hansenology (SBH), which acts in the training of human resources for attention in medium and high complexity, as support to the Unified Health System (SUS) network; the Pan American Health Organization / World Health Organization (PAHO / WHO), which guarantees the supply of medicines and offers technical cooperation. Among so many other objectives, PNEH aims to change the control of the disease, seeking to achieve it at the municipal level[1].

Based on the principle of sustainability, the PNEH aims to effectively achieve the reduction of less than one case of leprosy for every ten thousand inhabitants. Although this condition is fundamental for the purposes of statistical control, from the point of view of citizenship, as long as there are cases, despite any mathematical magnitudes, the political dimension recognizes the rights and needs of prevention and treatment of a single case. It is the qualitative scope, not the quantitative, that will endorse citizenship. However, only with the efforts of everyone, government, health professionals and the population, will it be possible to eliminate the disease and achieve the desired results[2].

In August 2011, the Ministry of Health defined a set of endemic diseases that demand strategic actions to eliminate them as a public health problem or to drastically reduce the burden of these diseases. According to the classification of neglected diseases and others related to poverty (PAHO: CD49. R19 / 2009), these form a set of diseases that tend to coexist in areas where the population has precarious living conditions.

Despite being responsible for important morbidity and mortality, the burden of neglected diseases is underestimated in Brazil. At the beginning of 2011, the Health Surveillance Secretariat created the General Coordination for Leprosy and Diseases in Elimination (CGHDE), with the aim of strengthening the response to a group of diseases in which the results of national programs were considered insufficient and incompatible with the capacity of the Unified Health System (SUS) to solve the population's health problems. This group includes Hansen's disease, schistosomiasis, lymphatic filariasis, geohelminthiasis, onchocerciasis and trachoma[3].

In the 21st century, despite advances in scientific research, leprosy remains a very prevalent disease. In Brazil, the goal of eliminating the disease is part of the Public Health policy that proposes the offer of curative treatment, with increased access to health services, through the decentralization of control actions for basic health services. However, the inability to obtain a culture of the etiologic agent contributed to delay scientific advances that other diseases obtained, allowing leprosy to remain a neglected disease, generating lack of investment and delay in technological advances[4]. And despite the drop in the prevalence of leprosy in the last 20 years, largely justified by the introduction of polychemotherapy, the detection of new cases of the disease remains high.

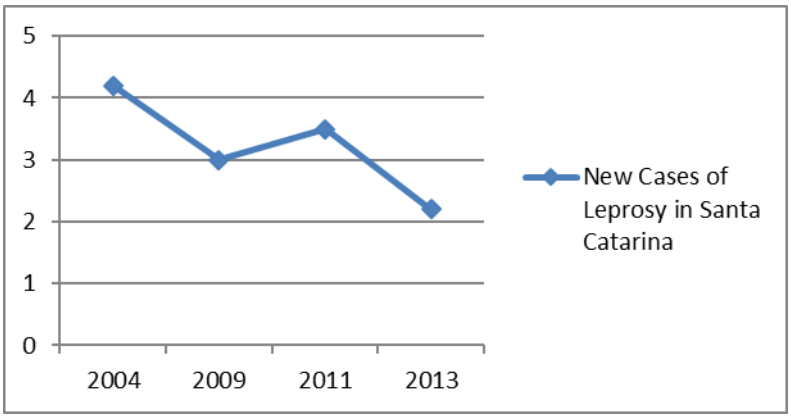
There was an evolution in the detection rate of new cases per unit of the federation between the years 2009 to 2013. In the period, there is a greater occurrence of cases in the states of the North region, followed by the states of the Midwest region. Of the states in the northern region, the one with the highest detection coefficient was Mato Grosso, with its highest coefficient in 2010 reaching 110.9 Q / 100,000 inhabitants and its lowest value recorded in 2009 being 97.2 / 100,000, the second state with the highest detection coefficient within the years studied was the state of Tocantins which had its highest value recorded at 105.9 / 100,000 in 2009 with a gradual drop in the detection coefficient in the following years reaching the year 2013 with a reduction considerable and a coefficient of 73.7 / 100,000. When looking at the federation units belonging to the South region, we realize that the coefficients are among the lowest values in the country, however when analyzing especially the state of Paraná we notice a distance from the other states in the south region, leaving with an average detection coefficient of new cases higher than the states of São Paulo, Minas Gerais and Rio Grande do Norte, among the years analyzed it went from 12.7 / 100,000 in 2009, to 11.1 / 100,000 in 2010, arriving in 2013 with the values of 9.4 / 100,000 inhabitants, a gradual and continuous reduction. Despite the important reduction in the prevalence rate of leprosy in Brazil, some regions demand intensification of actions to eliminate the disease, justified by a high endemicity pattern[5].

II. Material And Methods

A survey was carried out, in official databases of the Ministry of Health, more specifically in the Information System for Notifiable Diseases of the Informatics Department of the Unified Health System (SINAN / DATASUS), which is managed by the Foundation's National Epidemiology Center of Health of the Ministry of Health, the body responsible for preparing and issuing standards that govern its use and operation in the national territory. The study aimed to investigate health care actions in the fight against Hansen's disease. The investigation had as locus of analysis 23 municipalities in the State of Santa Catarina that had cases of Hansen's disease diagnosed and / or under treatment, from December 2012 to December 2015. The municipalities surveyed were: Anchieta, Barra Bonita, Bandeirante, Bom Jesus do Oeste, Rest, Dionísio Cerqueira, Flor do Sertão, Guaraciaba, Guarujá do Sul, Iporã do Oeste, Itapiranga, Iraceminha, Mondaí, Princess, Romelândia, Wealth, Saint Helena, São Miguel da Boa Vista, São Miguel do Oeste, São Miguel João dos Oeste, Palma Sola, Paraíso and Tunapolis. The necessary documentation to register the patient in SINAN / DATASUS is the case notification form, it is through this system that it is possible to evaluate the result of the actions to control the endemic by means of indicators. The Ministry of Health monitors the performance and impact of the actions by agreeing on the following indicators: Detection coefficient; Prevalence coefficient; Proportion of cure among the new cases diagnosed in the years of the cohorts and proportion of cases with physical disabilities among the new cases detected and evaluated in the year. The purpose of research on health care actions in the case of Hansen's disease is directly related to the possibility of building references, which can show the reality of regional municipalities in relation to one of the neglected diseases with (re) emergent and age-old characteristics.

III. Results

From the survey carried out in the SINAN / DATASUS databases, there was a decline in the coefficient of detection of new cases of Hansen's disease in the general population of Santa Catarina, in the years 2005 to 2009. In the years 2010 and 2011 there was an increase the coefficient, falling again in the years 2012 and 2013. The years with the highest coefficient of new cases detected were the years 2004 with 4.2 and 2011 with 3.5. And, the year with the lowest coefficient of new cases was 2013 with 2.2, followed by 2009 with 3. In the other years, the coefficient ranged from 4.2 to 3.7.



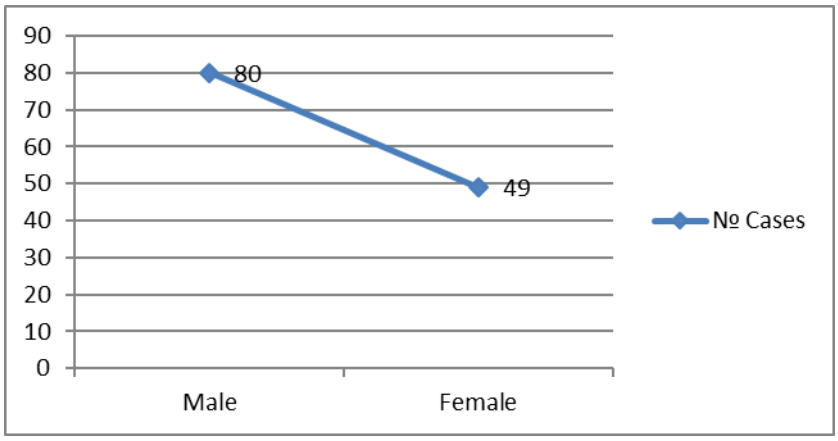
Graphic 1: Detection Coefficient of New Cases of Leprosy in the general population of Santa Catarina in the years 2004-2013

For the population under 15 years old, three periods of increase in the coefficient of new cases are observed, being in the years 2004 and 2007 with 0.4 and in 2013 with 0.7, in the other years it remained stable between 0.1 to 0,two. The prevalence of the percentage of new cases of leprosy in the State of Santa Catarina among males, in all years studied, was evident. For females, there was a variation in the percentage of new cases from 47 for the years 2004 and 2010 to 38 for the years 2010 and 2014. It should be noted that in all the years studied, the percentage of new cases in women never exceeded the percentage of new male cases.

The operational classification of leprosy is based on the number of skin lesions, so when there are up to five lesions it is called Paucibacillary (PB) and the cases with more than 5 *Multibacillary lesions*[1]. In the years 2004 to 2014, in Santa Catarina, there was a predominance of the percentage of new cases of Multibacillary Hansen's disease, given this concern, since these do not present resistance to the bacillus, and the same can multiply in the infected person's body, passing to be eliminated to the outside environment, infecting other people, thus characterizing the source of infection and maintaining the epidemiological chain of the disease[6].

Paucibacillary cases, on the other hand, had a lower percentage of new cases in all the years studied and are those that harbor a small number of bacilli in the body, insufficient to infect other people.

From January 2004 to December 2014, 129 leprosy cases were diagnosed in the São Miguel do Oeste Health Region, 80 (62%) of the cases are male and 49 (38%) cases are female. Among the cases found in males, the age range between 51 and 60 years stands out, however, the most prevalent cases are found in cases over 71 years, corresponding to 21 (16.28%). In females, the age group that most prevailed was also 51 to 60 years, corresponding to 15 (11.63%) cases, followed by the age groups 61 to 70 years, 10 (7.75%) cases and above 71 years, 9 (6.98%) cases.

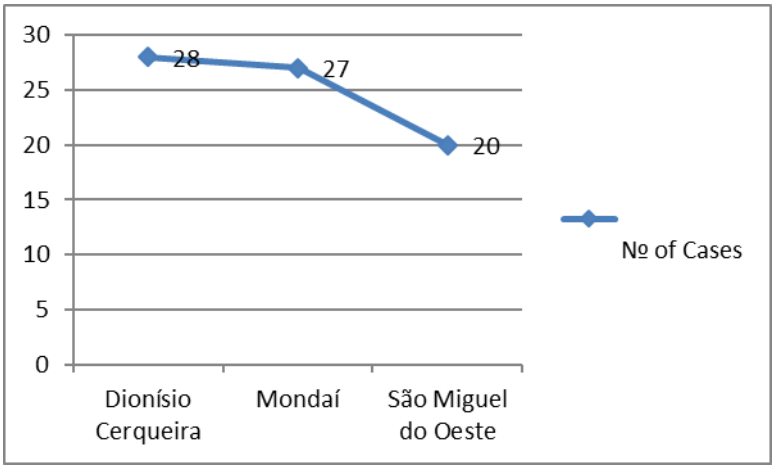


Graphic 2: Leprosy cases in the Health Region of São Miguel do Oeste - SC, between January 2004 and December 2014

A data survey carried out by the Santa Catarina State Department of Health (SES / SC) showed that males are the most affected by this disease from 2003 to 2012, with an average percentage of 57.62 % for men and 42.38% for women.

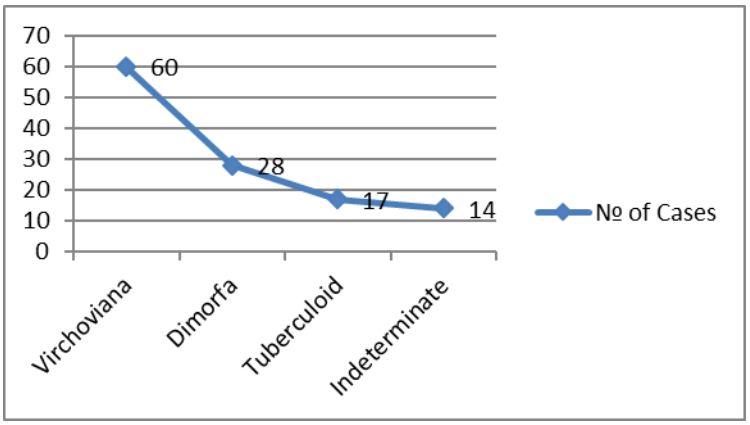
There was a low level of education with incomplete elementary education in 29.46%, corresponding to 38 cases. The three municipalities that stood out the most in the number of notifications in the studied period

were: Dionísio Cerqueira with 28 (21.71%) cases, Mondaí with 27 (20.93%) and São Miguel do Oeste with 20 (15.5%).



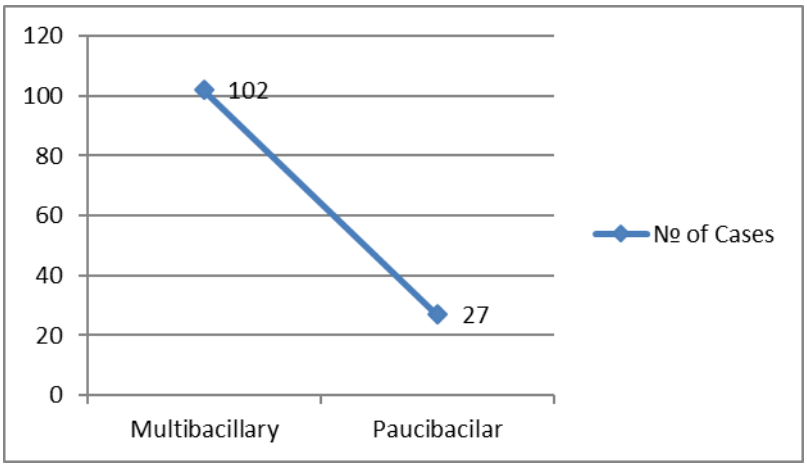
Graphic 3: Municipalities that stood out the most in number of notifications

Regarding the clinical form, virchovian was the most reported, presenting in 60 (46.51%) patients, followed by the dimorphic clinical form, 28 (21.71%) patients, tuberculoid, 17 (13.18%) cases, and undetermined, 14 (10.85%). In addition, 10 (7.75%) of the cases were not identified in the notification forms in SINAN.



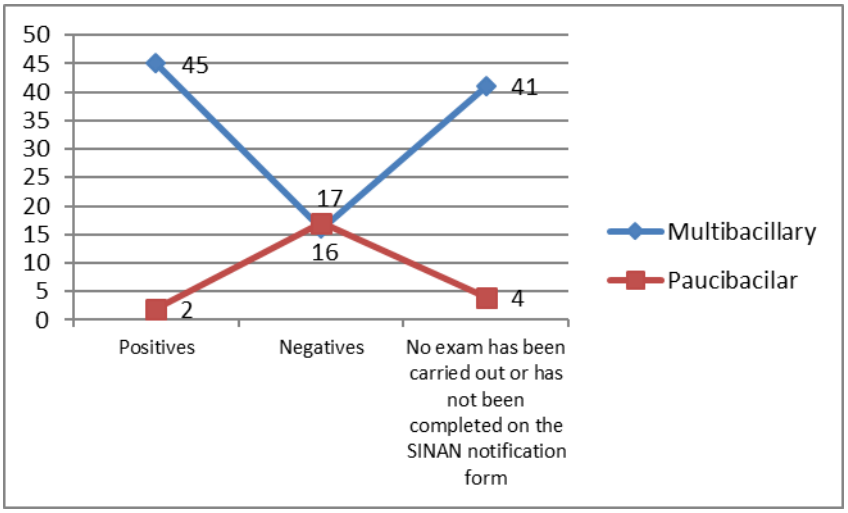
Graphic 4: Most notified clinical form

The multibacillary operational classification was found in 102 analyzed cases (79.07%), while paucibacillary was observed in the rest of the cases (27), representing 20.93% of the cases. However, it is important to note that the initial therapeutic scheme followed the pattern established by the Ministry of Health, as patients with a multibacillary classification underwent treatment of 12 cartons in up to 18 months, whereas in the paucibacillary classification, 6 cartons in up to 9 months.



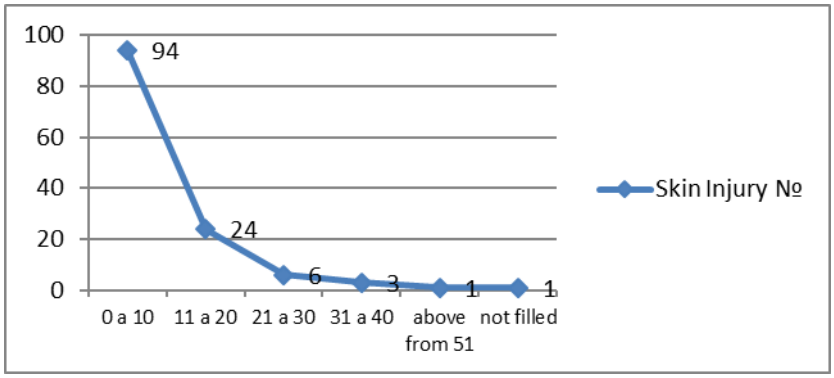
Graphic 5: Operational Classification

Regarding bacilloscopy, when performed in the multibacillary classification, 45 (34.88%) cases were positive, 16 (12.4%) cases were negative, 11 (8.53%) cases were not performed and 30 (23.26%) cases were not filled in the notification form at SINAN. In the paucibacillary classification, 17 (13.18%) cases were negative, 2 (1.55%) positive cases and 4 (3.1%) cases were not performed or were not filled out in the notification form.



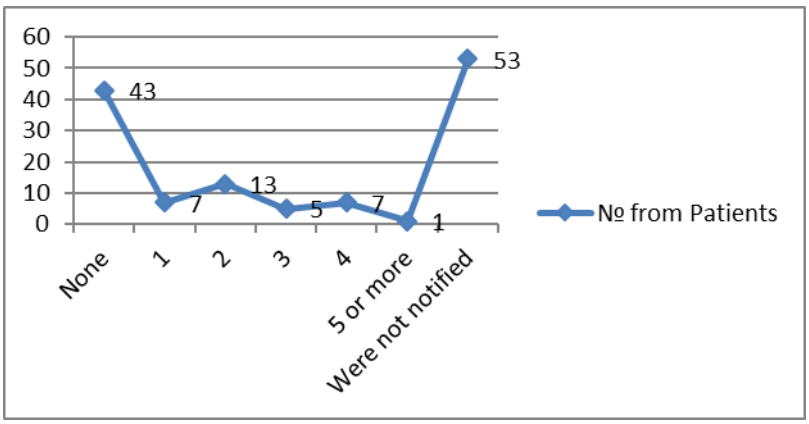
Graphic 6: Bacilloscopy

Regarding the number of skin lesions, it was observed that 94 (72.87%) patients had 0 to 10 skin lesions, regardless of size, color or shape; 24 (18.6%) patients between 11 to 20 injuries, 6 (4.61%) between 21 to 30 injuries, 3 (2.33%) between 31 to 40 injuries and 1 (0.78%) patient above 51 skin lesions. One case (0.78%) did not have this variable filled in the notification form.



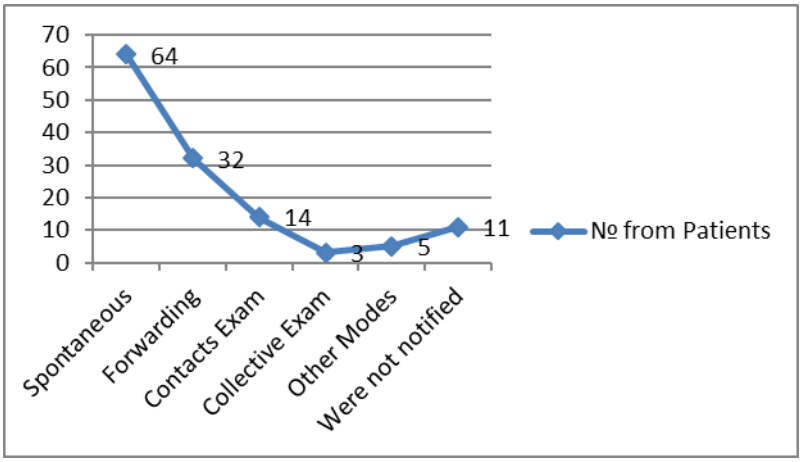
Graphic 7: Number of Skin Injuries

In most cases, 53 (41.09%) did not report the number of affected nerves in leprosy patients. 43 (33.33%) patients did not have any affected nerve, 13 (10.08%) cases with two affected nerves, 7 (5.43%) cases each with one and four affected nerve (s), 5 (3.88%) with three affected nerves and 1 (0.78%) case with 5 or more affected nerves.



Graphic 8: Number of Nerves Affected

Spontaneous demand was the most common mode of detection in this region, with 64 (49.61%) cases, followed by referral 32 (24.81%), contact examination 14 (10.85%), other modes 5 (3, 88%) and collective exam 3 (2.33%) cases. Also, 11 (8.53%) cases were not filled in the notification form at SINAN.



Graphic 9: Detection Mode

IV. Discussion

The bacilloscopy data obtained in the study drew attention, since in the region the bacilloscopy exam is used, by most municipalities, as the gold standard for diagnosing the disease. However, it is known from the literature that negative smear microscopy does not rule out the diagnosis of leprosy, showing that clinical diagnosis is the best way to identify the disease[7].

Spontaneous demand was the most observed mode of detection in the study, followed by referral of cases. These results indicate that the active search and the contact examination are not being carried out as recommended by the Ministry of Health, since only 14 (10.85%) contacts were investigated. The same result was found in a study carried out in the state of Manaus, realizing that some variables analyzed, even in states of the country very distant from each other and different degrees of endemicity, are the same[8].

The actions developed by the regional municipalities, to previously identify signs and symptoms of Hansen's disease, for the most part, are characterized as preventive. In this sense, it is important to highlight the actions of Permanent Education in Health as a mechanism that contributes to the adherence to treatment and, for the emancipation of subjects who already have the confirmed diagnosis, above all, so that the limitations caused by the disease occur.

There is an active search for new cases, however, the numbers presented in the research show that there was no decrease in the appearance of cases in the period studied. There is a need to implement an active search for contacts in suspected, investigated and diagnosed cases.

In order to eliminate the disease, leprosy prevention and treatment campaigns should be carried out in Health Units, with decentralized actions and through political and administrative actions by the State [9].

At the level of Brazil, plans were drawn up with goals and strategies to achieve the elimination of Hansen's disease, that is, to reach a prevalence rate lower than one case per 10,000 inhabitants. A reduction in the prevalence rate and an increase in the number of cases treated with polychemotherapy (MDT) was achieved. However, despite efforts, the elimination goal for the country has not yet been reached. Among the factors that prevented reaching the goal is the permanence of undiagnosed cases and the hidden prevalence, responsible for maintaining sources of contagion in the population[10].

The epidemiological investigation must include the examination of people who live or lived together at home or outside with the leprosy patient, whatever their clinical form, in order to discover the source of infection and to know other cases arising from it source[11].

The home environment is identified as an important space for the transmission of the disease, and epidemiological investigation in this context is fundamental for the discovery of cases among those who live with the patient as a strategy for reducing the burden of the disease.

According to guidelines, the contact exam can be performed by the nurse and the primary care physician[12]. It is worth remembering that, although the leprosy endemic can show signs of decline in the current decade, the detection coefficients are still very expressive in the studied Health Region, and one of the possibilities for the reality in question is, the late diagnosis, caused by the lack of investigation of contacts, which unfortunately makes many people at risk of developing physical disabilities and suffering, which could be avoided if diagnosis and treatment were made in the early stages of the disease.

The historical evolution of the disease points to stigma and prejudice against the patient, based on transmissibility and the possibility of mutilation of the individual. The proper investigation of contacts contributes to the interruption of the transmission chain, since it treats diagnosed cases early, preventing the spread of the bacillus and the installation of disabilities, as these can limit the individual's productivity and generate social marginalization[13].

It is important that in the initial approach of suspected cases and contacts, questions about personal and family history and concomitant illnesses occur. Recalling that the health promotion measures of people diagnosed with Hansen's disease must be the same as those applied to the general population, such as improving living and working conditions, housing, leisure, healthy eating, basic sanitation, among others.

Leprosy is a disease that manifests itself through dermatoneurological signs and symptoms, with compromised joints and skin lesions that manifest mainly in the eyes, testicles, ganglia, hands and feet. The high disabling potential of Hansen's disease is directly related to the ability of Mycobacterium leprae to penetrate the nerve cell and its immunogenic power.

Few diseases exemplify the superior value of a good anamnesis, associated with a detailed physical examination, as well as leprosy. Approximately 95% of the time, there are skin changes that can be detected by a trained professional, in a well-lit room, that is, where between sunlight. These lesions, however, range from an area of xerotic skin with loss of thermal and / or painful sensitivity, without changes in color or infiltration, through the famous “dormant spots”, to keloid-like nodules in apparently normal skin[14].

The lack of information about Hansen's disease and its forms of transmission places the individual himself as a passive person in the face of disease control, as many home contacts, despite the request to attend the health service for dermato-neurological examination, end up not attending . On the other hand, health teams seem to be unable to fulfill a program of active search for these contacts[13].

The treatment of leprosy includes, in addition to specific chemotherapy, the suppression of reaction outbreaks, the prevention of physical disabilities and physical and psychosocial rehabilitation. In this sense, the disabilities in Hansen's disease can be physical, psychological and social, but he believes that the physical ones can contribute decisively to the occurrence of the others[15].

Therefore, the set of measures with the purpose of treating the patient, must be developed, in health services, especially in Primary Care, through the notification of cases. And, the control actions carried out at progressive levels of complexity that should constitute the reference network of health teams in the municipalities or in the State.

First service is essential to establish a relationship of trust and respect between the user and the professional. The approach should encourage the exchange of ideas about the disease, beliefs and prejudices; form of contagion, cure and importance of family involvement in a possible treatment, including the examination of contacts. It is important to emphasize that, at no time, suspicion, diagnosis, treatment should the person suffer any kind of restriction in relation to the activities of daily living, performed with the family, at work, school and leisure[1].

It is important to remember that the integral treatment of a case of leprosy comprises, in addition to specific drug treatment, systematic monitoring, with a view to identifying and treating possible complications and complications of the disease and the prevention and treatment of physical disabilities.

Health indicators are used as a tool to identify, monitor, evaluate actions and support the decisions of professionals and managers. Through them it is possible to identify areas of risk and highlight trends. In addition to these aspects, it is important to note that the monitoring of the results obtained strengthens the team and assists in directing activities, thus avoiding the waste of time and efforts in ineffective actions. Information is a subsidy for planning a work team[16].

The analysis category is directed to the observation of established and observed indicators in the control of Hansen's disease in the municipalities, based on the active search for symptomatic and contacts, diagnosis of new cases, supervised treatment and cure. In this respect, notification of cases can be used as an important indicator in planning actions aimed at coping with the disease. Leprosy is a disease that is compulsory to be notified throughout the country and must be investigated. Each diagnosed case must be notified in the epidemiological week of diagnosis, using the notification and investigation form SINAN / DATASUS. The notification form should be sent to the hierarchically superior epidemiological surveillance agency, with a copy remaining in the medical record. The case notification forms must be completed by professionals from the Health Units where the patient has been diagnosed. The notification of cases of recurrence must be made by the reference service that proceeded with the diagnostic confirmation[1].

In the health sector, information supports the decision-making process, since it helps in the knowledge about health conditions, mortality and morbidity, risk factors, demographic conditions, among others[17].

The training of professionals who provide assistance in leprosy is one of the expected results with the development of the National Leprosy Elimination Plan, established by the Ministry of Health in order to support the elimination of leprosy as a public health problem in the municipalities[18].

It is important to remember that the intervention model proposed by the Ministry of Health to control leprosy is based on early diagnosis, timely treatment of all cases diagnosed until discharge by cure, prevention of disabilities and surveillance of household contacts, but that for this to happen it is essential that the professionals who make up the teams are qualified enough.

Attention to the person with Hansen's disease, its complications and sequelae, must be guaranteed, according to the need of each case and with the principles of equity and comprehensiveness. Thus, control actions must be implemented in all Primary Care units, so that the entire population has quality access to the services offered.

The lines of care must be in accordance with the current guidelines proposed by the National Leprosy Control Program. Aiming to subsidize the organization of services, the rationalization of resources, the optimization of work, the improvement of the quality of care and the permanent and systematic evaluation of the care provided. Therefore, the guidelines should guide professionals regarding clinical management, according to the complexity of each point of care, and the flow of care to users of these services. Ultimately, they try to establish strategies and guidelines for improving the population's health conditions.

In order to eradicate the disease, public health policy proposes the offer of curative treatment, with increased access to health services, through the decentralization of control actions for basic health services. There was a drop in the prevalence of Hansen's disease in the last 20 years, largely justified by the introduction of polychemotherapy, however, the detection of new cases of the disease in Brazil and in the world remains high. And, in the 21st century, despite advances in scientific research, leprosy remains a very prevalent disease[19].

V. Conclusion

The results showed that the actions developed in the cities surveyed, to previously identify signs and symptoms of Hansen's disease, for the most part, are characterized as preventive. However, the figures presented in the survey conducted at SINAN / DATASUS show that there was no decrease in the appearance of cases in the period studied. Where it is concluded that there is still a need to implement an active search for contacts in suspected, investigated and diagnosed cases in the municipalities.

It is important that in the initial approach of suspected cases and contacts, questions about personal and family history and concomitant illnesses occur. Recalling that the health promotion measures of people diagnosed with Hansen's disease should be the same as those applied to the general population, such as improving living and working conditions, housing, leisure, healthy eating, basic sanitation, among others.

What causes a lot of damage to the population, and makes leprosy still a public health problem is the late diagnosis, which contributes to the maintenance of the transmission chain, with the emergence of new cases of the disease. As for the instruments of registration and monitoring in the surveillance of contacts. It was observed that the professionals carry out the required records, highlighting the Compulsory Notification (SINAN), notes in the patients' medical records, files and notebooks that are handled by the professionals, however, they do not have a specific standardization, they are notes according to the understanding of the professional who attends the case at the moment, when the patient seeks the service in the Health Unit.

It was noticed that regarding leprosy surveillance and control, the monitoring and evaluation actions performed in the sphere of the surveyed municipalities, have limitations and have an unsystematic configuration, thus limiting the adoption of decision making based on the monitoring results and evaluation of the Program.

In the literature consulted to analyze the information collected, it was possible to notice that there is a consensus that monitoring is not a contemplative activity, therefore, it monitors itself to make decisions based on the results achieved and with a view to improving the effectiveness of the program. Monitoring consists of regular data analysis and wide dissemination to all those who need it.

It is worth pointing out that Health Information Systems play an important role in the organization of services, since the states and municipalities in possession of the information are able to adopt disease control measures in an agile way, as well as plan actions for promotion, protection and health recovery, supporting decision-making. The systematic use of the data generated by the System, in a decentralized manner, contributes to the democratization of information, allowing all health professionals to have access to information and make it available to the community.

It is also important to remember that the intervention model proposed by the Ministry of Health for the control of leprosy is based on early diagnosis, timely treatment of all cases diagnosed until discharge by cure, prevention of disabilities and surveillance of household contacts, but for that to happen it is essential that the professionals that make up the teams are qualified enough.

In conclusion, it is worth pointing out that health care for people diagnosed with leprosy is not limited to health services, being before and after access to treatment, it is a complex issue that needs to overcome the stigma of the disease, in all spheres of everyday life; the lack of knowledge of health professionals about the disease; lack of specific training for diagnosis, treatment and cure; neglect of the evidence and; excessive daily activities in Health Units that end up hampering quality care, are challenges that must be overcome in disease control.

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