



## RESUME OF LEPROSY CONTROL POLICIES IN BRAZIL: FROM COMPULSERY TO CURRENT DAYS

### RESGATE DAS POLÍTICAS DE CONTROLE DA HANSENÍASE NO BRASIL RESCATE DE LAS POLÍTICAS DE CONTROL DE LA HANSENIASIS EN BRASIL: DE LA COMPULSERIDAD A LOS DIAS ACTUALES

Clodis Maria Tavares<sup>1</sup>, Nataly Cavalcante Gomes<sup>2</sup>, Tâmyssa Simões dos Santos<sup>3</sup>, Thiago Pereira da Silva Flores<sup>4</sup>, Magda Levantezi<sup>5</sup>, Nayara Alexandra Rodrigues da Silva<sup>6</sup>

#### RESUMO

**Objetivo:** resgatar desde as primeiras ações no século XIX chegando à portaria 149 de 02 de fevereiro de 2016 que aprova as diretrizes para vigilância, atenção e eliminação da hanseníase como problema de saúde pública no Brasil. **Método:** trata-se de uma pesquisa documental, que utiliza o método histórico a investigação de acontecimentos do passado e sua influência na atualidade. Para o bom desenvolvimento do estudo foi organizado em três categorias: Políticas Públicas e o surgimento dos primeiros leprosários; Ações de controle da hanseníase e implantação do tratamento e Reconstrução e descentralização das ações de saúde. **Resultados:** as principais recomendações do I Congresso Internacional de Lepra, realizado em 1897, em Berlim, foram: o isolamento compulsório, a notificação obrigatória dos casos e a vigilância dos contatos, os quais foram adotados no Brasil, até o início do século XX. Uma das primeiras ações de controle da hanseníase surgiu com a implantação do tratamento, na década de 1940. E no período transcorrido entre 1985 e 1991, acontece uma fase de reconstrução de descentralização das ações de saúde. **Conclusão:** a pesquisa nos mostra a evolução da história da hanseníase em várias vertentes, como o desenvolvimento da relação do paciente com a sociedade, desde a exclusão pela sociedade e órgãos oficiais até a necessidade de reintegrá-lo com segurança e dignidade a liberdade.

**Palavras-chave:** Hanseníase. Saúde Pública. História.

#### ABSTRACT

**Objective:** to rescue from the first actions in the nineteenth century reaching the decree 149 of 02 February 2016 that approves the guidelines for surveillance, attention and elimination of leprosy as a public health problem in Brazil. **Method:** it is a documentary research, which uses the historical method to investigate events of the past and their influence at present. For the good development of the study was organized into three categories: Public Policies and the emergence of the first leprosarium; Actions to control

<sup>1</sup> PHD. Federal University of Alagoas/UFAL. Maceió (AL), Brazil.

<sup>2</sup> Nurse. Federal University of Alagoas/UFAL. Maceió (AL), Brazil.

<sup>3</sup> Master. University Center Maurício de Nassau/UNINASSAU. Maceió (AL), Brazil.

<sup>4</sup> Master (doctorate student). Pontifical Catholic University de Minas Gerais/PUCMINAS. Belo Horizonte (MG), Brazil.

<sup>5</sup> Master (doctorate student). Brasília University/UNB. Brasília (DF), Brazil.

<sup>6</sup> Nurse (master student). Federal University of Alagoas/UFAL. Maceió (AL), Brazil.

leprosy and implementation of treatment and Reconstruction and decentralization of health actions. **Results:** the main recommendations of the First International Leprosy Congress, held in Berlin in 1897, were: compulsory isolation, compulsory notification of cases and surveillance of contacts, which were adopted in Brazil until the beginning of the 20th century. One of the first actions to control leprosy emerged with the implantation of treatment in the 1940s. And in the period between 1985 and 1991, a reconstruction phase of the decentralization of health actions occurred. **Conclusion:** the research shows the evolution of the history of leprosy in several aspects, such as the development of the patient's relationship with society, from exclusion by society and official bodies to the need to safely reintegrate it with dignity and freedom.

**Keywords:** Leprosy. Public Health. Story.

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## RESUMEN

**Objetivo:** rescatar desde las primeras acciones en el siglo XIX llegando a la ordenanza 149 de 02 de febrero de 2016 que aprueba las directrices para vigilancia, atención y eliminación de la hanseniasis como problema de salud pública en Brasil. **Método:** se trata de una investigación documental, que utiliza el método histórico la investigación de acontecimientos del pasado y su influencia en la actualidad. Para el buen desarrollo del estudio se organizó en tres categorías: Políticas Públicas y el surgimiento de los primeros leprosarios; Acciones de control de la lepra e implantación del tratamiento y Reconstrucción y descentralización de las acciones de salud. **Resultados:** las principales recomendaciones del I Congreso Internacional de Lepra, realizado en 1897 en Berlín, fueron: el aislamiento obligatorio, la notificación obligatoria de los casos y la vigilancia de los contactos, los cuales fueron adoptados en Brasil, hasta el inicio del siglo XX. Una de las primeras acciones de control de la hanseniasis surgió con la implantación del tratamiento, en la década de 1940. Y en el período transcurrido entre 1985 y 1991, ocurre una fase de reconstrucción de descentralización de las acciones de salud. **Conclusión:** la investigación nos muestra la evolución de la historia de la lepra en varias vertientes, como el desarrollo de la relación del paciente con la sociedad, desde la exclusión por la sociedad y órganos oficiales hasta la necesidad de reintegrar con seguridad y dignidad a la libertad.

**Palabras-clave:** Hanseniasis; Salud Pública; Historia.

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## INTRODUCTION

This article invested in the recovery of specific Public Health Policies for the control of leprosy, going through the period of compulsory hospitalization to the present day, through a historical record from when the disease arose, still called "leprosy" in the middle of its process of social, moral and religious stigmatization that its bearers faced, until the development of forms of confrontation and consequent healing.

Leprosy is a disease that has been known since antiquity, known for about four thousand years in India, China and Japan, already existing in Egypt from 4,300 years BC There are records of "Hansen's disease" spread throughout

Eastern Europe by the Persian armies , later by the Romans, the Saracens and the Crusades, and in the West by the Spaniards and the Portuguese.<sup>1</sup>

In the Middle Ages, patients were isolated from leprosy patients, which were mostly administered by charity. Some of the famous and enduring leprosariums were: Kalaupapa (Hawaii); Chacachacare (Trinidad); The Basin (Victoria) and Spinalonga (Crete). In addition, several colonies were located on islands in order to segregate patients from the rest of the population.<sup>2</sup>

Over the centuries, the disease has undergone changes in its territorial expansion and, as there has been a tendency to disappear in Europe, endemic outbreaks were maintained in Asia and Africa and, as a consequence, was introduced in the New World, from of the Spanish and Portuguese conquests, and in the importation of African slaves, and during the period of colonization Latin America gradually became a new endemic area of the world.<sup>1</sup> The first information on the familial outbreaks of leprosy in Brazil dates back to 1820 and was provided by the Visconde de Oeynhausen. It was evidenced that the human clusters, especially, the familiar ones, would be the possible causes of the contagion.<sup>3</sup>

From the end of the nineteenth century, Brazilian legislation began to consider health issues as a social problem, which should be interfered with by the government in its resolution. Thus, the Public Health Councils, Inspectorates, Public Health Departments and Services were created, which had the task of making recommendations, regulations and orders, as well as promoting sanitary surveillance and maintaining a notification and statistical service, the first public health policies in Brazil.<sup>4</sup>

In 1903, in Rio de Janeiro, then the capital of Brazil, President Rodrigues Alves appoints Dr. Osvaldo Cruz as the public health director of the State. From this act, leprosy began to receive greater public attention and to be part of government programs to combat communicable diseases. The control policies of "leprosy" in Brazil were aimed at segregating the sick, since the disease was seen not only as a serious illness, but as a kind of divine condemnation. Thus, in 1904, the Union Health Regulations came into force, determining that leprosy, in addition to being a compulsory notification disease, placed patients under the control and custody of the public authority.<sup>5</sup>

The first control measures for leprosy in Brazil were carried out by means of decrees and ordinances, especially Decree 16.300, of December 31, 1923,

which approves the regulation of the national health department. The measures for the then prophylaxis policy of "leprosy" become official as national public policy.<sup>6</sup> And Law No. 610 of January 13, 1949, repealed by Law No. 5,511 of 1968, was the first and only national law which regulated the compulsory hospitalization of people affected by leprosy and the separation of their children.<sup>7</sup>

The national policy of segregation and compulsory hospitalization was framed by Portaria nr. 165, dated May 14, 1976, of the Ministry of Health, and leprosy control is part of the actions of the general health services, aiming at reducing morbidity, preventing disabilities, preserving family unity and stimulating the social integration of patients.<sup>4</sup>

It is important to mention that, with the promulgation of Law 11,520 / 07, which granted special compensation to all persons who were compulsorily isolated in Brazil as a result of leprosy, until 1986, the State acknowledged that it promoted compulsory isolation in an illegal manner for 18 years after the repeal of Law 610 of 1949.<sup>4</sup>

In the history of public health in Brazil and in the treatment and control of leprosy, there is another important milestone with the promulgation of the Federal Constitution of 1988, which recognized health as a right of the citizen and duty of the State.<sup>8</sup> Law 8.080/90 creates in Brazil the Unified Health System - UHS as the regulator of the constitutional text, obliging the State to provide the conditions necessary for its full exercise in the formulation and execution of economic and social policies aimed at reducing risks diseases and other diseases.<sup>9</sup>

The objective of the study is to rescue from the first actions in the nineteenth century, arriving at Ordinance 149, of February 2, 2016, which approves the guidelines for surveillance, attention and elimination of leprosy as a public health problem in Brazil.

## **METHOD**

It is a documentary research that uses the historical method for the investigation of events of the past and its influence in the present time, being used with the same paths of the research of bibliographical documentary revision, being intriguing, sometimes, to distinguish them.<sup>10-11</sup>

Bibliographical research uses sources made up of already elaborated materials, basically composed of books and scientific articles located in libraries, while documentary research uses sources without analytical treatment, more diversified and dispersed, such as statistical tables, newspapers, magazines, reports, official documents, letters, films, photographs, paintings, tapestries, company reports and videos of television programs.<sup>10-13</sup>

Documentary research can be organized in the following steps: theme choice; delimitation of objectives; selection of sources; reading the identified material; filing and archiving of selected materials; analyze; interpretation of data and final study writing.<sup>14</sup>

In this study, the instruments used to construct the research were: articles, dissertations, books, articles, laws, ordinances, report, technical standard, guide, decrees, Constitution of the Federative Republic of Brazil, Manual of Leprology and Caderno do Morhan. These were analyzed with respect to the chronology of events and related to the object of the proposed study, rigorously. Of all the references, some have not gone through any scientific treatment before.<sup>12</sup>

For the good development of the study, this was organized into three categories: Public Policies and the emergence of the first leprosarium; Actions to control leprosy and implementation of treatment and Reconstruction and decentralization of health actions.

## **RESULTS AND DISCUSSION**

### **Public Policies and the emergence of the first leprosy**

In 1741, two court doctors drafted the first regulation to combat leprosy in Brazil, considered a contagious disease. At that time, the isolation of the patients was established as a control measure and should be carried out in special asylums, according to gender and social conditions. The health authorities then begin the construction of asylums to create laziness, after the implementation of the regulation, in several places in the country.<sup>15-16</sup>

The main recommendations of the I International Leprosy Congress, held in Berlin in 1897, were: compulsory isolation, compulsory notification of cases and surveillance of contacts, which were adopted in Brazil until the beginning of

the 20th century and, Thus, in this period, we can observe the records of philanthropies in the control of leprosy that is known.<sup>15-16</sup>

Carlos Chagas, renowned sanitarista, in 1916, like president of the I American Congress of Lepra, approves the following conclusions: to register the lepers of all the States; different anti-Leprosy legislation in force; open colonies to fight contagion; uniform plan for the fight, applied simultaneously throughout the national territory. In 1920, the National Department of Public Health was created, and for the first time, health activity was observed in the fight against leprosy in Brazil.<sup>15-16</sup>

Since, at the time of the creation of the Ministry of Education, health was linked to it, a new type of disease control had been adopted, in which the federal government, in 1941, created the National Leprosy Service (NLS) with the purpose of outlining actions of control, maintenance and creation of the tripod model, based on: (a) leprosarium, which served the infected patients in a prison system as a way to prevent the spread of the disease; (b) preventorium, who took care of communicators, "healthy" children; (c) dispensary, which were special rooms located in health units, identified as "Special Leprosy Service", where new diagnoses of the disease were performed. Epidemiological surveillance controlled home treatments and cases considered non-contagious and also sought to carry out health education work with the population, emphasizing the importance of a medical examination.<sup>17</sup>

At the Seventh International Leprosy Congress held in Tokyo in 1958, it was considered that the form of transmission was not hereditary and that, through treatment with antibiotics and sulfa drugs, it was possible to cure the disease, reinforcing the thinking of that after receiving treatment for leprosy, there would no longer be a need to isolate the citizen. The sanitary control was based on the following aspects: sulphonic treatment of the patient; control of their communicators; health education of the patient, communicators and the general population.<sup>17</sup>

In the triennium 1956-58, according to the guidelines of the Fight Against Leprosy campaign, Brazil was stratified into five areas. The established measures sought to achieve, together: the decentralization of care, with the increase of population coverage; stratification of the country, based on epidemiological and operational criteria; the identification for the withdrawal of records, the cases of deaths, absent or cured, and health education.<sup>16</sup>

## **Actions to control leprosy and treatment implantation**

One of the first actions to control leprosy emerged with the implementation of treatment. In the 1940s, there was progress in the treatment of leprosy patients, with the appearance of dapson, which was only used in the treatment of leprosy in 1943, known as sulfone (DDS).<sup>18</sup>

The drug regimen used was given by sulphonic monotherapy or clofazimine by the Ministry of Health. Such a regimen was changed with the combination of rifampicin and indicated in the clinical cases of virchowiana, dimorphous forms, including suspected cases of sulfone resistance.<sup>19</sup>

After a little over 30 years, there was concern about the deformities that were seen in people with leprosy. Thus, in 1963, a technical norm of the Ministry of Health draws attention to the application of the prevention of deformities by non-surgical methods, this provision having subsequently given rise to the prevention and treatment of disabilities and surgical corrections of physical deformities. After a few more years, in the course of the year 1976, a new ordinance established a policy of leprosy control: health education actions; application of BCG; detection of patients and prevention and treatment of disabilities.<sup>16</sup>

In this scenario, the World Health Organization (WHO) was betting on the efficacy of the treatment and redefined the therapeutic scheme, since sulfone-resistant strains of *Micobacterium leprae* were proven. In many countries, monotherapy was common. Rifampicin was included in the new leprosy treatment and the use of multidrug therapy (MDT-WHO) was consolidated. In the tuberculoid and undetermined Mitsuda positive cases, classified operationally as paucibacillary, the regimen was the association of sulfone with rifampicin, whereas in virchowian cases, dimorphous and indeterminate, Mitsuda negative, the combination of sulfone with rifampicin and clofazimine.<sup>20</sup>

The MDT principle was to eliminate the conditions that favored transmission, hoping to achieve a short-term epidemiological impact, and for the effectiveness of treatment, it was necessary to perform several control activities, such as early diagnosis, prevention and treatment of physical disabilities, contact surveillance and health education.<sup>16,20</sup>

In Brazil, the Ministry of Health did not immediately adopt this scheme, for fear of poor results, which only occurred in 1986, after an evaluation that

showed an increase in the number of annual cases, including children under 15 years. This fact was the driving force for the implementation of polychemotherapy (PCT) in some pilot units.<sup>16</sup> Multidrug therapy, implemented (MDT-WHO) since 1986 in some pilot areas of Brazil, was recommended for all endemic countries with the aim of interrupting the transmission of infection in the community and ensuring the cure of the patient.<sup>16,21</sup>

The high cure rate of leprosy patients was rare in the past; however, in view of the patients' clinical cure for the sulfone, even with physical disabilities, this possibility was already believed. To avoid social stigma, at that time, the new term had been instituted. That is to say: the word leprosy has been replaced by the term leprosy, used with the firm intention of honoring Gerard Amauer Hansen, discoverer of the etiological agent of this pathology.<sup>16,22-23</sup> Thus, the Ministry of Health, through the National Coordination of Health Dermatology (NCHD), adopted multidrug therapy (MDT-WHO) as the only treatment for all leprosy patients.<sup>16,24</sup>

In the indication of the MDT-OMS schemes, called the polychemotherapy (PCT), according to the Leprosy Control Guide (1994), the patient should be classified, for treatment purposes, according to the diagnostic methods, in paucibacillary and multibacillary. This classification facilitates the diagnosis, being of great importance for programs of control of patients with leprosy.<sup>16,25</sup>

The criteria for the operational classification of leprosy patients are: paucibacillary, when they present the indeterminate and tuberculoid clinical forms, with negative bacterioscopy, and multibacillary, classified as Virchowian, dimorphic and with positive bacterioscopy in any of the smears examined and the unclassified.<sup>16,26</sup>

### **Reconstruction and decentralization of health actions**

In the period between 1985 and 1991, there is a phase of reconstruction of the decentralization of health actions. In relation to leprosy, it was a period with many changes, facing the stigma of the disease, and the reintegration movement of the leprosy patient takes force with the effective participation of the user. The updating and implementation of Ordinance No. 165 advocates the end of isolation and social reintegration of patients, but only in 1991 and 1992,



the Ministry of Health adopted PCT as the only treatment regimen in Brazil and the fixed dose in the routine of health services.<sup>16</sup>

In 2004, the Brazilian government, through the Ministry of Health, considers that the assistance and asylum situation of the former leprosy colony hospitals in the country is distinct, unknown and that the asylum people are the result of a policy of compulsory isolation that persisted, mistakenly, over time and in need of hospital and social assistance. It was when he decided to establish a Working Group, by means of Portaria n. 585, of April 6, 2004, with the purpose of performing a Situational Diagnosis of the current reality of these institutions.<sup>27</sup>

The Working Group was composed of members representing the segments of public power and users, involved in leprosy activities living in colony hospitals. It was concluded that, in that year, there were in the country thirty-three colony hospitals with problems which make it difficult for the daily life of the residents who have been affected by leprosy and still remain in those institutions, asylum or even in the residential areas, due to the absence of family ties broken in the past with their families or because they constituted a family in the area of colonies.<sup>27</sup>

As part of the final report of the Working Group, the Ministry of Health transferred to the states, through the state health fund, financial resources for managers to invest in institutions, mainly in the reform of the physical area, community spaces and services rehabilitation.<sup>28</sup>In the context of the obligation of the State to recognize the violations generated by compulsory hospitalization and to indemnify the victims of the country's policy until 1986, the Interministerial Evaluation Commission.<sup>29</sup>

The Interministerial Commission, established by Provisional Measure 373 of 2007, in article 2, establishes its composition by representatives of the organs: Special Secretariat for Human Rights of the Presidency of the Republic, which will coordinate it; Ministry of Health; Ministry of Social Security; Ministry of Social Development and Fight against Hunger and Ministry of Planning, Budget and Management.<sup>30-31</sup>

The federal government approved Provisional Measure No. 373 of 2007, regulated by Decree No. 6168 of July 24, 2007, which establishes the right to a special pension and instructions to apply for recognition of violations of human rights, and especially in the approach the right to freedom of patients. Therefore, persons who have been affected by leprosy and who have been forced to isolate

themselves or go to colony hospitals until 31 December 1986 are entitled to a special pension. The provisional measure also establishes that the pension is lifelong, monthly and retroactive to the date of publication of the deferral, therefore, the person with a favorable opinion will receive payment as of December 1986.<sup>30-32</sup> The sanitary policy of segregation and compulsory hospitalization, instituted by the Brazilian State, recognized the violation of the fundamental rights committed to patients affected by leprosy, and this recognition was given by Law 11,520 of September 18, 2007.<sup>31</sup>

The key role of MORHAN (Reintegration Movement for People Affected by Leprosy), which is a non-governmental, non-profit organization, founded on June 6, 1981, made the situation of people who were still living, forgotten, in the colony hospitals in Brazil, with the elimination of leprosy by means of awareness-raising activities and a focus on the construction of effective public policies in the prevention, treatment, diagnosis and rehabilitation of people affected by leprosy. of Law 11,520.<sup>31,33</sup>

The Ministry of Health, on March 29, 2009, proposed Ordinance No. 125, which deals with health education practices for the control of leprosy, which should be based on the policy of permanent education and the national health promotion policy. Activities should include, at least, comprehensive care, encouragement for self-examination and self-examination of self-care contacts, self-care, prevention and treatment of physical disabilities and psychological support during and after treatment.<sup>26</sup>

WHO has developed the Global Strategy for Further Reducing the Burden of Leprosy and Sustaining Leprosy Control Activities: 2006-2011, based on early detection of new cases and treatment with multidrug therapy, which is offered free of charge by the Novartis Foundation through PAHO / WHO in Brazil. The main elements of the strategy were: to sustain leprosy control activities in all endemic countries; use case detection as the main indicator to monitor progress; registration and reporting in all endemic communities; ensure quality diagnosis and case follow-up; strengthen routine and referral services, and discontinue the campaign-based approach.<sup>34</sup>

The main challenges of the five years of the strategy were: to continue moving towards the target of less than one case per 100,000 inhabitants in countries that have not yet reached the target; maintaining the quality of services in integrated health systems and in situations of low endemicity;

strengthen surveillance and development of an efficient referral network; reduce stigma and discrimination against those affected and their families. The goals were to achieve further reduction of the burden of leprosy and to promote access to quality leprosy control services for all affected communities, following the principles of equity and social justice.<sup>34</sup>

In collaboration with the National Leprosy Control Programs and other partners, WHO developed in 2010 the Global Leading Strategy for Further Reducing Leprosy Burden: 2011-2015, which emphasizes sustaining health care with quality services and reducing the burden of leprosy not only by early detection of new cases but also by reducing disability, stigma and discrimination, by promoting the social and economic rehabilitation of those affected. The Global Strategy for Further Reducing the Burden of Leprosy and Sustaining Leprosy Control Activities: 2006-2010 and the Global Lead Strategy for Further Reducing the Burden of Leprosy: WHO, 2011-2015, focus on further reduction of burden of disease in all endemic communities.<sup>35</sup>

At the same time, it is necessary to ensure that the quality of services is not compromised, and every person affected by leprosy should have easy access to the diagnosis and free treatment with multidrug therapy, ensure that sustainable activities are carried out, and that quality services are provided within a framework integrated network that includes an effective reference network to effectively address the complications related to leprosy.<sup>35</sup>

In 2016, the Ministry of Health, by means of Ordinance No. 149, approves the guidelines for the surveillance, attention and elimination of leprosy as a public health problem, which was published that same year with the aim of guiding the practices of this disease, as well as the case definition and strategies for reducing the disease burden in the country.<sup>36-37</sup>

## **CONCLUSÃO**

The research shows the evolution of the history of leprosy in several aspects, such as the development of the patient's relationship with society, from exclusion by society and official bodies to the need to reintegrate him safely and dignity to freedom. The legislation, according to the work of the movements, recognized the importance of the discussions and decided to pay compensation to people who were in compulsory hospitalization. In the investigation, the importance of experimental science in the development of medications and their

evolution up to the present time was expressed, with the sensitivity of access to medication free of charge by the official governments and the patient. The sanitary surveillance has marked relevance in epidemiological aspects of the disease where it provided strategies for the control and prevention of the disease in endemic communities.

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