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#### Abstract

This article discusses the historical aspects of the policies for controlling Hansen's disease in the state of Amazonas from the second half of the nineteenth century until the dismantling of this model in 1978. We present the historical changes in the local institutions and policies, and their relationship with national policies. The history and policies related to Hansen's disease in the state of Amazonas are analyzed through the following institutions: Umirisal, the Oswaldo Cruz Dispensary, the Paricatuba Leprosarium, the Antônio Aleixo Colony, and the Gustavo Capanema Preventorium. We seek to show that these institutions cared for the people who suffered from Hansen's disease and those related to them, and were also responsible for carrying out the policies for fighting and controlling the disease.

Keywords: Hansen's disease; history of science; history of health sciences; healthcare policies; Amazon.

The history of Hansen's disease, beginning in the last decade of the nineteenth century, took a new path when the disease became seen as an international public health problem. This arose from two experiments to fight leprosy: In Norway, under the leadership of Armauer Hansen (1841-1912), and in Hawaii. The two experiments were based on the use of isolation as the principal prophylactic measure, due to the inability to cure the disease. The first International Conference on Leprosy, in 1897, endorsed the experiments and recommended isolation as a political and prophylactic strategy for fighting the disease (Cabral, 2013).

Hansen's disease has a long history dating back to biblical times, but here we will highlight how institutions and health policies in the state of Amazonas approached the problem. Our analysis is delimited by two dates: 1908, when the first institution officially fulfilling the function of caring for those with leprosy was established; and 1978, when the Antônio Aleixo Colony was closed. Like most Brazilian states, Amazonas adopted the national guidelines and rules for dealing with the disease which, of course, had unique, typical characteristics. For this reason, it is important to analyze the development of this policy and its relationship with national policies.

This article attempts to analyze the history of Hansen's disease through related public policies, allowing us to understand the processes of the current policy, which was the result of many achievements, both medical and relating to movements that sought and seek to respond to this public health problem. The methodology used consisted of researching Amazonas state official documents, reports by institutions and administrators, and scientific articles by local physicians. This history is, therefore, of policy and institutions, but also represents the processes that excluded and stigmatized individuals and families.

## The national and local context of Hansen's disease

Some events in the international arena are important as context for the history of Hansen's disease and in order to understand the reasons why it developed in different ways. In 1874, in Norway, physician Gerhard Henrik Armauer Hansen defined the agent causing the disease. The first International Conference on Leprosy, held in 1897 in Berlin, is another event worth mentioning and that strongly influenced the practices and the treatment of leprosy (Pandya, 2003). This conference is treated, in the history of the disease, as the first event organized to internationalize the issue and to defend isolation as a universal practice. Although support for the model was not unanimous, isolation was the best known policy and its effects still resonate today.

Caring for lepers, until the twentieth century, was mostly done by the Church (Maciel, 2007), and became a national health problem in the last century. The public health movement in the 1910s did not initially consider leprosy to be a national problem, but with the alarming data on the growth of the disease in the states, from the 1920s on, a specific policy was needed to fight it (Cabral, 2013). Beginning in the 1910s, the need for each state to create its own leper colonies, in order to prevent the transit of those suffering from the disease, was discussed (Hochman, 1998). However, there was no consensus on an isolation policy to fight leprosy.

Until the early 1930s there were two trends regarding isolation: (a) the humanist or liberal viewpoint, which defended treatment in small colonies and in homes, with selective isolation for patients with more advanced lesions, and against compulsory internment. This strategy was used by the Leprosy and Venereal Disease Prophylaxis Inspectorate during the 1920s; (b) the isolationist viewpoint, which defended full isolation and restricting patients to colonies, managing and treating people who had contact with patients and, finally, compulsory internment (Monteiro, 2003; Cunha, 2010; Cabral, 2013). The latter became the hegemonic policy for treating leprosy in Brazil, and São Paulo state was the first to establish the architectural and bureaucratic system that served as a reference for all of the other states (Monteiro, 2003). The São Roque Leper Colony, in the state of Paraná, was the first to be inspired by the American model at Carville, Louisiana (Cabral, 2013).

Leprosy was transformed from the object of charitable acts to the object of knowledge. This change is marked by the establishment of a Bacteriological Laboratory at the Hospital dos Lazaros in Rio de Janeiro in 1894, reorienting the way the disease was treated (Cabral, 2013). In Amazonas, the regulations governing the Paricatuba Leper Colony stated that the function of the director, a bacteriologist physician, was to "carry out all microscopic, bacteriological, chemical and experimental studies needed to clarify diagnoses, obtain a cure, and perform etiopathogenic and therapeutic studies of leprosy" (Regulamento..., 1 out. 1929, p.6).

The history of leprosy in Amazonas, according to the physician and leprologist Alfredo da Matta, can be divided into three phases: 1889-1907, 1908-1921, and 1922-1929. The first phase is characterized by caring for the leprosy patient at Santa Casa de Misericória, the same as for other diseases. This period was marked by two problems: there were no separate facilities for these patients, and towns in the countryside sent their sick to the state capital (Matta, 1929a). This period was characterized by expressive migration to the state of Amazonas due to the rubber boom, and this had a significant impact on the growth of the disease.

The second period (1908-1921), according to Alfredo da Matta (1929a), was marked by the relative isolation of patients in the institution called Umirisal, created in the nineteenth century for the isolation of smallpox sufferers, and at Linha do Tiro. During this period, maintenance of these facilities and medical monitoring of patients was the responsibility of the State Public Health Service. Despite this initial isolation, "more than fifty lepers roamed the public roads, slept in the open, on garden benches, on theater steps, in the warehouses of Manaus Harbor, begging openly" (Uchoa, 1926, p.13). The precarious facilities in these locations could not care for many patients, and there was also no specific clinic in the city for follow-up and treatment. These sites were destroyed upon inauguration of the Paricatuba Leper Colony at the end of the 1930s. At that time there was no nationwide centralization, and each state responded to the problem as it saw fit. Only in 1918 did leprosy become endemic in rural areas and, beginning in 1921, action became centralized (Cabral, 2013).

The third phase (1922-1928) was characterized by the spread of the disease, with new facilities needed. The period was marked by the start of the work of the Public Health and Rural Prophylaxis Service in Amazonas, which was described by the physician as the most rational policy to fight leprosy (Matta, 1929a). One feature of the period was the centralization of the policy of the Leprosy and Venereal Disease Prophylaxis Inspectorate, which established

the tripod clinic-school-leprosarium. Leper colonies began to be established during this period, but a more liberal policy for treating the disease still predominated (Cabral, 2013).

The state of Amazonas signed an agreement with the federal government in 1921, establishing the Amazonas Public Health and Rural Prophylaxis Service as a service specifically for the prophylaxis of leprosy. Samuel Uchoa<sup>2</sup> became head of Rural Public Health and appointed the physician Alfredo da Matta to be responsible for leprosy prophylaxis. Individuals were treated at the Oswaldo Cruz Dispensary and the Gabizo subdispensary, both established in 1922, for Hansen's disease and for venereal diseases, respectively (Schweickardt, 2011). During this time period the Amazonas Leprosy Census was carried out as part of the national census. Samuel Uchoa made the creation of a leper colony in the state of Amazonas a priority, with the Paricatuba building adapted for this purpose.

National legislation during this period stated that compulsory notification and isolation were mandatory for the disease: at home, or in agricultural colonies, sanatoriums or hospitals and asylums (Souza-Araújo, 1956). The isolation model to be adopted in Brazil was the subject of debate, but all agreed that the patient should be isolated as soon as the disease was diagnosed. Amazonas had no isolation system compatible with standards for treatment of and fighting against leprosy, as the patients were only managed at the precarious Umirisal and Linha do Tiro facilities, which consisted of wooden houses with thatched roofs, and were solely to house the patients.

National policy regulations for controlling leprosy also called for a national census, as there was no idea of the extent of the problem. The production of leprosy statistics was an important investment by the leprologists in order to convince the government that the disease was a national problem (Cabral, 2013). According to the data from the census carried out between 1920 and 1925, Brazil had a total of 11,174 people suffering from the disease, with most of the cases in the Southeast and the North. In the latter, the states of Pará, Amazonas and Maranhão had the most cases, 2,013, 691, and 653, respectively (Souza-Araújo, 1956).

The Amazonas census, published in the first report of the Public Health and Rural Prophylaxis Service, in 1922, analyzed the following data: age, gender, place of birth, race, profession, marital status, residence, age at which the disease became apparent, initial symptom, relatives with leprosy, Hansen's diagnosis, isolation, treatment, and observations. All cases were assessed by the physician Alfredo da Matta, including those patients who had already been monitored at Umirisal. The census showed that patients were scattered throughout the city of Manaus and along rivers in the state of Amazonas (Matta, 1922b). The locations with the greatest prevalence of the disease were along the Solimões and Purus rivers, and the municipalities with the greatest number of sick were Fonte Boa and Lábrea. The rivers that were frequented by a large number of migrants because of the rubber taping industry contributed to the higher numbers of individuals sick with Hansen's disease. Also, according to the census, 118 people died from the disease between 1905 and 1922 (Matta, 1922b).

According to Alfredo da Matta (1929b), 971 people were resurveyed between 1922 and 1928 and the physician concluded that there were still 800 individuals with Hansen's disease at the end of 1928. However, the doctor estimated that the true figure was 25% higher because of the difficulty in diagnosing the disease and in geographic access. In relation to the professions

of the patients, the census revealed that: 31 worked in trade, 156 worked in residences, 211 worked in the fields, 93 were rubber tappers, and 89 were unemployed. With respect to the mode of contagion, the patients said that they must have caught the disease: from relatives (174), from working with "lepers" or residing with them (97), from an unknown source (679), and 21 were disqualified. The large number of people working in rural contexts and in the rubber tree fields stand out. Another piece of information that stands out is the general lack of knowledge of most patients on the origin of the disease, which is not totally unexpected for the period given the limited information available on forms of contagion.

Alfredo da Matta (1922b, p.273) stated that census-taking was more difficult because of displacement via tributaries of the Amazon river and also due to the distribution of the population in the Amazon valley: "The census, easy in other regions, via inspections and exams, is extremely difficult here, as it depends on unpredictable factors such as the availability of vessels and oars or propellers to get around." In this regard, today we would have similar difficulties. The 1924 census cited an approximate number of one thousand sick individuals in an estimated population of 300,000. In 1932, 1,569 cases of Hansen's disease were diagnosed (Coimbra, 1932).

The health inspector's primary concern was the individuals in which there was no manifestation of the disease, since this "was the group most dangerous to society, mobile carriers of leprosy" (Matta, 1922b, p.273). According to Matta (1922b, p.274), these people were "apparently healthy, with no marks or trophoneurotic lesions, or even sores, but suffered from leprosy; they transferred the bacillus to healthy people. They are horrible sources of contamination." Thus, the physician proposes more detailed examinations of people with certain symptoms: "the physician should look for, or better yet probe, the small or not small zones that patients say are numb" (Matta, 1922b, p.287). These zones were more important than marks, according to the physician. In theses cases, not even microscopic examination helped, since the bacillus had unknown variations. He also warned of the disease's incubation period and asked medical professionals to remain mindful of marks because patients would not show them spontaneously, since they did not relate them to the disease. According to the survey, of every hundred patients examined, 95 did not think that the marks were important (Matta, 1922b).

During this period, in which Rural Public Health activities were at their peak, namely April 1922 to October 1929, 951 cases were encountered. Alfredo da Matta clinically described each case, noting the symptoms and the type of exam performed. Of this total, 427 people were hospitalized and isolated at the Paricatuba Leper Colony, of which 75 were old cases treated via isolation at Umirisal. Based on the cases observed and studied, the sanitarian questions the classification proposed by Muir, because he found the criteria defined by the English leprologist – who used a system based on lesion stages and types of leprosy – to be "not very practical." "These, of a pathological order; those, according to the invasion and virulence of the bacilli" (Matta, 1922b, p.258). Muir's three stages – quiescent, inflammatory and resolution – could, according to Afredo da Matta, be seen in a single patient and were thus not adaptable for clinical classification.

The difficulties in managing the disease were of a technical and political nature because, until the end of the 1920s, there was no suitable system for monitoring patients. In 1916 (p.78),

Alfredo da Matta defended the patient isolation policy, as practiced in Europe, but felt that "leprosy is, perhaps, one of those diseases that requires voluntary isolation." The physician assumed that people would seek isolation voluntarily in order to not infect others. There was almost no hope of a cure, says Matta (1916, p.79): "the individual had little expectation of recovery, the horrors of his state weighed on his spirit, turning him melancholy. The leper was surrounded by a endless night with no dawn." In the physician's opinion, Amazonas should build an asylum-colony on an island near Manaus, a sort of river leper colony, inspired by Oswaldo Cruz's proposal for a leper colony on Ilha Grande in Rio de Janeiro (Cabral, 2013). Despite his political weight on the local scene, since he occupied the post of President of the State Assembly from 1916-1918, he was not able to implement this proposal.

In 1930, when Getulio Vargas took the presidential power, leprosy policy initially suffered a setback because the Leprosy and Venereal Disease Prophylaxis Clinics were eliminated, creating discontinuity and disorganization in leprosy care. In 1935, the policy was reimplemented with the National Plan of Struggle Against Leprosy, broadly supporting the construction of leper colonies, with internment becoming mandatory (Maciel, 2007; Cabral, 2013).

In Amazonas, the policy of isolating Hansen's Disease patients was only implemented after the inauguration of the Paricatuba Leprosarium, in December 1930. The institutions responsible for carrying out the policy for the disease were: Umirisal (1868–1931); Linha do Tiro (nineteenth century-1930); Oswaldo Cruz Dispensary (1921–1950); Belisário Penna Hospital-Colony – Paricatuba Leprosarium (1931–1967); Antônio Aleixo Colony (1942-1978); Alfredo da Matta Foundation (1950-present); and Gustavo Capanema School (1949-present). In the following section we will analyze these institutions and their role in the health policies of the state of Amazonas.

## First isolation: smallpox to leprosy

The first isolation site was Umirisal, which was used to isolate patients with smallpox in the mid nineteenth century to the early twentieth century. Epidemics instilled strong fear in the population, since prophylactic vaccines were not yet effective, thus the policy of isolating people in homes, clinics or hospitals. The Amazonas Public Health Regulations, in 1899, provided for the construction of a Vaccine Institute to replace import of vaccines, but the institution was never effectively established. The quality of vaccines improved and the population began to collaborate with vaccination. Thus Umirisal was gradually converted to provide isolation for "Hansen's patients" until it was deactivated upon the inauguration of the "Paricatuba leprosarium" at the end of the 1930s.

Umirisal was located in the São Raimundo district on the left bank of the Negro river, separated from downtown by the Cachoeira Grande falls, three kilometers upstream of downtown Manaus, on a high embankment, generating multiple access problems. The building was made of wood with a thatched roof, requiring constant repairs, as it was used only during epidemics. Shortly before its closure the building contained 48 rooms, two thatched sheds, an office, a dispensary, three wooden sheds and a chapel (Matta, 1922a). Public Health authorities always complained about the physical conditions at the site.

In the report by the president of the province, in 1867, Umirisal appears as a "lazaretto" for isolation of cases of "bexiga" (smallpox) and other diseases but, according to the same text, the site had already been used for isolation in prior years, whenever there was an epidemic. The location was formally identified as isolation by provincial law No. 171, of July 18, 1867, authorizing the public health inspector to establish on the site "a hospital for treatment of patients suffering from Greek elephantiasis, and to remove a minor named Maria from the facilities, to whom shall be granted a daily stipend of 500 reis" (Gama e Abreu, 1868, p.460). The owner of the land was Dr. Antonio David Vasconcelos de Canavarro, who offered the location freely for isolation of cases of contagious diseases. The lazaretto director was Dr. Thomé Maria Cavalcante from February 21 to March 29, 1868, when smallpox was eradicated from the capital.

According to Alfredo da Matta, Umirisal also housed leprosy patients from the beginning, with the first being a minor from the municipality of Silves, in 1868; three years later another two people arrived. In 1908, the location was officially commissioned exclusively for the isolation of sufferers of Hansen's disease, since until then patients were treated at the Santa Casa de Misericórdia Hospital. The site served to isolate increasing numbers of Hansen's disease patients (Matta, 1922a).

Although Umirisal was called an isolation colony, it did not fulfill this role exactly, as it served more as a place for the sick to live after they had been repudiated by their families. In 1922, it housed 171 people. In 1930, there were 207 patients living there, who received State support in the form of medication, food, clothing and schooling (Porto, 1920). Umirisal was stigmatized as a leper colony and, when closed in the late 1930s, it was burned by the Public Health Service.

## **Oswaldo Cruz Dispensary**

The Oswaldo Cruz Dispensary was inaugurated on April 21, 1922, under the direction of physician Alfredo da Matta, assisted by physicians Linhares de Albuquerque, responsible for venereal diseases, and Antônio Ayres de Almeida, responsible for the leprosy and skin diseases division. The service had offices in the same building as the Pasteur Institute, also run by Alfredo da Matta, next to the prison on Rua Municipal (now named Sete de Setembro), where the Hospital de Custódia is now located).

The Dispensary was set up by the Amazonas Public Health and Rural Prophylaxis Service, based on an agreement signed by the state and the federal government in 1921. Actions to fight leprosy already existed through the Public Health Service Board, but focused on aiding patients isolated in two locations in the city of Manaus: Linha do Tiro and Umirisal. The physicians Clementino Ramos, Alfredo da Matta, Miranda Leão and Fulgêncio Vidal, from the Hygiene Department, took turns working at the two sites. The Public Health Regulation of 1921 recommended that notification and isolation follow the same guidelines as for prophylaxis of tuberculosis.

Assistance for patients with venereal diseases, and dedicated professionals and space for treatment and management of patients was unprecedented in Amazonas. Prophylaxis of venereal diseases only appears in the 1921 Public Health Service Regulation, showing that

there was an intention to establish a specific dispensary for this type of service. The Dispensary became responsible for the diagnosis and treatment of venereal diseases. Before the creation of this institution, patients were monitored in private clinics and in two hospitals in the city of Manaus, the Santa Casa de Misericórdia hospital and the Hospital Beneficente Português do Amazonas.

The Dispensary performed the first diagnosis, laboratory exams and studies on the clinical and therapeutic aspects of Hansen's disease. According to Alfredo da Matta (1922b, p.83), the Dispensary served as a site for clinical research: "Mitigation of evil is manifest in many patients. There are cases where the examination of nasal mucus has revealed the absence of Hansen's bacillus. The numbness at the site of the marks also changed notably in some patients, with sensitivity returning, and the tegumentary color gradually returning to normal. In the 1950s, it changed name and address, became known as the Alfredo da Matta Dispensary and moved to the Cachoeirinha district. The name was in honor of the physician who worked in public health in the state of Amazonas for fifty years. During this time he was a public health physician, head of the Public Health Service, state representative, senator, and founder and supporter of various health institutions. As if that was not enough, he was also a researcher recognized by his peers, having published about 230 articles in international, national and local publications in different fields of scientific knowledge (Schweickardt, 2011).

# Vila Belisário Penna Hospital-Colony – Paricatuba Leper Colony

"The great threat" was the title given by Samuel Uchoa, head of the Amazonas Public Health and Rural Prophylaxis Service in his report *Um ano de campanha* (1922) on the situation of the "leper" in Amazonas. The text followed the alarmist tone of Brazilian physicians, but intended to draw attention to the seriousness of the problem. The physician was concerned both by the precariousness of the institutions responsible for treating the sick and by the large number of individuals who were not assisted. The alarmist discourse was a political strategy to obtain both support from the government, in order to receive greater funding, and societal involvement. The medical discourse for the problem of generalized contamination had been developing since the first decade of the twentieth century, but is was the public health movement that stood out. The first national and international conferences warned of the growing number of sufferers, which was not fully confirmed by the census conducted (Cabral, 2013).

Uchoa's argument was based on the history of Hansen's disease in Amazonas, prepared by the physician Alfredo da Matta, who stated that the increase in cases began at the start of the twentieth century, with rare cases before then. Physicians in Amazonas supported the claim that the disease emerged in Amazonas due to migration from states in which the disease already existed, and from bordering countries like Peru and Colombia. Recall that intense migration due to the rubber economy led to contact between relatively isolated populations, such as indigenous groups. The river basins, which had previously been sparsely populated, began to be inundated with migrants from the Northeast of Brazil between 1885 and 1910, radically changing the epidemiological profile of the region. During this period, health services far from the city were episodic, usually in response to epidemics.

"Leprosy" was the type of disease that mobilized society with charitable works and spontaneous contributions from individuals and companies. Merchants and tradesmen donated resources to renovate the Paricatuba building.<sup>3</sup> We believe that no other illness moved the population in this way; the fear of being "contaminated" served as a strong motivator, but the patients' situations and their physical conditions were also reasons for an appeal to "charity." The "threat" was disseminated in the papers and served as a way to alert or even "frighten" the population with respect to the disease; however, this also mobilized society, or part of it, to "protect the lepers." Although the Rural Public Heath Service was responsible for setting up a leprosarium, the State should have helped care for patients at Umirisal, but as it was suffering a financial crisis, the campaigns represented important source of funds (Uchoa, 1924).

The isolation policy was defended by most of the local medical elite and had the support of government officials, as well as the state population. Samuel Uchoa argued that isolation should be mandatory for the hospital-colony model. There was a local consensus among doctors and managers that the best way to treat leprosy was by isolating the sick, avoiding any contact with the "healthy" population.

This compliance was not a global reality, nor a national one. The first policy requiring isolation for lepers had been proposed by Hansen at the International Leprosy Conference in 1897 (Santos, Faria, Menezes, 2008). The first São Paulo Medical Congress was held in Brazil in December 1916, with the topic of leprosy intensely debated by participants. The resolutions of this congress ratified the need for prophylaxis based on isolation, preferably not at home, and finally decided that isolation would be at an asylum and compulsory (Maciel, 2007).

São Paulo, contrary to what the National Inspectorate and its director Eduardo Rabello preferred, defined compulsory isolation as the standard for the state (Cabral, 2013). According to Cunha (2010), what was called the "São Paulo model" led to the isolation of all Hansen's disease patients, regardless of the clinical form or stage of the disease, which strongly distinguished it from methods used by doctors and other state authorities. In São Paulo patients of non-contagious forms of the disease could be interned shortly after diagnosis and this required the construction of leper colonies.

In the state of Amazonas the Public Health Service was closed and health management was transferred to the Public Health and Rural Prophylaxis Service. The Paricatuba area was transferred to the new management, which was to adapt the building to house a leprosarium. Construction begun in 1896 and was completed in 1905. The building was located on the right bank of the Negro river above Manaus, so the only access to the site was by boat. The initial purpose of this building was as a way station for immigrants from European countries, but the state government was unable to entice foreign immigrants to the Amazon rainforest. After the building was built, the facilities were used for the recently established Amazonas Affonso Penna Industrial Agriculture Institute, inaugurated by President Affonso Penna himself in 1906. The objective of the Institute was to educate boys, preferably indigenous ones, in arts and crafts such as carpentry, tailoring and shoemaking (Schweickardt 2011, p.200).

In the 1910s, the site was transformed into a prison and later shared the space with the Public Gardens. On June 10, 1917, the newspaper *A Imprensa* reported on the visit of governor Alcântara Bacelar to the prison and Gardens. When management of the building

was transferred to the Amazonas Public Health and Rural Prophylaxis Service the detainees were transferred to the penitentiary in Manaus, according to regulation No. 1479, of July 1, 1924.

The building underwent a major renovation in order to house Hansen's disease patients and comply with the hospital-colony philosophy. The renovation and construction of new buildings resulted in the following: the main building, chapel, cemetery, mortuary, water reservoir, reception, boiler room, manager's house, married couples' houses, workers' houses and the port. Some of these buildings have withstood time, with some being reused, even today, for community purposes, such as the chapel and the cemetery.

The Paricatuba renovation had great support from Amazonas society, through donations and promotions. Samuel Uchoa led several campaigns and suggested that people donate a monthly amount to the project. Thus physicians, attorneys, judges, journalists, tradesmen and many others contributed to the campaigns. In 1923 the entity Ladies Protecting the Leprosarium, which sought to raise funds for the same project, was founded (Mesquita, 1926).

The Paricatuba building was transferred to the Rural Public Health Service by Decree No. 1,479 of July 1, 1924, by Governor Turiano Meira, but the process was interrupted by the revolutionary movement in July 1924. In January 1925, through federal intervenor Alfredo Sá, the building was finally transferred to the Rural Public Health Service. The work to adapt the facilities began in February 1925. Engineer Angelino Bevilaqua was invited to direct the adaptation and construction of the Paricatuba complex. The inauguration of the "leprosarium" was scheduled for December 24, 1925, but did not happen.

When governor Ephigênio Salles took office in 1926 he decided to reopen the discussion on Paricatuba because he wanted to use it as a way station for migrants. He thus decided to build a new leprosarium on the banks of the Negro river, on a site named Paredão, opposite the island of Marapatá, downriver from Manaus. Alfredo da Matta supervised the construction and overseeing of the project. Decree No. 149 on December 31, 1927, named the new facilities Vila Belisário Penna, and they were large enough to house 400 people, with 24 semidetached houses and four buildings to house twenty people. However, before the patients were transferred, the work was condemned by the leprologist and physician Achiles Lisboa (2002), because he thought that the facilities were inadequate for the treatment of Hansen's disease. He reconsidered the Paricatuba facilities, which had to be modified, and were approved by federal intervenor Álvaro Botelho Maia on June 14, 1931. The 226 Hansen's disease patients isolated at Umirisal were transferred to the new building. Some materials were recycled and then the houses were burned. The new site could house 300 patients and kept the name of the famous promoter of Brazilian rural public health, sanitarian Belisário Penna (Schweickadt, 2011).

The Belisario Penna leprosarium followed the model of hospital-colonies in Brazil and abroad: Carville, in the United States, and Curupaiti, in Rio de Janeiro (White, 2003); Itapuã in the Porto Alegre region (Fontoura, Barcelos, Borges, 2003); Santo Ângelo, Pirapitingui and Padre Bento in São Paulo (Monteiro, 2003), creating and adapting an architectural complex and bureaucratic system to care for patients, who were taken by boat to the isolated town of Paricatuba. The colonies were to function as a town or micro-city: far from the city,

self-sufficient and able to provide "consolation to the patients". The area was divided into a "patient area" and a "healthy zone," which the regulation defined as distinct, "one for administrative staff, and the other for isolating the sick" (Regulamento..., 1 out. 1929, p.5).

The lack of professionals to care for Hansen's disease patients led physicians to organize the patients themselves to assist in providing services inside the isolation area: "among the patients themselves, an administrator, two nurses and their assistants, a cook and helper, laundry washer, guards and carpentry and metalworking workshops." Thus the patients could "help the public service, with each one receiving an insignificant remuneration, which serves as motivation" (Matta, 1929a, p.11). The practice of putting patients to work was part of the strategy to occupy each patient in productive activities, a model used in asylum-colonies (Matta, 1922c).

Between 1965 and 1967, Vila Belislário Penna was closed and its patients were transferred to the Antônio Aleixo Colony, which had been operating as a hospital-colony since 1942. Currently, the Paricatuba site is home to a community that lives among the ruins of the main building, which represents this period in the history of Hansen's disease in the region. You can still talk to some of these former patients, who recount their stories of living in an isolation facility.

## **Gustavo Capanema School**

An institution called a preventorium was linked to hospital-colonies or leprosariums, and was part of the isolation policy for Hansen's disease. The preventorium was used to care for the children of Hansen's disease patients, taken from their parents soon after birth. The institution sought to raise these children or find families for them. The first institution with this purpose was the Alice Sales nursery school, established in 1926, located in the Cachoeirinha neighborhood, when the Amazonas Public Health and Rural Prophylaxis Service was managing it (Uchoa, 1922, p.15).

On July 6, 1939, the Gustavo Capanema School was founded. It also sought to care for the healthy children of parents with Hansen's disease, interned in the leprosarium. Several campaigns were carried out in order to build the School, officially opened in 1942 as an institution in support of leprosy control in Amazonas, with the main objective of supporting the children of patients interned at the Belizário Penna leprosarium and the Antônio Aleixo Colony (Tavares, 2011). The institution's building still exists, located in the Oliveira Machado Colony.

The children who arrived at the preventorium were taken immediately to the disinfection pavilion, where they remained in quarantine until they had been evaluated for Hansen's disease. After the quarantine period was over, they were housed in accommodations with other children. These measures to separate children from their sick parents were justified in Brazil as a means to break the cycle of transmission of Hansen's disease from one family member to another (Tavares, 2011). The separation of minors from the focus of infection was considered an effective measure, but the psychological and social harm to the children and their families was immeasurable.

# The Antônio Aleixo Colony

Founded on February 10, 1942, during the term of governor Álvaro Maia, it was named as a tribute to the Minister of Education at the time. The colony's structure followed the same model as other hospital-colonies in Brazil, and patients were taken there by boat or car.

According to Tavares (2011), the history of this colony can be divided into four stages: 1942-1966, complete isolation of patients; 1967-1972, relatives could visit and families could form; 1973-1977, transformation into a hospital-colony with patient assessment and possibility of release; 1978-1979, closure. We note that the criteria follow the national policy of opening up hospital-colonies, first to family members and patients and subsequently to society in general.

The structure of the colony consisted of pavilions for women, men, children and adolescents. The couples had separate houses or rooms in the pavilions. In 1968, the colony's population was 1,468 (Talhari et al., 1981), which was greater than the site's physical capacity and capacity for clinical management by doctors, church staff and patients. Patients came from cities inland, and also from the states of Rondônia, Roraima and Acre. Arriving in Manaus, patients were screened at the Alfredo da Matta Dispensary, also known as the "Yellow House", and confirmed cases were moved to the Colony by car or by boat. The best-known boat, remembered by older patients, was called Adolpho Lutz.

The Franciscan Sisters of Mary took over administration of the colony from 1966 until 1979, when it was closed – a fact that radically changed the relationship with patients, according to reports from people who experienced the change. The Sisters organized the inmates into work areas and began to administer medications regularly, which had not happened previously, according to the testimony of a former patient. A school was founded to teach the adults to read, and later for teaching the children (Tavares, 2011). According to Sister Angela, former director of the Colony, under the nun's management work was organized, with the patients set to work on shoemaking, baking, pottery, fishing and farming. In addition to the pavilions and houses there was a community center, ladies club, sports field, wells and water supply network, housing for workers and the nuns, and a police station (Angela, 2012).

The sisters also obtained resources from Holland through Father João de Vries, to build a residential complex that was named Guilherme Alexandre in honor of the Prince of the Netherlands. The complex, which exists to this day, consists of 99 semidetached and was intended for couples (Angela, 2012). The sisters asked the State Department of Health to close Villa Belisário Penna, as they were finding it difficult to maintain the two treatment sites. The Paricatuba patients were distributed throughout the colony's premises, with couples in the Guilherme Alexandre complex and single individuals in the dormitory pavilions.

The isolation policy was eliminated with Law No. 3,542 of 1959, which became effective through Decree No. 968 of May 7, 1962. The Antonio Aleixo Colony was closed by Decree No. 4,464 of December 18, 1978, signed by Governor Henoch da Silva Reis. This was followed by the recommendation in Ministry of Health Directive No. 165 of May 14, 1976, that recommended closure of all hospital-colonies in Brazil. Negotiations between the different agencies and institutions began in August 1978, at a meeting held at the Rio Negro Palace with the governor. On that occasion, a shutdown commission was established to develop a plan,

and included the participation of various official entities. About 600 people still lived in the Colony, according to a document from the Commission, which had 12 months to carry out the plan, which was not possible, and the initial recommendation was revoked on June 13, 1979, through Ministry Directive No. 469/79, due to lack of political support (Tavares, 2011).

The Commission's objectives were clearly compatible with the principles of including the patients in social life and citizenship: transform the Antônio Aleixo Hospital-Colony into an open community; reintegrate the Hansen's disease patients into society, providing them with the means to make a living; allow them to live a normal life and enjoy the rights of citizenship; involve institutions and public agencies so that they provide the services needed by the community.

The medical staff who worked at the Colony had the following proposals: create an asylum for people with severe mutilation; create a health center for medical and dental care of patients from the former colony and new residents; donate the houses to the residents; create dorms for young people living in the pavilions; ensure continued operation of the existing cooperative through agreements with the National Institute of Agrarian Reform; transform the Colony into a neighborhood through understandings with the city of Manaus; communicate the changes to the inhabitants of Manaus (Talhari et al., 1981).

Among the proposals for closure of the colony was the foundation of the Geraldo da Rocha Asylum, to serve and treat patients with major physical disabilities and the creation of a health center for medical and public health care of the community. The first decision of the Health Department was to discharge all patients that were in good physical condition, and assist in returning those who had recovered to their original homes. Another measure was to grant retirement benefits to everyone who had been interned in the hospital-colony.

After the dismantling process began on January 6, 1979, the newspaper *A Notícia* published the following note next to photographs of the mutilated, "600 lepers threaten to come down to beg – the Antônio Aleixo Colony went on sale on the 2nd of this month, when it began to be shut down and transformed into a neighborhood" (quoted in Talhari et al., 1981, p.183). The lack of scientific information about the disease, associated with the stigma related to it, made the closure a social question in the city. Inside the Colony some residents opposed the closure because they knew that they would lose the advantages and gains that they had made during internment.

After transformation of the Colony into a neighborhood, many families moved to the site, relatives of patients, patients or new residents with no connection to the disease. The neighborhood continued to enjoy some benefits, such as exemption from payment of electricity, rent and water. Five years after closure, only the State Department of Health remained continuously in the neighborhood, taking responsibility for solving problems in other sectors of the public administration (Relatório..., 1983).

The health services provided in the new neighborhood were: the Antônio Aleixo and Lago do Aleixo health centers, which performed immunization and laboratory tests, as well as medical and dental care; the Izabel Nogueira Maternity Hospital, with ten beds; the Geraldo da Rocha Center, with 120 beds intended for leprosy patients with severe mutilation, serving as asylum; the Chapot Prevost Isolation Hospital, with forty beds for chronically ill and terminally ill cancer patients.

Currently, the Antônio Aleixo neighborhood has all the infrastructure services of an urban neighborhood. Some of the old Colony structures are still there, such as some pavilions, houses in the Guilherme Alexandre complex, the mothers club, the cinema, and the charity organization. Some pavilions have been completely renovated and given new structure and new names. According to the 2010 census, there are 16,602 people in the district.

### **Final considerations**

The purpose of this study was not to carry out an assessment of the political decisions of the different historical periods, but rather to look at how these policies developed in the state of Amazonas. To this end, we described the organizational structure that was set up to care for sufferers of leprosy. During a period of less than 100 years various services, structures, policies and plans were developed to control Hansen's disease and care for patients with the disease.

The various institutions in Amazonas followed national anti-leprosy policies, but there were local characteristics, such as the phenomenon of mass migration from the Northeast, and the dispersion of the population over an immense region, cut by rivers and lakes, resulting in precarious healthcare services in areas that were difficult to reach. Services related to leprosy were concentrated in the capital, although some municipalities established small isolation sites, such as Lábrea and Parintins.

The ability to cure leprosy with multidrug therapy in the early 1980s led to new forms of care, changing the profile of the institutions and control policies. However, this brief history of policies and health institutions discusses various strategies for treatment and management of and support for leprosy patients. This article systematized the information on the history of Hansen's disease and the public institutions and policies that addressed this disease in Amazonas.

### **NOTES**

- <sup>1</sup> The word leprosy is used in the historical sense of the term. A change in terminology occurred due to Health Ministry Decree No. 165, of May 14, 1976.
- <sup>2</sup> The Sanitation Service was led by the physician Samuel Uchoa and operated until 1928. For more details on the Service, see Schweickardt (2011).
- <sup>3</sup> A list of merchants who had contributed to renovating Paricatuba can be found in *Diário Oficial do Estado do Amazons* (29 nov. 1925).

### **REFERENCES**

ANGELA, irmã.

[Depoimento]. Entrevistador: Julio Cesar Schweickardt. Manaus: Fiocruz Amazonas. 1 CD de áudio (2h). Depoimento concedido ao Projeto Memória da Hanseníase no Amazonas. 2012.

CABRAL, Dilma.

Lepra, medicina e políticas de saúde no Brasil (1894-1934). Rio de Janeiro: Editora Fiocruz. 2013.

COIMBRA, Antônio Rogério.

Relatório apresentado ao ex. sr. dr. Getúlio Vargas, chefe do governo provisório da República. Manaus: Imprensa Pública. 1932.

CUNHA, Vivian da Silva.

Isolados "como nós" ou isolados "entre nós"?: a polêmica na Academia Nacional de Medicina sobre o isolamento compulsório dos doentes de lepra. *História, Ciências, Saúde – Manguinhos,* v.17, n.4, p.939-954. 2010.

### DIÁRIO...

Diário Oficial do Estado do Amazonas. p.6. 29 nov. 1925

FONTOURA, Arselle de Andrade da; BARCELOS, Artur; BORGES, Viviane Trindade.

Desvendando uma história de exclusão: a experiência do Centro de Documentação e Pesquisa do Hospital-Colônia Itapuã. *História, Ciências, Saúde – Manguinhos*, v.10, n.1, p.397-414. 2003.

## GAMA E ABREU, José Coelho.

Exposição do presidente de província do Amazonas lida em 25 de novembro de 1867. Manaus: Typographia do Amazonas. 1868.

### HOCHMAN, Gilberto.

*A era do saneamento*: as bases da política de saúde pública no Brasil. São Paulo: Hucitec. 1998.

### LISBOA, Achiles.

Campanha contra a lepra no Amazonas. Manaus: Secretaria de Estado de Cultura do Amazonas. 2002.

### MACIEL, Laurinda Rosa.

"Em proveito dos sãos, perde o lázaro a liberdade": uma história das políticas públicas de combate à lepra no Brasil (1941-1962). Tese (Doutorado em História) – Instituto de Ciências Humanas e Filosofia, Universidade Federal Fluminense, Niterói. 2007.

MATTA, Alfredo Augusto da. Escorço histórico da lepra no Estado do Amazonas. *Brasil Médico*, n.10. (separata). 1929a.

## MATTA, Alfredo Augusto da.

Os sintomas iniciais das leproses: seu contágio e evolução relativamente rápida. Ciência Médica, ano 7, n.5. (reimpressão). 1929b.

### MATTA, Alfredo Augusto da.

Relatório do Dispensário Oswaldo Cruz. In: Uchoa, Samuel. *Três meses de atividade*: relatório do Serviço de Saneamento e Profilaxia Rural do Amazonas. Manaus: Imprensa Pública. 1922a.

## MATTA, Alfredo Augusto da.

Relatório do Instituto Pasteur. In: Uchoa, Samuel. *Um ano de campanha*: relatório do Serviço de Saneamento e Profilaxia Rural do Amazonas. Belém: Casa Editora A Semana. 1922b.

MATTA, Alfredo Augusto da.

Relatório do Dispensário Oswaldo Cruz – Colônia Umirisal. In: Uchoa, Samuel. *Um ano de campanha*: relatório do Serviço de Saneamento e Profilaxia Rural do Amazonas. Belém: Casa Editora A Semana. 1922c.

## MATTA, Alfredo Augusto da.

*Geografia e topografia médica de Manaus*. Manaus: Tipografia da Livraria Renaud. 1916.

#### MESOUITA. Carlos.

O hospício Eduardo Ribeiro e o leprosário de Paricatuba. Manaus: Tipografia Reis. 1926.

## MONTEIRO, Yara Nogueira.

Profilaxia e exclusão: o isolamento compulsório dos hansenianos em São Paulo. *História, Ciências, Saúde – Manguinhos*, v.10, n.1, p.95-121. 2003.

### PANDYA, Shubhada S.

The First International Leprosy Conference, Berlin, 1897: the politics of segregation. *História, Ciências, Saúde – Manguinhos*, v.10, n.2, p.161-177. 2003.

### PORTO, Dorval Pires.

Mensagem apresentada à Assembleia Legislativa do Amazonas. Manaus: Imprensa Pública. 1930.

### REGULAMENTO...

Regulamento da Leprosaria Vila Belisário Penna. Decreto n.247. Manaus: Imprensa Pública. 1 out. 1929.

#### RELATÓRIO...

Relatório do secretário de Estado de Saúde do Amazonas, Nelson Antunes Araújo Filho: gestão 1983. (Coordenação Estadual de Hanseníase, Manaus). 1983.

SANTOS, Luiz Antônio de Castro; FARIA, Lina; MENEZES, Ricardo Fernandes de. Contrapontos da história da hanseníase no Brasil: cenários de estigma e confinamento. *Revista Brasileira de Estudos Populacionais*, v.25, n.1, p.167-190. 2008.

## SCHWEICKARDT, Julio.

*Ciência, nação e região*: as doenças tropicais e o saneamento no estado do Amazonas (1890-1930). Rio de Janeiro: Editora Fiocruz. 2011.

SOUZA-ARAÚJO, Heraclídes César de. *A história da lepra no Brasil*. Rio de Janeiro: Departamento de Imprensa Nacional. 1956.

## TALHARI, Sinésio et al.

Hanseníase no estado do Amazonas: histórico e desativação do leprosário. *Anais Brasileiros de Dermatologia*. v.56, n.3, p.179-184. 1981.

### TAVARES, Tomázia.

*Antônio Aleixo*: de leprosário a bairro de Manaus. Manaus: Edição do autor. 2011.

## UCHOA, Samuel.

*A Leprosaria de Paricatuba*. Manaus: Tipografia Palácio Real. 1926.

UCHOA, Samuel.

*Um triênio de labor*: relatório do Serviço de Saneamento e Profilaxia Rural do Amazonas. Manaus: Lino Aguiar. 1924.

UCHOA, Samuel.

*Um ano de campanha*: relatório do Serviço de Saneamento e Profilaxia Rural do Amazonas. Belém: Casa Editora A Semana. 1922.

WHITE, Cassandra. Carville and Curupaiti: experiences of confinement and community. *História, Ciências, Saúde – Manguinhos*, v.10, n.1, p.123-141. 2003.

