

# The Inclusion/Exclusion Dialectic: a Study on Schools for Children of Leprosy Patients, during the 20<sup>th</sup> Century, in the Brazilian State of Paraná

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**ABSTRACT**— *Leprosy is a disease surrounded by taboos and a strong stigma ever since the most remote times. In Brazil, during the first decades of the 20th century, leprosy spread progressively and came to be a central public health concern. Thus, between 1926 and 1947, time span of this research, the solution proposed was isolating lepers from the society, which motivated the construction of leprosaria in several states of the federation. In the Brazilian state of Paraná, locus of the study, the São Roque Leprosarium began operating, serving as an autonomous colony, including hospital, school, prison, bakery, and what else was necessary to assist the day by day of the patients. The research discusses the insertion of that school for lepers' children in the wider project of a hospital-colony. The inclusion/exclusion dialectic in education, here represented by a perverse social insertion, involves the sick one entirely in his relationships.*

**Keywords**— *Leprosy, schools for children, leprosaria, inclusion*

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## 1. INTRODUCTION

Hansen's disease, or leprosy (as it is mostly known), is known since five centuries before Christ and was a stigma for its carriers, due to the terror that it caused. In the Brazilian state of Paraná, about 1816, many lepers started to appear, coming from the north. They lived mostly on alms and in isolated groups, since nobody wanted to come close to them. Already in the first decades of the twentieth century, the disease spread progressively in Brazil, becoming a major public health concern. As the knowledge on the transmission of the disease was insufficient for an efficient prophylaxis, the solution adopted by public authorities and endorsed by medical speeches was isolating carriers from the rest of the society. For that purpose, the government built several *leprosaria* and colonies that served as autonomous cities, with hospitals, bakeries, schools, churches, amusement houses and everything else needed for the day by day of the patients. In 1926, in the municipal district of Deodoro, currently city of Piraquara, in the state of Paraná, the São Roque *Leprosarium* – known today as Dermatologic Hospital of the State of Paraná – began operating, following the politics of segregating lepers. This work focuses on the compulsory isolation for lepers and the day by day of schools that served lepers' children, especially the Curitiba School, in the period of 1926 to 1947.

The research collected, analyzed and interpreted primary and secondary sources in regards to the public policies in Brazil in relation to lepers during the first half of the twentieth century. Bibliographical and documental researches took place, granting preference to legislative documents and articles and works published in medical newspapers of the time. The research also analyzed documents from the São Roque *Leprosarium* that are today in the file of the Memory House of the Cultural Foundation of Curitiba. As for the oral research, the collection of the history of the institution relied on the valuable considerations of Dr. Rui Noronha de Miranda, who dedicated his life, from 1935 to 2010, to working with lepers. The results obtained allow for a better understanding of the reality lived by parents and children involved with the disease.

## 2. LEPROSY

Leprosy is an infectious disease. In 1873, the Norwegian doctor Gustav Armauer Hansen identified the pathogenic microbe that causes the illness: the bacillus of Hansen, or *Mycrobacterium leprae*, which belongs to the same family of the tuberculosis agent and prefers to attack skin, mucous membranes and outlying nerves. The disease disseminates through personal contact, abrasions and bites of insects. Its incubation period is long, sometimes up to years. In the history of humankind, “maybe there is no disease that has caused so much fear and disgust as leprosy”, says Richards (1993: 153). The physical deformities, the suppurative wounds and the mephitic odor caused by leprosy inspired fear and, thus, the exclusion of the lepers, justified in the medieval society by religious and moral principles. The reason to segregate lepers far away from the others was the fear of infection, whose process was unknown. Isolation did not serve to cure lepers, but to avoid their contact with the healthy. People believed that objects touched by lepers, sexual contact and infected breathe transmitted leprosy.

The study of marginality, developed by Duby and Geremek (1992: 94), pointed the focus to the plan of mental attitudes and social policies directed to the disease, propitiating the development of studies on group and individual existences, as well as on the representation in particular. Lepers, in that context, began to represent a very specific type of marginal. Marginal par excellence, excluded, which bore the stigma, the danger of carnal contamination. Paradoxically, fear and love for others confuse themselves. The lecture of the Church was that lepers should be treated with compassion, since they were, in a certain sense, favored by God, who allowed them to suffer in this life, like Christ. That stimulated compassion as a form of obtaining salvation. In the Middle Ages, the “leper’s case”, occurred in France, is illustrative: the leper, for which Jesus would have a special predilection, received alms and donations from those that saw in him the best middleman between man and God. The king of France, knowing that the *leprosaria* were accumulating wealth from those donations, enviously decided to confiscate the goods of lepers. “As it was necessary to justify the conflict, he accused the lepers of organizing an international plot to destroy the world, through the poisoning of wells [...]” (Geremek, 1993: 09).

Based on those reflections, the marginality of lepers in the European Middle Ages was unquestionable. Leprosy is curable today, but it was not up until the middle of the twentieth century. Medical diagnosis was complicated, since the same symptom could indicate several diseases, and several diseases could produce the same symptoms. It was common to demand the use of distinctive clothes and the use of rattle, bell or trumpet, through which lepers should announce their approach, aiming to prevent the danger, since the disease was contagious.

When taking notice of the public health policies effective in Brazil last century, however, the researcher realized that the confinement, used during the Middle Ages as a support to address the leprosy problem, was still in use in the first half of the twentieth century. She became interested, then, in investigating it.

In Brazil, as in other countries of the Americas, there is no record of leprosy among the indigenous. The disease entered Brazil by several points of the coast, brought by the first Portuguese settlers, mainly Azoreans. Later, other European peoples might have collaborated for its spread (Monteiro, 1987; Terra, 1926). After the introduction of the disease in the main centers of the colony, the infection would have accompanied the march of the colonization, according to Maurano (1944). From São Paulo, it would have followed the pioneers to Minas Gerais, Mato Grosso and Goiás, reaching also the Southern states, yet in the eighteenth century (Magalhães, 1882, *apud* Eidt, 2004: 76).

Freshly emancipated from São Paulo, in 1853, the province of Paraná had an economy initially based on the maté<sup>1</sup> and, later, on the extraction of wood. It was incipient when compared to great national centers like Rio de Janeiro and São Paulo, where the coffee economy developed. It emerged, therefore, as one of the less wealthy provinces, with scanty resources for social investments in its territory, occupied dispersedly by Brazilian and European immigrants that migrated looking for better life conditions.

Regarding that purpose, Siqueira says (1980: 02):

In provincial Paraná, the hygiene conditions of the population and the basic sanitation in cities and towns were precarious. Due mainly to the almost complete lack of medical-sanitary and hospital resources for the population, this situation became worse in epidemic periods. In addition, the provincial government could do little or almost nothing, and the solutions that it proposed were not immediate, due to the shortage of financial resources, except when referring to contagious or epidemic diseases. In these cases, by imperial decrees, certain special budgets aimed a fast solution.

They said then, before the almost complete lack of resources needed to install an appropriate and permanent sanitary service, that the province had “good conditions of health” compared to other provinces of the empire. It is certain that that possibility resulted from the great salubrity of its climate and from the dispersion of its communities, which hindered the propagation of several contagious diseases common at the time.

Until the twentieth century, legislative measures to control leprosy in Brazil had been topical, in the states of Rio de Janeiro (1756), Bahia (1787) and Pará (1838). The disease, however, was spreading, while almost no action contained its expansion. According to Maurano (1939), during the I South American Congress of Dermatology and Syphilography of Rio, in 1912, Emílio Ribas highlighted significant needs. He emphasized the importance of compulsory notification and scientifically rigid leprosy treatment, along with “humanitarian isolation” in hospital-colonies that not only sheltered lepers, but also acted prophylactically, adopting measures like moving healthy newly born children away from their sick parents and giving them assistance in schools.

In 1916, in Rio de Janeiro, Adolfo Lutz and others created the Commission of Leprosy Prophylaxis. The period between 1912 and 1920 signals the recognition, by Brazilian authorities, of the concern associated to leprosy.

In 1920, the government created the National Department of Public Health, prioritizing the construction of *leprosaria* in all endemic states. The period of “good airs” in Paraná ends about 1920 as well, with the development of cities and the

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<sup>1</sup> Dictionary.com defines it as “a tealike South American beverage made from the dried leaves of an evergreen tree” (<http://www.dictionary.com>)

emergence (still shy and limited) of the urban working class and liberal professions, occasion in which the governments started to worry about the “social”, refraining from addressing only economic interests of oligarchies. Paraná's public health was then able to, in the last five years of the 1920s, accomplish some of its old projects, among which the São Roque *Leprosarium* (for all lepers of the state) and the Isolation Hospital Oswaldo Cruz (for the bearers of acute transmissible diseases).

Inaugurated on October 20, 1926, the São Roque *Leprosarium* was willfully located far from the city of Curitiba to shelter compulsorily all the lepers of the state of Paraná. Model institution at the time in the country, it had the entire basic infrastructure of a small city, from drinkable water supply to radiophonic and cinematographic equipment.

The *Leprosarium* initially accommodated 250 patients and grew progressively to shelter new cases that the Leprosy Prophylaxis Services detected through lepers' registration, which covered the entire state. To illustrate the constant enlargements, the number of patients in the end of the 1950s exceeded a thousand (Fernandes, 1988: 22).

Contracting the disease, however, meant losing freedom and the right to come and go. It also meant punishment by the state under the excuse of treatment, feeding, dwelling and amusement, guaranteed in the São Roque Colony, built for that purpose. In accordance with those provisions, since Paraná already had a model institution, members of the leper's family were obliged to notify the disease. The notification was also mandatory for state authorities with such attributions, and for managers of hotels or any collective dwellings (which should communicate the existence of suspicious bearers to the sanitary service, under penalty of fine).

According to article one of Ordinance 1.194, of October 09, 1926, isolation in the São Roque *Leprosarium* (located in the municipal district of Deodoro) was mandatory for all lepers in Paraná, since this was the only way to avoid the spread of the disease and to extinguish it.

Home isolation was exceptional, affordable only by the wealthy who, by chance, had contracted the disease. Violating the conditions set for home isolation resulted in fine from 500\$000 to 1:000\$000 imposed by the doctor (article three), situation that came to reinforce the affordability only by the rich. Under a certain view, therefore, Paraná's state norm proved more drastic and contusing than the real medieval dictates: the privilege of home isolation consolidated the difference of treatment in function of economic power.

Surprisingly, the duty of notifying leprosy for isolation was extensive to the members of the leper's family, with the possibility of granting home isolation to the spouse not infected by the disease (article nine). The stigma related to leprosy reached not only lepers, but also relatives and people that had some proximity with them. Smaller children with no signs of the disease at the time of their parents' isolation, as well as those born in the *leprosarium*, would be directed immediately to special institutions maintained by the state, which would be in charge of their maintenance, education and professional teaching (article eleven). Moreover, the number of lepers in the state was significant, while the chance of hospital discharge was almost null. Thus, the São Roque Colony grew constantly.

In the beginning of the twentieth century, the only available medicine for treating leprosy was chalmugra oil, an oily substance for subcutaneous inoculation in lepromatous wounds. Multiple wounds demanded multiple inoculations, in an extremely painful treatment that nevertheless did not change the course of the disease. The mortality in the *leprosarium* was thus high, with about 62 deaths per year, according to Dr. Rui Noronha de Miranda, who served as Director of the São Roque Colony in the period. The doctor adds that the compulsory isolation of lepers ended, despite much resistance from part of the society, only when the treatment started to use sulfones, a medicine that did not treat leprosy but prevented the infection of others.

### 3. SCHOOL LIFE IN THE SÃO ROQUE COLONY

Discipline in the São Roque Colony could be considered good. Nacli (1959: 16) describes that patients lived in an organized community, with social life, amusement, instruction and work (labor therapy), receiving small wages that would, many times, help the maintenance of them and their spouses. Far from their family, relatives, friends and social relationships, lepers tried to adapt to the new environment, living a new existence, creating new bonds, new objectives, without, however, erasing the feelings and ties of their previous life. Nonetheless, the freedom expected in function of the treatment was their supreme objective.

Yet, lepers were in a permanent state of deep sorrow, overwhelmed by moral and affectionate complexes. Not rarely lepers escaped from the colony for missing their loved ones or for being concerned with the poverty in which their families were, headed by a leper.

Lepers worked performing activities of maintenance of the premises of the colony, which was economically interesting for the government. Besides that, their occupation prevented thoughts about escaping.

The sanitary services law prescribed that lepers who had small children, when discharged, should live separate from them. This determination was hardly accepted. Most people preferred to let children under the care of relatives, usually paternal or maternal grandparents, who declared in writing to the Leprosy Prophylaxis Division the place where they

would live with the children, also committing to keep them far from the parent at issue until the sanitary surveillance services informed that they could live together.

According to the General Regulation of the Public Health Service of the State of Paraná, published on July 04, 1930, lepers' children and children that lived with lepers could only attend schools under rigorous surveillance and provided that they demonstrated, in repeated tests, absence of germs (article 347). These children underwent testing at least five times a year and any suspicious symptom resulted in removal (sole paragraph).

Interviewed by the researcher, Dr. Rui Noronha de Miranda, doctor who is devoted to working with lepers, emphasized that, in the period under study, there was a so-called leprosy prophylactic tripod: *leprosarium*, school and dispensary. The *leprosarium* served to contagious patients, whose hospitalization was mandatory; the school served to contagious ones' children, separated from their parents because of the hospitalization, and the dispensary served to control communicators and benign cases of leprosy. He mentioned that that tripod originated in a movement led by the Director of the National Service of Leprosy, Dr. Ernani Agrícola, in the technical and medical parts, and by Eunice Weaver, from the Society of Protection to Lazars, in the sense that schools for children of the contagious ones should be built in all states of Brazil.

Following that campaign, relying also on the support of the Getúlio Vargas' government, they introduced the Curitiba School, in the neighborhood of Higienópolis. It has assisted up to 100+ minors, boys and girls, who stayed there isolated from their parents, while these received treatment in the São Roque Colony, in Piraquara. Taking a large area in the neighborhood, the school received children since their very first hours of life, taking care of them until their parents were cured and discharged from the Sanatorium, or until they turned 18 years of age, if their parents were not sick, but poor. Children were sent to the school by the Leprosy Prophylaxis Division, accompanied by guides, and by the São Roque Sanatorium-Colony, with an official letter. Before joining the other children, newcomers went by the Observation Pavilion, where they stayed for a certain time under rigorous observation, concerning the manifestation of any contagious disease, including leprosy. Once confirmed that they were not sick, these children began to live together with the other children, in the pavilion that constituted the school properly.

The Curitiba School kept Kindergarten, elementary school and courses to teach several occupations, with shoe store, mattress factory etc. Boys also worked in farming and in animal breeding. Girls, in addition to elementary school, learned to sew, receiving a certificate once they finished the course. They aided in all house cleaning and children day care services.

The state of Paraná granted the school a subsidy to feed the children. A doctor and a dentist visited the place twice a week. The children lodged in three masculine and two feminine bedrooms. Housekeeping was done by seven employees, aided by children aged enough to help. However, financial difficulties were always present in the maintenance of the institution.

Mandatory separation of the lepers from their families was disastrous, depriving the adult from affection and reflecting in the children's education. Some defended temporary separation, proposing that the government and the Society of Protection to Lazars and Defense against Leprosy protected the children, returning them to their parents only when the danger of infection vanished.

Sanitary authorities, guided by prejudice, lack of knowledge and fear of leprosy spread in society, took on extreme stances, reflected in norms that resulted in the segregation and social isolation of lepers, as well as exclusion of their children and family.

In 1956, in Rome, the global scientific community proclaimed the abolition of mandatory internment of lepers, consolidating the cure of leprosy through ambulatorial treatment based on antibiotics. The school started to lose its original purpose, by assisting other children and adolescents not related to lepers. The place in which lepers previously found despair, suffering, isolation and abandonment changed.

The governmental authorities rethought public health matters, and the São Roque *Leprosarium* started to shelter former sick ones, those without family or other social bonds. The sick body, “absent from history and, nonetheless, one of its places” (Le Goff and Nora, 1995: 142), began to take its place in history.

#### 4. FINAL CONSIDERATIONS

In Brazil, during the first half of the 20th century, being a leper meant losing freedom and the right to come and go. It also meant punishment by the state under the excuse of treatment, feeding, dwelling and amusement. In the Brazilian state of Paraná, this care for lepers, from 1926 on, was backed by the construction of the São Roque *Leprosarium*, which demonstrated a new attitude in regards to public health in the state. The President of the State, Caetano Munhoz da Rocha, had signed decrees that guaranteed compulsory isolation of lepers as well as mandatory leprosy notification to everyone who had contact with lepers: family members, state authorities, as well as other professionals with such attributions. Thus, the healthy no longer took chances of getting the disease.

In regards to the education of minor children of lepers, they immediately went to special institutions maintained by the state, regardless of any signs of the disease. The same happened to children born in the leprosarium. In these schools, the state was in charge of maintenance, education and vocational training.

Mandatory separation of the lepers from their families was disastrous, for both the child and her parents, reflecting in the education of the child. On the other hand, despite not being lepers, lepers' children were marginalized and excluded, since they could not study at regular schools along with other children. They could not share spaces with other children, despite representing no threat of contagion.

Providing school for the children of lepers, while considering them a threat to the established control, sets the inclusion/exclusion dialectic in schools of children of lepers in the first half of the 20th century in Paraná. Inclusion in these schools meant exclusion from schools of children of ordinary citizens.

This treatment given to lepers and their children, in Brazil as a whole, somehow reminds the behavior of the Middle Ages. In both cases, they marginalized and excluded lepers. They considered lepers a threat to the established order and control, because of the fear, intolerance and prejudice of their society.

## 5. REFERENCES

- Duby, G., Geremek, B., "Passions communes", Paris, Éditions du Seuil, 1992.
- Eidt, L. M., "Breve história da hanseníase: sua expansão do mundo para as Américas, o Brasil e o Rio Grande do Sul e sua trajetória na saúde pública brasileira", *Saúde e Sociedade* vol.13, no.2, pp. 76-88, maio-ago 2004.
- Fernandes, L., "Memória – Secretaria de Estado da Saúde do Paraná (1853 a 1983)", Curitiba, Imprensa Oficial do Estado do Paraná, 1988.
- Geremek, B. "Leçon inaugurale", Paris, Collège de France, 1993.
- Le Goff, J., Nora, P. "História: novos objetos", Rio de Janeiro, Livraria Francisco Alves Editora S. A., 1995.
- Maurano, F., "História da lepra em São Paulo", São Paulo, 1939.
- Maurano, F., "Tratado de leprologia", Rio de Janeiro, Serviço Nacional de Lepra, 1944.
- Monteiro, Y. N., "Hanseníase: história e poder no Estado de São Paulo", *Hansenologia Internationalis*, São Paulo, vol. 12, no. 1, pp. 1-7, 1987.
- Nacli, A., "O mal de Hansen e o serviço social no Sanatório-Colônia São Roque", Curitiba, Imprensa Oficial do Estado, 1959.
- Richards, J., "Sexo, desvio e danação – As minorias na Idade Média", Rio de Janeiro, Jorge Zahar Editor, 1993.
- Siqueira, M. T. A. D., "Condições sanitárias e as epidemias de varíola na Província do Paraná (1853-1889)", Curitiba, Universidade Federal do Paraná, 1980. Dissertação de mestrado.
- Terra, F., "Esboço histórico da lepra no Brasil". *Anais brasileiros de dermatologia*, Rio de Janeiro, vol. 2, no.1, pp. 3-4, 1926.