

# Adhesion and Abandonment of Hansen's disease Treatment in Maranhão

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**Abstract**— The abandonment and irregularity of treatment are the main causes of the impasses in the control of Hansen's Disease, since they lead to a greater risk of transmission, creating a serious problem for public health. The objective of the research was to evaluate the causes of the abandonment of Hansen's Disease treatment in the State of Maranhão. Data from the Information System and Diseases and Notification related to the disease were analyzed in a total of 33,308 cases reported in the Health Units of Maranhão from 2008 to 2014 and analysis of 60 records in a field survey in a reference hospital for Hansen's Disease in the State. The multibacillary operational classification was the predominant one, with 23,320 cases (77.6%), with a more frequent clinical form. Males had the highest frequency (64.4%), aged 20 to 34 years (19,357 cases). As for ethnicity, the brown breed had the highest frequency and there was preponderance of low level of education, from 1st to 4th grade, followed by the illiterate. Of the 775 patients who initiated treatment, 60 were either absent or abandoned. The main reasons for abandonment were: side effects of medication, lack of understanding of information about the disease and identification of symptoms, prejudice, idea of religious healing, non-acceptance of the disease and embarrassment of going to health units every month.

**Keywords**— *Transmission. Hospital. Reasons.*

**Resumo**— A hanseníase é uma doença infecciosa e contagiosa marcada pelas desigualdades sociais e tem como uma das fontes principais da disseminação da doença a hanseníase na forma clínica virchowiana. Evidencia assim um grave problema de saúde pública no Estado do Maranhão, bem como no Brasil. O Objetivo do presente estudo foi analisar o comportamento da incidência da hanseníase virchowiana a partir das notificações do SINAN do Estado do Maranhão no período de 2008 a 2013. Trata-se de estudo epidemiológico descritivo, retrospectivo de abordagem quantitativa. O resultado deste estudo estimou a taxa de incidência da hanseníase virchowiana no estado do Maranhão de 10,3 casos por 100.000 habitantes e a taxa média incidência, 15,1 por 100.000 habitantes no sexo masculino. 1% (3) dos municípios apresentam taxa média de incidência muito alta (20,00 a 39,99); 17% (37) apresentaram taxa média de incidência alta (10,00 a 19,99); 55% (120) apresentaram taxa média de incidência média; 15% apresentaram taxa média de incidência baixa e 12% dos municípios apresentam um silêncio epidemiológico. Os resultados deste estudo são indicativos que tem como finalidade, subsidiar gestores da saúde e educação do estado dos municípios do Maranhão nos processos de planejamento, gestão e avaliação de políticas e ações de controle da hanseníase, portanto, dentre as medidas a serem adotadas, está a intensificação da busca ativa de casos da hanseníase na forma clínica virchowiana, diagnóstico, vigilância de contatos, tratamento e acompanhamento dos casos até a cura com engajamento na atenção primária a saúde, afim de melhoria da qualidade da assistência e controle efetivo da endemia.

**Palavras chave**— *Saúde Pública, Infecção, Incidência.*

## I. INTRODUCTION

Hansen's Disease is a contagious disease caused by *Mycobacterium leprae*, which exists since before Christ. Society and even religious institutions were cruel to

Hansen's Disease sufferers from antiquity to the present day. Lack of knowledge about the disease only made lepers worse. And even when the Hansen's Disease bacillus was identified by the Norwegian physician

Gerhard Armauer Hansen in 1873 and treatments began to emerge, the biased and distant behavior towards the lepers remained. In the Modern Age isolation, which had been practiced since antiquity, became compulsory, leading to the creation of leprosariums, places where patients were abandoned, without assistance, and eventually died, leaving offspring who were already born with the disease. Even after the discovery of the tuberculosis bacillus in Brazil, Hansen's Disease sufferers were treated with neglect and discard. Even considered a public health problem in Brazil Republic, compulsory notification was not put into practice due to the difficulties of diagnosis, doctors of that time classified Hansen's Disease as other dermatological diseases. And for a long time all individuals with cutaneous manifestations throughout a disease were considered lepers.

Although programs for the eradication of the disease, Brazil, can not achieve the goals of the United Nations - UN<sup>1</sup>, cites that Brazil presents "about 30 thousand new cases per year, corresponding to an average of 15 people contaminated for every 100 thousand inhabitants. Brazil is the only country in the world that has not yet reached the goal of the World Health Organization - WHO by 2015, of up to 10 cases per 100,000 inhabitants "<sup>2</sup>. The studies on the possible causes of the abandonment of the Hansen's Disease treatment can contribute significantly to a reflection on the use of its results in the elaboration and implementation of projects of public policy and control programs.

The serious problems caused by irregular treatment and abandonment constitute the main impediments for the control of the disease. Another barrier to treatment is the side effects of medication, because in most patients there are bad and painful reactions to the effect of medications. Many patients believe that the medication acts in a contrary way, aggravating the disease and even provoking other diseases, this being another frequent reason for abandoning treatment.

The lack of adherence to treatment is one of the factors for the increase of cases and that non adherence occurs for several reasons, mainly because the affected one resists accepting the disease, because despite the existence of treatment there is still a lot of prejudice regarding Hansen's Disease. Associated with this is the lack of knowledge about the disease, since the patients' statements reveal that the knowledge acquired came from experience with the disease and not from information passed by health professionals<sup>3</sup>.

Regarding the obstacles to adherence to the treatment of the person with Hansen's Disease, Garcia et al. <sup>4</sup> points out as one of them the health professional's own contact, which can be fraught with fear and prejudice.

Most people with Hansen's Disease belong to a class of lower purchasing power, a condition that may make it difficult to understand the disease and thus its adherence to treatment. Low or no schooling leads to a misunderstanding of the terminology employed, or even the shame of these people to expose themselves are barriers to recognizing the need for treatment<sup>4</sup>.

When reporting difficulties in adhering to Hansen's Disease treatment, nurses participating in a study stated that there is no good patient adherence due to the lack of knowledge about the importance of treatment, the lack of clarity in the guidelines given to patients and also as a result of the drug reaction<sup>5</sup>.

The diagnosis of the disease can be seen by the patient as frustration and feeling of impotence, because it brings the person physical, social and even personal obstacles, making it difficult to satisfy their needs. This situation requires the health professional to help the patient to develop positive attitudes, so that he can re-establish his life plan, stimulating him to dialogue and participate in his treatment. The patient's first contact with the doctor may influence treatment adherence<sup>6</sup>.

Hansen's Disease is an aggressive disease that causes loss and the affected person faces a number of problems such as bias, rejection. In addition to these, when adhering to treatment, life difficulties do not diminish, therefore, medication eventually results in a variety of side effects, reactions of the body, often understood as non-effectiveness of this medication. The reactions lead the individual to abandon the treatment, which presents as a serious obstacle to the goal of extinction of the disease. For this disease, if there are obstacles to adherence to treatment, there are many difficulties in continuing with it.

Among the actions of the Ministry of Health in combating Hansen's Disease one of them is to prevent the patient from abandoning treatment. The causes of the abandonment are discussed, but the studies focus mainly on the clinics. The abandonment and irregularity in treatment are constant concerns, since they mean the maintenance of the chain of disease contagion, the appearance of sequelae and incapacities, and even resistance to PTQ<sup>7</sup>. Considering the consequences of abandoning treatment, practitioners and scholars agreed that it was important to identify the causes of such abandonment. The Ministry of Health considers cessation of treatment those in which the paubacilar and / or multibacillary who did not complete the number of doses of the medication in the expected time and did not attend the health service in the last twelve consecutive months. Non-attendance at monthly appointments for the supervised dose characterizes a faulty patient.

Supervised treatment contributes to decreasing cessation of treatment and increasing the number of people cured<sup>8</sup>. This study aims to identify the reasons that influence the adherence and abandonment of Hansen's Disease treatment in a public hospital in the State of Maranhão.

## II. METHODOLOGY

The research is an exploratory study, with bibliographical and documentary research, carried out to present data such as those occurred in the period from 2008 to 2014, in order to check the degree of adherence and abandonment of patients with Hansen's Disease in the State of Maranhão. A descriptive survey aims to study the characteristics of a given reality, to raise opinions and attitudes of a population and to discover the relationship between variables without identifying factors that determine the occurrence of the phenomena.

The study was conducted in the State of Maranhão, Brazil. The State has 217 municipalities, distributed in an area of 331,937,455 km<sup>2</sup>, with a population of 6,774,789 inhabitants, whose demographic density is 19.81hab / km<sup>29</sup>. At the AquilesLisboa Hospital (HAL), located in Ponta do Bonfim, separated from the city center by the Bacanga River, in the city of São Luís, the semi-structured interviews were carried out, from 01/11/2016 to 02/01/2016. The choice of HAL was due to the fact that it is the reference hospital in the treatment of Hansen's Disease in relation to the other units that act in the treatment of the disease in the state of the MA.

The sample of this study was composed of 60 records of patients registered at the Hospital AquilesLisboa, attended from 2008 to 2014, whose recorded data were analyzed, to obtain information that led to the identification of the causes that lead to adherence and abandonment of the treatment. It should be emphasized that this study had as a criterion the quantification of active patients, with cognitive status preserved.

The study considered as inclusion criteria the registration of the cases in the medical records of the AquilesLisboa hospital, with sufficient information for analysis, as well as data from the Notification of Injury Information System - SINAN referring to cases of Hansen's Disease registered in Maranhão in the period of 2008 to 2014, from which it became possible to quantify the cases of adherence and abandonment of the treatment and excluded, the cases that although reported in the records of the AquilesLisboa hospital and SINAN, were cases of recidivism as well as of cases not reported in SINAN and in the Reference Centers for the Treatment of Hansen's Disease, in the State of Maranhão, from 2008 to 2014.

To collect data to characterize the main reasons that led Hansen's Disease patients adherence or abandonment of the treatment was performed by analyzing the medical

records of patients with Hansen's Disease of the Hospital AquilesLisboa and the quantitative data of SINAN. These data come from the Hansen's Disease notification and research records between the years 2008 to 2014.

1st stage - Initially a bibliographic research was carried out, in order to verify, based on a specific literature, the essence of this study.

2nd stage - Direct observation was made to the ex-patients remaining from the Bonfim colony. The technique of observation uses the senses to obtain certain aspects of reality, is not restricted to seeing and hearing, but also analyzing facts or phenomena to be studied.

3rd - A semi-structured interview was conducted with 12 residents of the Colony and 7 professionals working at the AquilesLisboa hospital, considering a more consistent and complete measurement. The interview was conducted through a questionnaire composed of 16 questions; The interview period lasted from September 28 to October 28, 2016, during the afternoon shift, with a duration of 30 minutes, within a period of one month on alternate days, which consisted in verifying the main causes that commonly lead to adherence and abandonment of Hansen's Disease treatment.

4th stage - Analysis of 60 records of follow-up and collection of secondary data through the National System of Notification Diseases - SINAN.

The project was submitted to the Brazil Platform, the Unified National Base of Records and Research involving human beings for the entire CEP / CONEP system (APPENDIX), the same was approved on 01/09/2017 by the ethics and research committee of the São Domingos Hospital.

## III. RESULTS AND DISCUSSION

In the case of Hansen's Disease in Maranhão, he deported himself to the former Colonia AquilesLisboa Sanitary, also known as Colônia do Bonfim, founded on October 17, 1937, in order to isolate people with Hansen's Disease<sup>10</sup>. Currently known as the Aquiles Lisbon Hospital, the unit had its treatment method modernized and its patients no longer live in isolation as in the past when the site was chosen because it was far from the city and difficult to access<sup>11</sup>.

According to the survey, Maranhão state authorities stated that the Bonfim Colony had a capacity of up to 400 people affected by Hansen's Disease, although hospital records, even precarious ones, do not confirm this information<sup>12</sup>. Currently the people who live in the houses of the old Bonfim Colony are classified as graduates. Studies of the time indicate that the hospital built had a more symbolic purpose than treatment. The objective was to unravel the image of Maranhão in

relation to the picture and numbers of Hansen's Disease sufferers, which until then was one of the largest in the country.

In principle, patients were placed in the Gavião Asylum, a kind of warehouse where they were abandoned. However, it was from 1937 that these patients were referred to the Colonia Aquiles Lisboa Sanitary, and from then on they forgot the previous life, the relations, beginning a new stage of life without knowing if they would return to live with the family and friends<sup>12</sup>.

According to information obtained in the interview with the chief nurse W. M, on September 6, 2016, Aquiles Lisboa functions as a reference hospital in dermatology, focusing on Hansen's Disease, only with outpatient care, with 15 beds for cases in which there is need of hospitalization. According to this professional,

non-adherence to the treatment of Hansen's Disease has as main obstacle the prejudice suffered by the person carrying the disease, the side effects of medications, which mostly cause disorder to the patient.

We identified a total of 33,308 reported cases of Hansen's Disease in the Health Units of the state of Maranhão from 2008 to 2014. Of these, 5,842 cases occurred in the municipality of São Luis - MA. Regarding the operational classification and clinical form, it was verified that there was a predominance of Multibacillary operational classification with 23,320 cases (Table 1), it should be noted that among these, the clinical form Dimorfa was the most frequent. In the total population studied, there was a higher frequency of reported male subjects with 19,357 cases and aged between 20 and 34 years (Table 2).

Table 1 - Operational Classification

Type	Year							Total
	2008	2009	2010	2011	2012	2013	2014	
Paucibacillary	1.755	1.474	1.537	1.420	1.408	1.262	1.123	9.988
Multibacillary	3.376	3.224	3.321	3.236	3.301	3.504	3.358	23.320

Source: SES/MA/SINANNET/TABWIN<sup>24</sup>

During the research at the Aquiles Lisboa Hospital, 60 (sixty) medical records were analyzed, where 59% of the medical records are male, and 41% female, which corresponds to 16 medical records. This reference to males increases the hypothesis that men may be more

prone to disease by the conditions: greater interpersonal relationships, greater resistance to participating in disease prevention programs, greater exposure to the environment, among other cases (Table 2) .

Table 2 – By Gender

Gender	2008	2009	2010	2011	2012	2013	2014	Total
Female	2.065	1.933	2.039	1.971	1.957	2.088	1.898	13.951
Male	3.067	2.768	2.819	2.685	2.753	2.679	2.587	19.357

Source: SES/MA/SINANNET/TABWIN<sup>24</sup>

When the variables, gender and age, were analyzed, a greater frequency was observed in males (age group 20 to 34 years, Table 3); however, the lowest age was 1 year and the highest was 88 years, being the average between 20 and 49 years. In the age range between 20 and 34 years, analyzing hypothetically refers to the issues related to the beginning of emancipation, freedom of choice, greater probability of multiplying relationships, among other factors. As for younger age (1 year), the idea of direct transmission of family members is also reinforced

due to lack of information and care for the patient and the child. There were also withdrawals due to abandonment of treatment in all the analyzed years, with great relevance also in 2008, where there were 384 cases of patients who abandoned treatment of the disease.

The Genésio Rêgo and Aquiles Lisboa Health Units were the ones that presented the highest number of Hansen's Disease cases, with 1,940 and 775 cases, respectively, in the period from 2008 to 2014, since these units are references for the treatment of the disease.

Table 3 - Age Group

Year	1-4	5-9	10-14	15-19	20-34	35-49	50-64	65-79	80 e+	Total
2008	25	150	276	401	1.420	1.161	1.064	520	115	5.132
2009	12	150	284	320	1.370	1.035	922	525	82	4.700
2010	16	145	297	329	1.413	1.075	903	522	78	4.778
2011	17	156	284	308	1.247	1.062	971	501	110	4.656
2012	19	143	254	281	1.189	1.070	991	537	126	4.610
2013	10	155	262	273	1.237	1.048	1.017	553	111	4.666
2014	10	155	262	273	1.237	1.148	1.017	553	111	4.766

Source: SES/MA/SINANNET/TABWIN<sup>24</sup>

According to the SINAN Information and Injury and Notification System, in Maranhão, 33,308 cases of Hansen's Disease were reported in the period from 2008 to 2014, of which 5,842 were in the municipality of São Luís - MA. The variation in cases increased and from 2012 to 2014, the number of cases reported decreased, as shown in table 4. In the survey, 775 cases of Hansen's Disease were identified, registered only at the Aquiles Lisboa Hospital.

The highest percentage found in the city of São Luís -MA was male with 3,315 cases reported. With regard to age, a higher frequency was observed in the population aged over 14 years. For Veronesi<sup>13</sup> the greater or lesser prevalence of cases depends on the exposure to multibacillary patients with viable bacilli. The age of the patients ranges from infancy to older people.

Table 4 - Adherence to the treatment of Hansen's Disease in SINAM between 2008 and 2014

HEALTH UNIT	2008	2009	2010	2011	2012	2013	2014	Total
Health Center Amar	7	14	17	8	6	5	4	61
Health Center Bezerra M.	16	8	6	5	5	5	2	47
Health Center Clodomir P.	8	7	5	6	4	3	1	34
Health Center Cohab Anil	11	10	10	5	5	3	2	46
Health Center da Liberdade	0	0	0	1	0	0	3	4
Health Center da Liberdade	0	0	1	0	1	3	2	7
Health Center Vila Lobão	4	3	0	5	0	1	0	13
Health Center Fátima SAE	46	43	42	36	32	43	87	329
Health Center de Pedrinhas I	4	3	2	0	0	0	2	11
Health Center de pedrinhas II	1	0	0	0	0	0	0	1
Health Center Djalma Marques	3	0	0	0	0	0	0	3
Health Center Djalma Marques	11	8	15	18	9	4	12	77
Health Center do João Paulo	7	5	4	1	3	0	1	21
Health Center Radional	3	3	5	0	0	1	0	12
Health Center Tibiri	8	4	9	4	3	3	4	35
Health Center Turú	37	45	49	21	24	36	24	236
Health Center Antonio G.	3	5	0	0	0	1	7	16
Health Center José Macieira	6	7	3	2	0	0	2	20
Health Center José Frazão	3	6	2	2	1	2	0	16
Health Center Fabriciana M.	13	13	10	4	2	3	1	46
Health Center Gapara	1	1	0	0	0	0	0	2
Health Center Genésio Filho	15	13	18	3	3	1	3	56
Health Center Genésio Rego	85	59	151	420	434	399	392	1.940
Health Center Itaperta	0	0	1	0	0	0	0	1
Health Center Janaína	0	8	8	2	5	8	2	33
Health Center João de Deus	4	5	2	0	0	2	3	16
Health Center L. Vasconcelos	0	2	3	2	0	3	7	17
Health Center Maracanã	0	2	0	1	2	0	1	6

Health Center Maria Lourdes	0	1	0	0	1	0	0	2
Health Center Nazaré Neiva	9	7	7	6	8	4	2	43
Health Center Quebra Pote	0	3	0	3	3	7	0	16
Health Center Salamão	13	25	13	12	12	12	4	91
Health Center Santa Barbara	12	16	5	6	4	1	1	45
Health Center São Cristóvão	6	2	3	5	4	3	0	23
Health Center São Francisco	8	4	9	3	2	2	1	29
Health Center São Raimundo	3	7	1	0	0	0	0	11
Health Center Thalles Ribeiro	8	11	6	4	2	7	5	43
Health Center Vila Embratel	11	10	2	11	8	8	1	51
Health Center Vila Itamar	6	8	5	4	1	2	1	27
Health Center Vila Nova	3	2	0	0	0	0	0	5
Health Center Yvis Parga	2	2	0	1	1	0	1	7
Aquiles Lisboa Hospital	56	70	81	85	122	193	168	775
AdersonSo.Vila Luizão Hospital	0	3	3	8	39	7	0	60
Djalma Marques Hospital	0	0	0	1	0	0	0	1
UFMA University hospital	27	63	154	65	56	41	27	433
Pan Diamante Hospital	18	19	1	0	0	0	0	38
Health Station Pedrinhas	2	6	3	3	4	2	3	23
Sarah São Luís	0	0	0	0	0	1	0	1
Health Unit Coqueiro	3	2	1	0	0	1	2	9
Unit Jardim São Cristóvão	7	6	5	0	1	2	1	22
Health Unit São Bernardo	2	0	0	0	1	0	0	3
Health Unit Olímpica I	19	16	9	16	9	2	5	76
Health Unit Olímpica II	8	12	2	8	6	4	1	41
Health Unit Olímpica III	3	8	10	14	16	21	26	98
Health Unit Pirapora	7	3	6	4	1	0	1	22
Health Unit Santa Clara	13	14	9	10	9	13	0	68
Health Unit Santa Efigênia	10	9	12	2	1	3	6	43
Health Unit Vila Sarney	5	7	2	6	5	4	0	25
Mixed Unit São Bernardo	29	39	30	23	6	14	9	150
Mixed Unit Bequimão	31	31	30	23	24	11	10	160
Mixed Unit Coroadinho	45	48	26	19	13	7	0	158
Mixed Unit Itaquí-Bacanga	26	26	27	22	19	4	13	137
TOTAL	688	754	825	910	913	902	850	5842

Source: SES/MA/SINANNET/TABWIN<sup>24</sup>

The M.S. in its decree nº 3.125 of 10/2010, defines as case of abandonment, the patient who did not attend the health service in the last 12 months. Faulty Hansenians were those who had passed more than 9 months of treatment in Paucibacillary cases and over 18 months in Multibacillary cases (Table 5).

Table 5 - Abandonment of Hansen's Disease treatment at SINAM between 2008 and 2014

HEALTH UNIT	2008	2009	2010	2011	2012	2013	2014	Total
Health Center Amar	0	1	1	1	0	0	0	3
Health Center Bezerra de M.	2	2	1	0	1	0	1	7
Health Center Clodomir Pinheiro Costa	0	0	1	0	1	0	0	2
Health Center Cohab Anil	0	0	0	1	1	1	0	3
Health Center Vila Lobão	0	0	0	1	0	0	0	1
Health Center Fátima SAE	4	4	5	0	7	2	9	31
Health Center of Pedrinhas I	0	0	1	0	0	0	0	1
Health Center Djalma M.	1	0	3	0	1	0	1	6
Health Center of João Paulo	0	2	0	0	0	0	0	2



Health Center Tibiri	0	0	2	0	1	1	0	4
Health Center Turú	1	3	3	0	1	0	2	10
Health Center Antonio G.	0	1	0	0	0	0	2	3
Health Center José Macieira	2	0	0	1	0	0	1	4
Health Center José Ribamar	0	1	0	0	0	0	0	1
Health Center Fabriciana M.	0	3	1	0	0	0	0	4
Health Center Genésio Filho	2	1	0	0	0	1	2	6
Health Center Genésio Rego	4	7	7	36	12	10	23	99
Health Center Janaína	0	2	0	0	1	0	0	3
Health Center João de Deus	1	0	0	0	0	0	0	1
Health Center Laura V.	0	0	0	0	0	0	1	1
Health Center Nazaré Neiva	1	2	1	2	2	0	0	8
Health Center Quebra Pote	0	1	0	0	0	0	0	1
Health Center Salamão F.	0	0	1	1	1	2	0	5
Health Center Santa Barbara	0	1	0	0	0	0	0	1
Health Center São Francisco	1	1	0	0	0	0	0	2
Health Center São Raimundo	1	2	0	0	0	0	0	3
Health Center Thalles G.	0	0	0	0	0	1	0	1
Health Center Vila Embratel	1	0	0	0	1	0	0	2
Health Center Vila Itamar	0	1	1	0	1	1	0	4
Health Center Vila Nova	1	1	0	0	0	0	0	2
Health Center Yvis Parga	0	1	0	1	0	0	0	2
Aquiles Lisboa Hospital	6	7	6	7	9	13	12	60
Aderson Sousa Hospital	0	2	1	1	2	0	0	6
UFMA University Hospital	1	5	8	2	2	3	2	23
Pan Diamante Hospital	0	1	1	0	0	0	0	2
Health Station of Pedrinhas	1	1	0	0	0	1	0	3
Health Unit Coqueiro	0	0	0	0	0	1	1	2
Health Unit São Cristóvão	1	2	0	0	0	0	0	3
Health Unit Olímpica I	1	2	1	2	2	0	0	8
Health Unit Olímpica II	0	1	0	0	1	0	0	2
Health Unit Olímpica III	1	1	2	5	1	4	6	20
Health Unit Pirapora	1	0	0	0	0	0	0	1
Health Unit Santa Clara	4	4	1	1	0	4	0	14
Health Unit St <sup>a</sup> Efigênia	0	0	1	0	0	1	0	2
Health Unit da Família Vila Sarney	1	0	0	2	0	1	0	4
Mixed Unit São Bernardo	3	4	1	2	1	2	0	13
Mixed Unit Bequimão	1	0	2	0	2	0	1	6
Mixed Unit Coroadinho	1	2	0	1	0	0	0	4
Mixed Unit Itaquí-Bacanga	1	2	6	2	0	0	2	13
Total	384	308	339	285	302	267	244	2.129

Source: SES/MA/SINANET/TABWIN <sup>24</sup>

The predominance of the diagnosis of multibacillary forms with 23,320 reported in Maranhão is similar to the study done by Amaral<sup>14</sup> in which there was a predominance of multibacillary clinical forms - dimorfa and virchowiana - in relation to paucibacillary - indeterminate and tuberculoid. For Goulart et al.<sup>15</sup> this would be a sign that the diagnosis is late, helping to maintain the chain of transmission of the disease.

The form of the disease, as well as the proximity of the primary case, contributes to the risk of becoming ill. Extending the criteria of the contact condition beyond those domiciliares, the majority of the incident contacts could be related to a previous case of Hansen's Disease<sup>16</sup>. Hansen's Disease can target people of all ages, of both sexes. However, the involvement of children under 15 years is an indicator of high endemicity of the disease<sup>17</sup>.

In a study conducted by Camello<sup>18</sup>, it was demonstrated that the use of intradomiciliary contact examination of the new cases detected and the follow-up of intradomiciliary contacts, detected in the last 10 years.

Regarding the breed, of the 60 (sixty) charts of patients analyzed at the Hospital, 53% of the patients were classified as brown, corresponding to 32 charts analyzed.

There is no justification as to color / race, however, one may suggest that it is about ethnicity, with a greater predominance of brown color.

One of the main reasons for the worsening of the disease is the long incubation period, insidious evolution and prejudice, which can lead to death (Table 6).

Table 6 - Deaths of patients with Hansen's Disease

HEALTH UNIT	2008	2009	2010	2011	2012	2013	2014	Total
Health Center Amar	0	0	0	1	0	0	0	1
Health Center Clodomir	0	0	0	1	0	0	0	1
Health Center Fátima	0	1	0	1	0	1	1	4
Health Center Djalma M.	1	0	0	0	0	0	0	1
Health Center João P.	1	0	0	0	0	0	0	1
Health Center Turú	1	0	1	0	0	0	0	2
Health Center G.Filho	0	0	1	0	1	0	0	2
Health Center G. Rego	1	0	4	2	4	5	3	19
Health Center Salamão	1	0	0	1	0	0	0	2
Health Center Embratel	1	0	0	1	0	0	0	2
Aquiles Lisboa Hospital	1	1	2	0	0	2	2	8
Universitary hospital	1	1	2	0	0	0	0	4
Pan Diamante Hospital	1	0	0	0	0	0	0	1
Health Unit Olímpica II	0	0	0	0	1	0	0	1
Health Unit Olímpica III	0	0	0	0	0	1	2	3
Mixed Unit São Bernardo	0	1	0	0	0	1	0	2
Mixed Unit Bequimão	0	0	0	0	0	1	0	1
Mixed Unit Coroadinho	0	0	0	0	0	1	0	1
Mixed Unit Itaquí-Bacanga	0	1	1	0	1	0	0	3
<b>TOTAL</b>	<b>9</b>	<b>5</b>	<b>11</b>	<b>7</b>	<b>7</b>	<b>12</b>	<b>8</b>	<b>59</b>

Source: SES/MA/SINANNET/TABWIN<sup>24</sup>

As for schooling were cataloged from the 60 (sixty) medical records, illiteracy and incomplete primary schooling were more prevalent. Some charts did not contain information about schooling. The question of information and knowledge is an important factor to improve the disease, abandonment and lack of adherence to treatment, 62% of patients did not complete high school, characterizing 37 charts analyzed, these data confirm that Hansen's Disease comes over the years involving people with a less enlightened level, where the lack of education, considerably favors the evolution of the disease.

According to Neves et al.<sup>19</sup>, low schooling is a problem that interferes with the understanding of the technical language used by professionals, leading to the compromise of information comprehension during the consultations. The individual monthly income of 41 patients was between 1 and 2 minimum wages, followed

by 15 who had income of up to one salary and 4 who had income less than 1 minimum salary.

Age ranged from 20 to 72 years. It was evidenced that 73% of the population of this study are part of the economically active population (20-59 years), an important aspect, because Hansen's Disease is a disease that can cause disability, and may lead patients away from work, resulting in economic losses<sup>20</sup>.

Regarding marital status, 31 were married, 14 were single, 6 were divorced and 9 were widowers. This is related to the average age of the patients, since a large part of the population already has a family, so the impact of the disease discovery is significant<sup>21</sup> Regarding the occupation, the patients who were absent and / or abandoned had occupation, being 18 self-employed workers, 14 with employment, 11 were retired or were separated from their activities and 17 unemployed. According to information from SINAN, from 2008 to 2014, the new cases of Hansen's Disease reported at the



Aquiles Lisboa Hospital are: Adherence to treatment at the Aquiles Lisboa Hospital from 2008 to 2013 has been increasing gradually, with a reduction in 2014, characterized by an increase of cases and / or more information to feed SINAN in 2013. The control programs also help considerably for people to seek the Hospital to perform the diagnosis and treatment.

When reporting difficulties in adhering to Hansen's Disease treatment, nurses participating in a study stated that there is no good patient adherence due to the lack of

knowledge about the importance of treatment, the lack of clarity in the guidelines given to patients and also as a result of the drug reaction<sup>5</sup>.

It was notorious that this picture of abandonment and / or resistance to treatment has been increasing, when analyzing the 60 (medical records), becoming a concern and that programs created by the government should minimize this. Regarding the cases of death in the abovementioned period considered small. Regarding the causes of adherence and abandonment (Table 7).

Table 7 - Data from the Aquiles Lisboa Hospital at SINAN, from 2008 to 2014

	2008	2009	2010	2011	2012	2013	2014	Total
Adhesion	56	70	81	85	122	193	168	775
Abandonment	6	7	6	7	9	13	12	60
Cured	37	60	55	59	75	131	101	518
Deaths	1	1	2	0	0	2	2	8

Source: SES/MA/SINANNET/TABWIN <sup>24</sup>

Adherence usually occurs with the help of family and friends, to attend a referral unit, which will perform the necessary tests to diagnose the disease, although, at the beginning, the patient may be confused with other pathologies, which only after consultation and examination are discarded other possibilities and, thus, will be referred to a multidisciplinary team that includes the social worker, so that the patient receives the first information about Hansen's Disease.

From the analysis of the medical records of the Aquiles Lisboa Hospital, a total of 775 cases of patients who started treatment between the years 2008 and 2014 were identified, of which 60 patients were reported to have missed or abandoned MDT treatment.

The patients' monthly income corresponds to the type of occupation and the educational level of the patients<sup>22</sup>. Low schooling and low income are risk factors for the development of Hansen's Disease, with an impact on quality of life, regarding social relations and acceptance of the disease<sup>23</sup>.

The patients interviewed who live in Bonfim Colony, when asked about Hansen's Disease, 2 reported not knowing the information about the disease and 3 showed some knowledge. The interviewees referred to the disease associating the clinical picture and prejudice experienced, according to the words:

This is a disease that stains our body and strikes the nerves. (patient number 1).

It's an evil disease, no one's expecting it, and even if we take care of it, it still has sequels. (patient number 2).

It is a dangerous disease, which agent is afraid of being close to others, which prevents the agent from working and still causes people who know that agent has the disease gets disgusted and afraid to get close to us, not to get the disease. (patient number 3).

In addition, the interviewees did not know the clinical form of acquired Hansen's Disease, and justified not remembering due to the language used by the professionals and the complicated nomenclature of the clinical form, nevertheless, they believed to have acquired the disease in the working environment or even in the street.

When questioned about the diagnosis of the disease, all said they had sought the health service due to the appearance of stains with numbness in the body, in addition to pain in the joints, in the hands and reported to feel burning in the body. The interviewees related signs and symptoms of Hansen's Disease demonstrating some knowledge about the signs and symptoms characteristic of the disease, which may be related to the media outreach campaigns.

In order to analyze the factors related to the absence or abandonment of the treatment, of the cases reported in the records, the intrinsic and extrinsic factors were divided, the motives mentioned to lack or to abandon the treatment of Hansen's Disease, the first was defined by arguments that explained the fact that they did not attend the health service only to seek medication and the desire to miss, and the extrinsic ones were characterized by justifications and situations that were independent of the patients' wishes and which constituted reasons to be absent.

In the research it was verified that the extrinsic factors justified the total absence in multibacillary patients and represented 70% of the cases of abandonment in these patients. Among these factors, the side effects of the medication that according to the research resulted in one of the main causes of abandonment, among the medications, one of the most relevant was Thalidomide. In spite of the legal control of the medication by the MS since 1986, through ordinances, technical norms and publication of therapeutic and informative guides, in 2005/2006 three new occurrences were notified, comprising four births.

Still using this classification, the intrinsic factors corresponded to 30% of the cases, where it was highlighted the absence of symptoms and thoughts of not needing to follow the treatment, as well as the occurrence of other health problems such as: depression; hemolytic anemia; non-acceptance of the disease; religious cure thinking and constraint related to the monthly trips to the units to receive the medication as it was possible to verify in the interviewees' reports:

I stopped because I was no longer able to take the medicine, I was full of pain, instead of getting better I felt worse (patient number 1).

I asked for a cure for God and he healed me, and since I did not feel anything else, I stopped taking the medicine (patient number 2).

I was not anymore because I was ashamed of others knowing that I was taking medicine for this disease, because I felt that the people they knew were avoiding being around me (patient number 3).

Because he does not receive adequate information, the patient supposes that from the reduction or disappearance of the symptoms that bother him, the use of the medication is no longer necessary. Side effects of medication is one of the main causes of neglect reported in the interview, where Social Care and Nursing professionals characterize as a factor that hinders the patient's return. This treatment is performed through Clofazimine, Dapsone, Prednisone, Rifampicin and Thalidomide, with effects being rejected by patients, who complain of joint pain, darkening of the skin, limb atrophy, onset of diabetes, hypertension, depression and psychotic conditions.

Prejudice, the fear of the unknown, the fear of facing the reality of the diagnosis, the image society makes about the disease, the self-discrimination, the patient does not continue the treatment after diagnosis, leaves to "avoid" being seen in the unit of health, as fear of facing family and friends;

The difficulty of moving to the health unit in residents of municipalities distant from the place of treatment, without financial driving conditions;

Alcoholism in patients with problems of chemical dependence that do not give continuity to the treatment by force of the dependence that gives more "pleasure" than the force of seeking the cure of the disease.

The extrinsic factors were cited by 42 of the total of 60 cases reported in the medical records, patients as a reason for non-attendance to treatment, including: lack of medication in the unit; work out of the city and constant trips which made it difficult for the monthly trips to Unity.

A total of 33,308 cases of Hansen's Disease were reported in the System of Information and Diseases and Notifications (SINAN) from 2008 to 2014. In the total population of 33,308 people, 5,842 cases occurred in the city of São Luis and 60 (sixty) medical records at the Aquiles Lisbon Hospital.

In SINAN data, it was observed that the highest frequency of reported individuals was male, with 19,357 cases and aged between 20 and 34 years. In the analyzed records, a higher frequency of males was observed with 44 charts and only 16 females. As for schooling, both SINAN data, medical records, illiteracy and incomplete elementary schooling were the predominance among patients with Hansen's Disease.

In the period from 2008 to 2014, 775 patients' adherence to Hansen's Disease treatment at the AquilesLisboa Hospital were notified at SINAN, in which 60 patients abandoned treatment, 8 died and 518 were cured.

It should be stressed that cases of Hansen's Disease deserve more attention, not only because of the risk to society as a whole, but also because of the biological, social and economic repercussions that this disease causes, and it becomes a public health problem.

#### IV. CONCLUSION

The main reasons that influenced adherence were the campaigns with information inherent to the disease, family influence, more accessible means of communication, and increase of health posts with access to treatment, labor market requirements.

Regarding abandonment the main reasons were prejudice, lack of information, despite the diversification of information media, side effects of medication, which is one of the main causes of abandonment reported in the interview and in the accompanying newsletter.

The reasons given for not attending regularly to the Units were intrinsic and extrinsic, for the intrinsic ones stood out: the fact of not attending the health service only to seek medication and the desire to miss.

As extrinsic factors were evidenced absence of symptoms; other health problems; non-acceptance of the disease; religious healing and constraint related to the monthly departures to the units and great relevance regarding the side effects of the medication, being one of the main causes of treatment abandonment.

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