

# Decentralization of the diagnosis and treatment of leprosy in Rio de Janeiro State: advances and problems

## Descentralização do diagnóstico e tratamento da hanseníase no Estado do Rio de Janeiro: avanços e problemas

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### Abstract

Brazil has included leprosy among the diseases assisted in basic health units, as part of the commitment to the Global Alliance for the Elimination of Leprosy. The Health Secretariat of Rio de Janeiro State defined the universal access to diagnosis, to WHO Disability Grade evaluation and to the treatment of leprosy sufferers as a political-technical priority in all the basic health units of the state. Decentralization of diagnosis and treatment of leprosy became a priority, and increased from 308 (20.04%) health units with these actions available in December, 2000, to 622 (40.79%) in July, 2004. Epidemiological indicators seem not to have been significantly influenced by this. Many problems disturb

the decentralization in Rio de Janeiro, We hope can obtain resources with government and non-governmental organizations to go on with current strategy (trainings, local supervisions, support to municipal managers in decentralization process, increase in the diffusion of signals and symptoms of the disease in communication media) to reach the target of leprosy elimination in Rio de Janeiro State.

**Key words:** leprosy; prevention and control

### Introduction

Rio de Janeiro State is in its way to the decentralization of the actions for control of leprosy, from the model used before: specialized, vertical, usually associated to general dermatologic services. The vertical action strategy allows a more precise diagnosis (better differential diagnosis with other cutaneous diseases or neurological abnormalities from conditions other than leprosy). It makes the early diagnosis difficult, however, because of the delay in the arrival of the patient to the secondary or tertiary level of assistance, in which the vertical attendance is exerted. It also limits the spectrum of control actions, because the reach gets too limited and the transportation of many patients toward these services is difficult, due to the distance and of the costs of traveling. This strategy does not allow daily and permanent access to the health services either, the use of financial resources is inefficient, and the stigma related to leprosy is reinforced<sup>2</sup>.

Since the decades of 60 and 70, there has been encouragement to integrate the activities of treatment and control of leprosy into the structures of the basic health system<sup>3,4</sup>. Many years have passed, and yet we find difficulties in the integration of leprosy control actions as part of the strategy of basic health assistance, in Brazil as well as in other countries<sup>5</sup>.

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The World Health Assembly established, in 1991, the goal of elimination of leprosy as a public health problem up to 2000, defining elimination as a prevalence rate lower than one case in 10,000 inhabitants<sup>6</sup>. This objective was not reached in Brazil in the planned period, and a new goal was established to obtain the elimination of the disease in all countries up to the year 2005<sup>7</sup>.

As a part of the compromise to Global Alliance for the Elimination of Leprosy, Brazil has included leprosy among the diseases whose diagnosis and treatment must be done in the basic health system<sup>8</sup>.

The decentralization of leprosy directed actions in the health basic system intends to allow a better access of the population to the assistance, and, consequently, a greater efficacy of the health services and actions, and a better sustainability of these actions, facing the decline of the disease prevalence<sup>2</sup>. It is, indeed, a fundamental strategy to obtain the goal of the elimination of leprosy as a public health problem<sup>8,9</sup>, and it constitutes the best option for the maintenance of the programs<sup>2</sup>. The cost of the decentralization is low, because the structure of health basic system is already existent<sup>2</sup>. However, it requires a continuing training of the professionals of the basic health units<sup>10</sup> in the signs and symptoms of the disease, in multidrug therapy, which is standardized, and in the identification of side effects and complications of the treatment or reactional episodes, to refer them to specialized municipal or regional services<sup>8,11</sup>.

This process requires political decision, and must be conducted gradually, being basic prerequisites:

- adequate training, ministered continually to the professionals who act in the basic health units, from professionals specialized and experienced in leprosy<sup>2,10</sup>;
- availability of a service (or services) of reference in the health structure, allowing skill development, technical supervision, counseling and development of operational research, with the necessity of systematic training in management, supervision, monitoring and evaluation of the integration of the leprosy programs<sup>2,8</sup>;
- warranty of strategies to obtain early detection of cases, total coverage with multidrug therapy and adequate follow-up of the patients, until the most peripheral level of the services of basic health system', which must function adequately<sup>12,13</sup>.

The Rio de Janeiro State Health Secretariat has defined as a political-technical priority the universal access to the diagnosis, to the evaluation of disabilities and to the treatment of leprosy, in all the units of the basic health system in the cities of the state. The decentralization of the diagnosis and treatment of the disease became a fundamental goal, which has been developed gradually.

In other states of Brazil, the decentralization process has obtained good results, for example in Minas Gerais, with an increase in the percentage of health services with leprosy control actions from 12% in 1991 to 65.8% in 2000<sup>14</sup>. Other studies demonstrate increase in the percentage of leprosy attendance in local level, as the successful experience of decentralization using the Family Health Program in Sobral, Ceará<sup>15</sup>, from one health unit attending patients with leprosy in 1999 to 26 units in 2001, with an increase in the detection rate and a decrease in the abandonment-from-treatment rate. The present study aims to demonstrate the evolution of the program actions in leprosy in Rio de Janeiro state, through the gradual rise in the percentage of basic health units with these control actions implemented, as well as to discuss the obstacles to the decentralization process and strategies to by-pass them.

## Developed strategies

The Sanitary Dermatology Department of Rio de Janeiro State Health Secretariat has carried out trainings to all ninety two cities of the state, to the basic health unit professionals and to the reference units of the cities, since 1998. These courses were done every year up to 2001. However, operational and financial difficulties lead to an interruption of these trainings in 2002 and 2003, being ministered again in 2004. Service supervisions and visits to the municipal managers of the leprosy programs were also developed, in all cities, until the beginning of the year 2003, being resumed in 2004. In these supervisions and visits health professionals and program managers were questioned in relation to the development of the leprosy control actions (diagnosis, treatment, disability evaluation, contact surveillance and health education), in the supervised units and in the municipality in general. The informations were drained from reports from every visit and local supervision.

The Sanitary Dermatology Department has been following, along the years, the rise in the percentage of basic health units who assist leprosy patients. The city managers are asked, through a periodic questionnaire, to maintain a continually up-to-date list of basic health units that offer diagnosis and/or treatment of leprosy, sending their name, address and telephone to the Sanitary Dermatology Department. These data are stored in the Secretariat, allowing a temporal evaluation of the evolution of the decentralization of the assistance to the leprosy patient.

Data from the Notification Disease Information System - Leprosy (SINAN/Hanseníase) are sent monthly by the cities to the Health State Secretariat, being analyzed by the Sanitary Dermatology Department, which is responsible for the analysis of the epidemiological indicators in the state.

Finally, during the visits, supervision, trainings and throughout the development of the daily work in the Dermatology Department, problems and obstacles to the decentralization process are continually identified.

## Results

In 1998, 1,815 health professionals from different categories were trained, in 1999, 1,015, in 2000, 357, and in 2001, 1,603 (see in table 1 the types of ministered courses and number of trained professionals).

Table 1. Health professionals trained in Rio de Janeiro state, according to ministered course and to year of training. Total: 4,790 trained professionals.

COURSES	YEAR			
	1998	1999	2000*	2001
Control actions for nurses	45	50	-	-
Nursery median level control actions	116	121	-	70
Leprosy in basic health services	1493	704	317*	893
Management	8	8	-	-
Disabilities prevention and rehabilitation	18	43	-	-
Leprosy in the municipal reference units	135	89	40*	533
Supervisor— instructor in leprosy	-	-	-	107
<b>Total</b>	<b>1815</b>	<b>1015</b>	<b>357*</b>	<b>1603</b>

<sup>1</sup> Data from year 2000 are incomplete.

Local supervisions were done, in a total of 280 yearly supervisions in the years 1998 and 1999, being the cities in metropolitan regions I and II, localized around the capital of the state (some of them concentrating the biggest prevalence rates in leprosy in Rio de Janeiro state) supervised monthly, in this period. Data from supervisions relative to the year 2000 are not available. In the year 2001, no local supervision was done; however, there were visits to the leprosy program managers and municipal health administrators in the 92 cities of the state, one visit each. The visits to the program managers, many of them including the health municipal managers, aimed mainly to stimulate the efforts in the decentralization to the assistance to leprosy sufferers in basic health units and in units of health family program.

In 2001, all 92 cities of Rio de Janeiro implemented leprosy program actions.

In table 2, we observe the evolution of some of the epidemiological indicators of leprosy in Rio de Janeiro, between 2000 and 2003. The indicators were relatively stable, with discrete decay of the prevalence rate, and with a slight raise in the detection of new cases under 15 years. There was a decrease in the percentage of cases with disabilities due to leprosy, among the evaluated ones each year. The release of multidrug therapy (MDT) medication blisters has been increased in relation to multibacillary blisters, but there were a decrease in ministered paucibacillary blisters in the same period (data not shown).

Table 2. Evolution of leprosy epidemiological

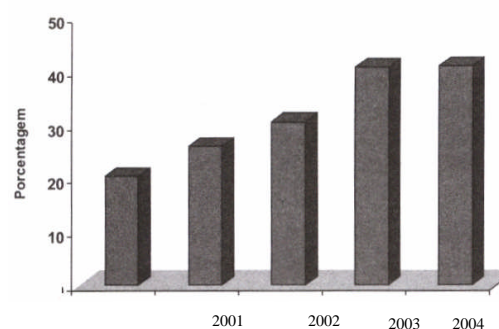
indicators in Rio de Janeiro state, years 2000 to 2003.

EPIDEMIOLOGICAL INDICATOR	2000	2001	2002 <sup>1</sup>	2003
Detection rate of new cases	2.08	2.01	1.99	2.14
Detection rate of new cases under age of 15 years	0.54	0.47	0.43	0.57
Prevalence rate	4.09	4.66	3.74	3.82
Percentage of new cases with disability grade evaluated	88.26%	83.51%	84.83%	86.9%
Percentage of new cases with disability grade II among those evaluated	9.19%	7.91%	7.09%	6.26%

Source: SINAN/Hanseníase.

The evaluation of the percentage of basic health units with leprosy assistance was done taking into account the data received from the cities leprosy program managers, being calculated for every geographical region and for Rio de Janeiro state, as a whole. In December, 2000, 308 health units already offered leprosy diagnosis and/or treatment, amounting to 20.04% of the total. In December, 2001, there were 392 health units with these actions implemented in the state, 25.05% of them. In the end of 2002, 460 health units had been developing leprosy program actions, being 30.12% of the total. In August, 2003, there were 617 units, representing 40.14% of the total basic health units of the state. In July, 2004, 622 units, with 40.79% of them (Figure 1).

Figure 1. Evolution of the percentage of the health units with leprosy control actions, Rio de Janeiro, 2000 to 2004.\*

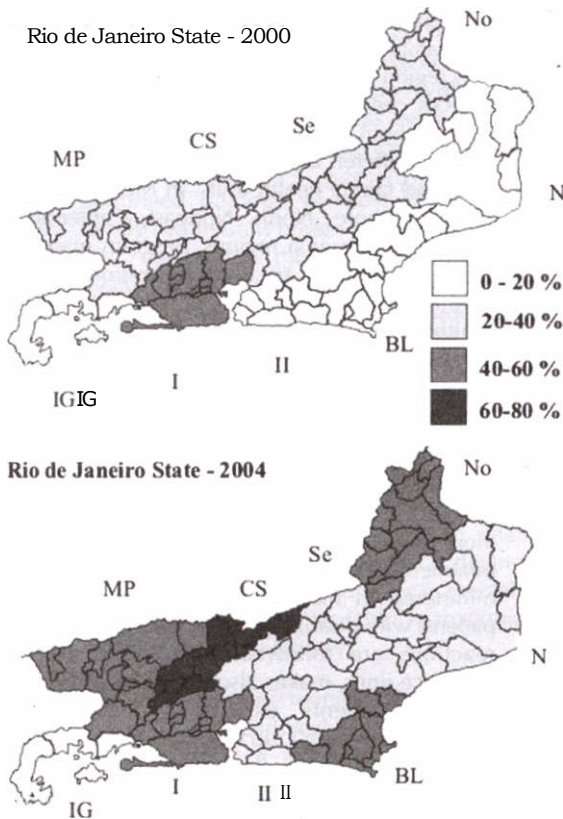


\* Health municipal secretariats.

In figure 2, we present the temporal evolution of the percentage of leprosy assistance in basic health units, by geographic region of the state, between the years 2000 and 2004. We notice that almost all regions presented a better decentralization of the leprosy actions in the latest years (Metropolitan II, North Seashore, North, Northeast, Center-South, and Median Paraíba). The Mountain and Metropolitan I regions were stable, although even in these regions we notice a better percentage of units with leprosy assistance, not sufficient to the change in the category (data not shown). South

state seashore maintained the percentage in steady low levels (7.5%) between years 2000 and 2004. In the other extreme, the central-south region presented the best levels of decentralization, passing from 36.72% of health units with leprosy diagnosis and / or treatment implemented in the year 2000, to 67.97% in the year 2004.

Figure 2. Coverage of leprosy in the health units of Rio de Janeiro state - 2000 to 2004.



Administrative regions of Rio de Janeiro state  
 I = Metropolitan I  
 II = Metropolitan II  
 BL = North Seashore  
 N = North  
 No = Northeast  
 Se = Mountain  
 CS = Center-South  
 MP = Median Paraiba  
 IG = Great Island Bay/ South Seashore

The problems detected by this Department to obtain an effective decentralization of leprosy program actions in Rio de Janeiro state, throughout the work developed in last years, are:

- high rate of replacement of the trained professionals in the basic health units, what generates a low number of professionals with effective knowledge about the disease;
- high rate of replacement of the municipal program managers, according to the political changes in the city administrations;

- low commitment of the municipal program managers to the decentralization process;
- difficulties in obtaining financial and logistic resources for the trainings. These resources must come from Non-Governmental Organizations (NGOs), or from governmental sources, and the last ones are submitted to bureaucratic procedures, which turn them difficult to obtain and delay the resource liberation;
- difficulties in obtaining resources for the local supervisions. From 1999 up to 2003, local supervisions were not done in Rio de Janeiro, and since 2003 the visits to the municipal managers to stimulate the program decentralization are not done either;
- inadequate functioning of the basic health units, with inadequate training of professionals in the management of the disease and lack of minimal local resources, in the dependence of the level of commitment of local authorities to public health;
- decentralization done in a incomplete way: in some of the basic health units, only the diagnosis is done, but the treatment remains restricted to the municipal reference unit. In others, suspected cases are guided to precise diagnosis to be made in the municipal reference unit, and only after that the patient returns to the primary health unit to carry on multidrug therapy;
- responsible personnel in the cities plan inadequately in relation to medications, in spite of their availability in the State Pharmacy Department in sufficient amount, which generates occasional lack of medications in health units;
- MDT treatment is ministered in the basic health units, and disabled patients or those with medication side effects or reactions are obligatorily accompanied in the municipal reference units.

## Discussion

The year of 2001 constituted a landmark to the effectiveness of decentralization of the leprosy actions in Rio de Janeiro, when we obtained the implementation of the program actions in all the ninety-two cities of the state. The leprosy programs, however, are moderately effective in their actions, depending on the level of commitment of the managers, on their autonomy in the political structure of each city, an even on the knowledge about the disease by the responsible professionals.

With the emphasis in the necessity to integrate leprosy assistance into the basic health units, we warrant the universal access of the population to the diagnosis and treatment of leprosy, allowing the patients of the most peripheral areas of the cities to be treated near their residence, what diminishes the treatment abandonment. The implementation of multidrug therapy facilitated this strategy, because the treatment is standardized. Therefore, generalist physicians or those with any specialty can be easily trained in the prescription of the treatment and in the follow-up of patients without complications<sup>2</sup>.

The effort of the Sanitary Dermatology Department of Rio de Janeiro Health State Secretariat with the municipal leprosy program managers has been important in the process of decentralization. Periodic visits to the municipal program managers were done, aiming to support the decentralization actions, trying to convince the health municipal authorities of the importance of warranting the access to leprosy diagnosis and treatment in basic health units and in family health units, according to the national instructions that rule the disease controls<sup>8-9</sup>.

Another important strategy has been the development of periodic trainings for the health professionals of basic health units (physicians, nurses, physiotherapists, intermediate level professionals), comprehending the diagnosis, multidrug treatment (MDT), disabilities evaluation and case notification, training professionals of various areas in the management of leprosy uncomplicated cases<sup>10</sup> (table 1). Theoretical and practical trainings to the medical and paramedical professionals constitute pre-requisite to the satisfactory integration in the leprosy control into the basic health system<sup>5,18</sup>.

Aiming to measure the institutional percentage of leprosy control actions, it is important to determine the percentage of basic health units which develop these actions<sup>8</sup>. Since August, 2003, we obtained a percentage of basic health units with leprosy patients assistance of approximately 40% in Rio de Janeiro state, when in December, 2000, this percentage was only about 20%. There is, however, much work to be done, because a percentage of 40% of health units with leprosy actions implemented is not satisfactory yet. Other states with a bigger number of cities reported they had obtained a better increase in the percentage of health units with leprosy patients assistance, although in a longer time period<sup>14</sup>. A very efficient strategy is the training of the crew of the Family Health Program in the diagnosis and treatment with MDT<sup>15</sup>, what makes it possible to cover a bigger population, including rural areas formerly precariously attended.

We therefore observed that the increase in the leprosy assistance coverage in health units, according to figures 1 and 2, did not reflect in a significant change in the epidemiological indicators (table 2). The new case detection rate, prevalence rate and case detection under the age of 15 years maintained relatively stable between 2000 and 2003. The percentage of cases with impairments among the new cases detected and evaluated in the year has decreased (although yet in intermediate levels), what indicates a better situation, with earlier diagnosis of the disease. There was an increase in the multibacillary blisters ministered, as well as a decrease in the paucibacillary blisters in the studied period, although these parameters are much influenced by the disposal of medication by the Ministry of Health, doesn't allowing an epidemiological analysis in a so short period of time.

The relative stability of the epidemiological indicators may reflect a low hidden endemy in Rio de Janeiro state; in other states, like Bahia, an opposite situation seems to happen, with a significant rise in the new case detection rate and in the detection rate under the age of 15 years in the last decades<sup>21</sup>.

In relation to the problems to get effective decentralization of the leprosy actions in Rio de Janeiro state, the most important issues are:

- the high rate of replacement of trainee professionals in the basic health units generates a continuous necessity of trainings;

- leprosy program managers with low commitment of municipal managers to the process of decentralization. This is the problem we identify, for example, in the South Seashore (Great Island Bay) region of the state, which maintains leprosy services centralized in the municipal reference units, without any additional efforts to implement leprosy sufferer assistance in the basic health units and family health units. In Metropolitan II, North Seashore, North, Northeast, Center-South and Median Paraíba regions, program managers highly committed to decentralization process gave impulse to the rise in leprosy assistance in health units, reaching more satisfactory levels in the Center-South region. The increase in the percentage of basic units with leprosy assistance in these regions reflected in the better percentage for the state, as a whole (figure 2);

- decentralization done in an incomplete way, generating additional expenses in the travelling, more difficulties for the patient and delay in the treatment. The fact that multidrug therapy is ministered in the basic health units, and any patients with disabilities, treatment side effects or reactions are followed-up in the municipal reference units, makes also the dislocation of the affected patients expensive and difficult. However, there isn't, up to now, a way to warrant specific training in the management of side effects and reactions for the professionals of basic health units, as well as there is no possibility to provide anti-reactional medications and alternative medications to multidrug therapy to be available in each basic health unit. Great part of the cities does not maintain physiotherapists adequately trained in leprosy, and many of the cities only maintain them in the municipal reference unit. With relation to anti-reactional medications, the greater difficulty is related to the control of medicine ministration to leprosy patients, because there is much demand, especially for thalidomide and prednisone, for patients with other diseases than leprosy, and that could lead to lack of medication to leprosy programs;

- difficulties in obtaining logistic and financial resources for the trainings and local supervisions;

- inadequate planning in relation to the storage of medications (this problem affects especially anti-reactional episode medications and the alternative medications for the cases of side effects that make the replacement of medications necessary in multidrug therapy).

These questions must be faced with special strategies. The actions of the Sanitary Dermatology Department of Rio de Janeiro State for the next years must include:

- efforts with governmental and non-governmental organizations to obtain financial resources for trainings, supervisions and educative actions directed to the general population. The NGOs establish important partnership relations, responsible for the success of the process of elimination of leprosy in various parts of the world<sup>15,13,19</sup>. This partnership, especially with American Leprosy Missions (ALM), has been successful in Rio de Janeiro State throughout the last decade;
- continued trainings of basic health units and family health units professionals, comprehending the diagnosis, multidrug therapy (MDT), evaluation of disabilities and notification, as well as identification of medication side effects or reactional episodes to send the affected patients to the municipal reference units<sup>10</sup>;
- trainings of professionals of municipal reference units for the adequate management of side effects and reactional episodes", as well as the differential diagnosis of the cutaneous and/or neurological signs and symptoms in relation to other diseases", for the correct diagnosis in difficult cases, in little children or in mental illness patients, as well as the management of disabilities due to leprosy;
- trainings and permanent follow-up of the professionals responsible for the information health system in the cities, so that the data obtained through SINAN / Leprosy (Notification Diseases Information System - leprosy) are trustworthy, allowing the adequate follow-up of the disease;
- to resume the service supervisions, for the evaluation of adequate performance of the control actions<sup>20</sup>;
- to seek, along with the program municipal managers and municipal health department managers, the commitment of increasing the percentage of basic health units with leprosy actions implemented, in a continuous conviction work aiming to face leprosy not as a different disease, but as a infectious disease which basic health system professionals can diagnose and treat<sup>13</sup>;

- to increase the diffusion, in communication media, of the signs and symptoms of the disease, to amplify the level of knowledge of the population, aiming early diagnosis and diminution of the stigma related to leprosy. To supervise managers in the spread of information to the inhabitants of each city, using available communication media in the best way.

## Conclusions

The present analysis takes into account preliminary and regional data, in a limited time. Additional studies must be developed in longer periods, making it possible to observe if the obstacles here noted could be by-passed through the implementation of the proposed strategies.

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## Resumo

Como parte do compromisso da Aliança Global para Eliminação da Hanseníase, o Brasil, desde 1998, incluiu a hanseníase entre os agravos atendidos pela rede de atenção básica prestada à saúde da população. A Secretaria de Estado de Saúde do Rio de Janeiro definiu como prioridade político-técnica a universalização do acesso ao diagnóstico, à avaliação do Grau de Incapacidade Física e tratamento da hanseníase, em todas as unidades básicas de saúde dos municípios. A descentralização do diagnóstico e tratamento da hanseníase passou a ser meta prioritária, e avançou de 308 (20,04%) unidades de saúde com ações voltadas ao atendimento de hanseníase implantadas em dezembro de 2000 para 622 (40,79%) em julho de 2004. Os indicadores epidemiológicos não parecem ter sido significativamente influenciados por estas conquistas. Muitos são os obstáculos ao aumento da descentralização no Estado do Rio de Janeiro. Espera-se obter recursos junto a fontes governamentais e Organizações Não-Governamentais para dar prosseguimento às ações (treinamentos, supervisões, apoio aos gestores municipais na descentralização, difundir sinais e sintomas da enfermidade nos meios de comunicação) para que assim possamos alcançar a meta de eliminação da hanseníase no Estado do Rio de Janeiro.

Palavras-chave: hanseníase; prevenção e controle

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