

Operational failures of leprosy control in household social networks with overlapping cases in endemic areas in Brazil*

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Abstract

Objective. To analyze institutional/programmatic vulnerability of health services in the development of health care actions for people affected by leprosy and contact surveillance. **Methods.** This was a cross-sectional study conducted in 2017 based on primary data from a sample of leprosy cases notified between 2001-2014 with overlapping cases in household social networks (HSN) in municipalities in the states of Bahia, Piauí and Rondônia, Brazil. **Results.** A total of 233 leprosy cases were analyzed, 154 (66.1%) belonged to HSN with 3 or more leprosy cases. In 53.2% of cases, 2 or more generations were affected, this being an outcome associated with absence of dermato-neurological examination (prevalence ratio 1.32; confidence interval [95%CI 1.10;1.59]; p-value=0.004). **Conclusion.** Operational failures in the surveillance of leprosy contacts in areas of high endemicity reinforce the character of institutional/programmatic vulnerability in HSN contexts with more than one case of leprosy in the three states analyzed.

Keywords: Leprosy; Epidemiology; Contact Tracing; Surveillance; Cross-Sectional Studies.

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Introduction

The leprosy burden in Brazil remains at high endemic levels, especially in the country's North, Midwest and Northeast regions.¹ Between 2012 and 2016, new case (NC) detection rates considered to be hyperendemic were recorded in states such as Mato Grosso (88.9/100,000 inhabitants), Tocantins (69.13/100,000 inhab.) and Maranhão (53.91/100,000 inhab.).¹ The size of the burden is evidenced by NC detection in the general population and in under-15 year olds, as well as by records of NCs diagnosed late that already had visible physical disabilities (grade II). Standing out as an aggravating factor is the greater expression of cases in more vulnerable populations.^{1,2} In their control guidelines, both the Brazilian Ministry of Health and the World Health Organization (WHO) emphasize the relevance of early diagnosis and timely treatment as priority strategic measures for reducing the burden of the disease.^{2,3}

Operational failures in leprosy health care and surveillance are critical and, probably, account for the undersizing of the endemic burden.

Brazil faces problems in ensuring comprehensive care for people/families in the context of its National Health System (SUS), including in the primary healthcare network.⁴ Operational failures in leprosy health care and surveillance are critical and, probably, account for the undersizing of the endemic burden.⁵ This latter issue includes contact coverage and quality of contact assessment.^{2,3}

Leprosy contact surveillance, officially in place, includes dermatology and neurology examinations, immunoprophylaxis with BCG (Bacillus Calmette-Guérin) vaccine and contact follow-up for at least five years following diagnosis of the index case (IC).² The indicator currently used to monitor these actions is the proportion of contacts examined, among registered contacts, with monitoring of coverage at the municipal and state level.^{2,3} On average Brazil has managed to assess 77% of registered contacts and this is considered to be a regular pattern.¹ However, no official indicators are available about the quality of the actions comprising examination of contacts, nor about surveillance continuity in the years following diagnosis.^{3,5,6}

In SUS organization policy, prevention, surveillance, control and care actions should be developed primarily in primary healthcare facilities, with reference services responsible for providing matrix-based support.² When well-developed, counter-referral is therefore an opportunity for continuing education. Priority situations for reference services should include, among others, uncertain diagnoses, child cases, complex physical disabilities, relapses, leprosy reactions and adverse effects caused by multidrug therapy (MDT).^{2,7,8} Notwithstanding, difficulties exist with regard to operational implementation of primary healthcare actions in a continuous, systematized and quality manner.^{3,9,10}

Vulnerability occurs in complex processes of increased biosocial fragility that are expressive of biological, existential and social values,^{4,11} demonstrating that it is essential to capture interferences between the multiple dimensions of the health-disease process. Distinct situations of vulnerability can be broken down, taking into account three interconnected components: (i) individual; (ii) social or collective; and (iii) programmatic or institutional.¹² The programmatic dimension relates to health services and the way in which they act to reduce vulnerability, whereby the possibility of scaling up these services is provided for.^{4,11}

However, it is possible for care centralization to create difficulties related to access and comprehensive care for people affected by the disease, including prevention and surveillance actions with contacts. The dimension of programmatic vulnerability is expressed by aspects relating to social resources intended to meet access needs and to solve problems that are felt and perceived.¹¹ This vulnerability implies operational failures in the way actions are established to control the disease, involving policies, planning, management, monitoring and evaluation in the light of the principles of the Brazilian National Health System (SUS): universal access; comprehensive health care; equity; decentralized management and service hierarchization; and social participation/monitoring.^{3,11}

Programmatic vulnerability can, therefore, contribute to leprosy remaining within a primary healthcare territory, with cases that remain as a "hidden endemic" failing to be detected in a timely manner.^{3,12} As such, programmatic vulnerability can often result in different generations being affected and a substantial number of cases in the same household social network over consecutive years. In these contexts, the possibility of contacts becoming new leprosy cases (coprevalent cases) is increased.^{13,14}

The scarcity of papers taking this analytical perspective justifies this study being conducted, the objective of which was to analyze the institutional/programmatic vulnerability of health services in the development of care actions for leprosy cases and surveillance actions for their contacts, with emphasis on HSN with overlapping cases of the disease.

Methods

This study was conducted in Brazilian municipalities selected according to patterns of endemicity and primary healthcare network structure. Two municipalities located in the state of Bahia (Vitória da Conquista and Tremedal), one in Piauí (Floriano) and one in Rondônia (Cacoal) (Figure 1) were included in the study.

With regard to the municipalities in the state of Bahia, the population estimated by the Brazilian Institute of Geography and Statistics (IBGE) for 2017 was 348,718 inhab. in Vitória da Conquista and 17,700 inhab. in Tremedal. In the state of Piauí the IBGE population estimate for Floriano was 58,969 inhab. and 88,507 inhab. for Cacoal in the state of Rondônia. Family Health Strategy coverage in 2016 was 100% in Tremedal and Floriano, while in Vitória da Conquista it was 48%, and in Cacoal it was 78.2%.^{15,16} In 2017, Floriano had the highest endemicity (69.7 cases/100,000 inhab.), while Vitória da Conquista had the lowest detection rate (17.2 cases/100,000 inhab.), with both rates being considered to be high.¹⁷

This was an analytical cross-sectional study conducted as part of the IntegraHans North-Northeast project (coordinated by the Federal University of Ceará [UFC]) and the IntegraHans Piauí project (coordinated by the Federal University of Piauí [UFPI] in partnership with UFC).¹⁸ These projects were developed between 2014 and 2015.

The study population involved 899 new leprosy cases notified between 2001 and 2014, resident in the four municipalities covered by the study, with no restriction as to age. The study sample was comprised of people with leprosy (index cases [IC]) who are part of an HSN with overlapping cases of the disease.

An index case (IC) was considered to be the first leprosy case diagnosed in an HSN, while a coprevalent case (CPC) was taken to be a contact in the HSN who became a new case (CN). In addition to the leprosy IC, the HSN included all household and social contacts as defined by the Ministry of Health,² as well as other

household and social contacts who became cases (coprevalent cases – CPCs). Identification of at least 2 leprosy cases in one HSN defined existence of leprosy “overlapping”, this being an indicator of increased risk.¹⁴

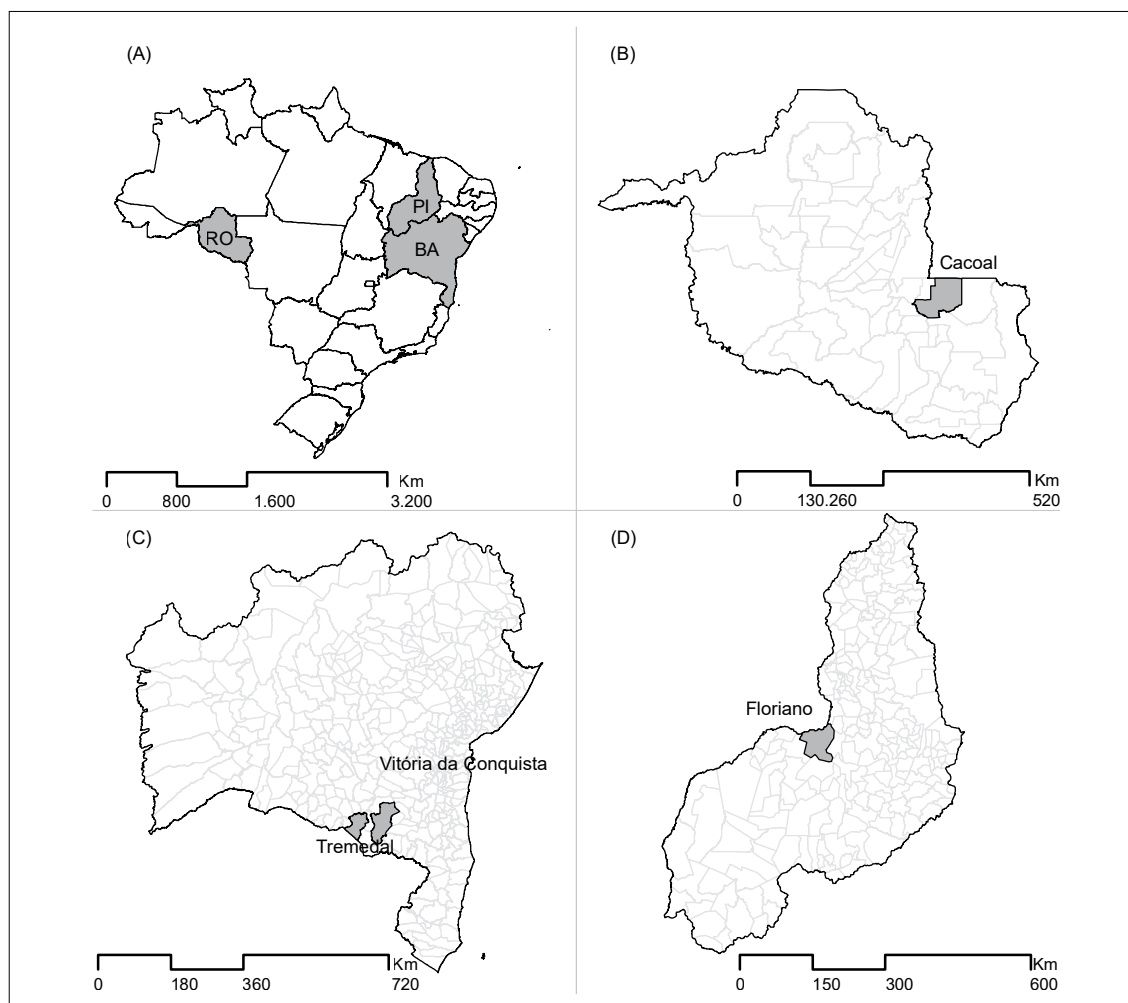
A structured instrument was administered for ICs located within the territory who agreed to take part in the study. The instrument was designed by the lead author of this study and by a collaborating researcher, both of whom are qualified in Nursing and Public Health. Both took part in the training conducted by the project coordinators. The data were collected using physical instruments and later consolidated using Epi Info version 7.1.5 (Centers for Disease Control and Prevention [CDC], Atlanta, USA).

The variables included in the analysis were as follows: prior registration of the household by a community health agent (ACS) (yes; no); place of initial healthcare upon suspicion of leprosy (primary healthcare center [UBS]; municipal reference unit; other); place of diagnosis (UBS; municipal reference unit; other); place of leprosy treatment, multidrug therapy (municipal reference unit; other); and knowledge of disease before diagnosis (yes; no).

For CPCs additional information was collected about surveillance activities: dermatology examination performed; neurology examination performed; BCG vaccine received; advised about BCG vaccine administration; advised about mobilizing other contacts; and guidance received on returning to the health service.²

As well as identifying the percentage of leprosy case contacts assessed among those who were registered (coverage indicator), identification of indicators of surveillance action quality was also considered to be necessary. This was done using the IntegraHans score which was built by the project for this purpose.

This score is based on six components which have different weightings: complete dermatology examination of the entire body surface performed (weight 6); complete neurology examination performed (weight 5); BCG vaccination when indicated (weight 4); guidance on returning to the health center, if symptoms appear or to attend an appointment made in advance (weight 3); advice on BCG (weight 2); and advice on tracing other contacts (weight 1). The score has three classifications: poor (0-6), regular (7-14) and excellent (15-21). Considering the importance of monitoring this form of surveillance, the score enables an indicator that is easy to interpret to be compiled, for use in the healthcare network.



A: Brazil and states taking part in the study.

B: State of Bahia (municipalities of Vitória da Conquista and Tremedal).

C: State of Rondônia (municipality of Cacoal).

D: State of Piauí (municipality of Floriano).

Figure 1 – Geographical location of the municipalities taking part in the study within their respective states

When assessing differences between the groups, Pearson's Chi-Square test (χ^2) was used for observation values equal to or greater than five, while Fisher's exact test was used for the remainder. During the crude analysis, we sought to verify existence of association between the IntegraHans score and two or more generations being affected in the HSN, as well as 3 or more leprosy cases in the same HSN. Prevalence ratios (PR) and their respective 95% confidence intervals (95%CI) were calculated. P-values <0.05 were considered to be significant. Stata 11.2 (Stata Corporation, College Station, USA) was used to analyze the data.

Variables were included that assess operational aspects of leprosy control actions. For ICs the following

variables were analyzed: 'household registered by ACS', 'first service accessed upon suspicion of leprosy', 'place of diagnosis' and 'place of treatment' (all of these had three alternative answers: UBS; reference unit; other); plus a further variable, 'ever heard of leprosy' (yes; no). For contacts the following variables were analyzed: 'dermatology examination', 'neurology examination', 'advice on BCG', 'BCG vaccine administered', 'advice on mobilizing other contacts' (for medical assessment) and 'guidance on returning to health services' (the answer to all these variables was: yes or no); plus the 'IntegraHans score' (excellent; regular; poor). In the case of discreet quantitative numerical variables, the average and respective 95%CI were calculated.

The study projects were submitted to and approved by the UFC Research Ethics Committee (Opinion No. 544.962, dated February 28th 2014) and the UFPI Research Ethics Committee (Opinion No. 1.115.818, dated July 17th 2015). Due respect was paid to National Health Council Resolution No. 466, dated October 12th 2012. The study was explained to all leprosy cases invited to take part before they agreed to do so and before they signed a Free and Informed Consent form. In the case of participants under 18 years, their legal guardians signed the Free and Informed Consent form and children aged over 12 signed a Free and Informed Assent form as well.

Results

In the selected municipalities, 405 (45.1%) leprosy cases that had at least one more leprosy case in their HSN were identified. Two hundred and thirty-three

(57.5%) of these cases were reached, the majority of whom were in the 41-60 age group (n=98; 42.1%) and were of brown race/skin color (n=147; 63.1%) (Table 1). There were 169 (41.7%) losses due to change of address and 3 (0.7%) refusals to take part.

Of the total 233 leprosy cases included in the study, 66.1% (n=154) were found to belong to HSN with 3 or more diagnosed leprosy cases, whereby the overall average was 4.1 cases per HSN, with standard deviation of 3.3 cases. In 53.2% of cases (n=124), the disease affected two generations, while in 20.2% of cases (n=47), it affected three generations.

A large proportion of the households had been registered by ACS (n=197; 84.5%); however, specialized health services were accessed more in the event of suspicion of having leprosy (n=167; 71.7%), confirmation of diagnosis (n=200; 85.8%) and treatment (n=178; 76.4%) (Table 2).

Table 1 – Socioeconomic and demographic characterization of contacts and index cases (n=233) in municipalities in the states of Bahia, Piauí and Rondônia, 2001-2014

Variables	Contacts	Index cases	Total
	n (%)	n (%)	n (%)
Sex			
Male	56 (50.9)	59 (48.0)	115 (49.4)
Female	54 (49.1)	64 (52.0)	118 (50.6)
Age range (in years)			
≤14	5 (4.5)	1 (0.8)	6 (2.6)
15-40	35 (31.8)	29 (23.6)	64 (27.5)
41-60	49 (44.5)	49 (39.8)	98 (42.1)
>60	21 (19.1)	44 (35.8)	65 (27.9)
Race/skin color			
White	14 (12.7)	18 (14.6)	32 (13.7)
Brown	70 (63.6)	77 (62.6)	147 (63.1)
Black	23 (20.9)	24 (19.5)	47 (20.2)
Yellow	3 (2.7)	4 (3.3)	7 (3.0)
Marital status			
Single	22 (20.0)	14 (11.4)	36 (15.5)
Married	60 (54.5)	64 (52.0)	124 (53.2)
Common-law partnership	10 (9.1)	8 (6.5)	18 (7.7)
Separated/divorced	10 (9.1)	23 (18.7)	33 (14.2)
Widowed	8 (7.3)	14 (11.4)	22 (9.4)
Schooling			
Illiterate	21 (19.1)	28 (22.8)	49 (21)
Literate	7 (6.4)	14 (11.4)	21 (9.0)
1 st to 3 rd grade	13 (11.8)	20 (16.3)	33 (14.2)
4 th to 7 th grade	31 (28.2)	23 (18.7)	54 (23.2)
Complete middle school education	4 (3.6)	3 (2.4)	7 (3.0)
1 st or 2 nd year of high school	15 (13.6)	4 (3.3)	19 (8.2)
Complete high school education	14 (12.7)	21 (17.1)	35 (15)
Incomplete higher education	3 (2.7)	4 (3.3)	7 (3.0)
Complete higher education	2 (1.8)	6 (4.9)	8 (3.4)
Total	110 (47.2)	123 (52.8)	233 (100.0)

The majority of CPCs reported that at the time the IC was diagnosed they did not undergo a dermatology examination ($n=62$; 56.4%) or a neurology examination ($n=63$; 57.3%). Although advice on BCG administration ($n=77$; 70.0%) was frequent, the majority had not been vaccinated ($n=82$; 74.5%). Many CPCs were advised to mobilize other contacts for assessment ($n=68$; 61.8%); but did not receive guidance on returning for new assessments in the following years ($n=57$; 51.8%). The IntegraHans score was classified as 'poor' ($n=62$; 56.4%) for a high proportion of cases (Table 2).

Association was found between two or more generations being affected and: contacts not having undergone a dermatology examination (PR=1.32 – 95%CI 1.10;1.59); having received guidance on BCG (PR=1.36 – 95%CI 1.16;1.58), not having received a BCG vaccination (PR=1.32 – 95%CI 1.14;1.53); having been advised to mobilize other contacts to get assessment (PR=1.26 – 95%CI 1.05;1.50); and having had a 'poor' IntegraHans score (PR=1.33 – 95%CI 1.10;1.61) (Table 2).

When the number of cases per HSN was compared with the quality of contact control actions, association was found between the 3 or more cases per HSN outcome and: contacts not having undergone a dermatology examination (PR=1.29 – 95%CI 1.07;1.56); not having had a neurology examination (PR=1.28 – 95%CI 1.06;1.55); lack of advice on BCG vaccination (PR=1.38 – 95%CI 1.18;1.62); and not having BCG vaccination (PR=1.34 – 95%CI 1.15;1.56). Association was also found between this outcome (3 or more cases per HSN) and lack of advice on mobilizing other contacts (PR=1.22 – 95%CI 1.02;1.47) and having a 'poor' IntegraHans score (PR=1.33 – 95%CI 1.10;1.61) (Table 3).

Discussion

The contexts analyzed in the North and Northeast regions of Brazil highlight considerable programmatic vulnerability with regard to provision and quality of leprosy contact surveillance actions. It is a complex problem, especially given the HSN with overlapping NCs, denoting increased risk of the disease. Decentralization of these actions to primary healthcare is not, however, sufficiently implemented in the municipalities studied. The high percentages of CPCs that did not have timely dermatology/neurology examinations, were not advised about and did not have BCG vaccinations, and did not receive guidance on returning to the health center,

very probably, contributed to leprosy remaining in these territories. The association found between a 'poor' IntegraHans score for the approach to contacts and (i) 2 or more generations being affected or (ii) existence of 3 or more cases in the same HSN stresses programmatic vulnerability and the need to restructure surveillance actions.

Despite the control guidelines established by the Ministry of Health, based on the WHO global strategy for 2020,² operationalization of contact surveillance actions has not been fully materialized in the contexts studied. The process of decentralizing healthcare to the Family Health Strategy is not yet effective, considering the high percentages of cases that seek references service for diagnosis and treatment. In endemic areas, it is possible that these services may be overburdened, including difficulty in effectively carrying out the actions for which they are responsible.^{2,9,10} Moreover, reflection needs to be given to the scope of actions in municipalities without access to specialized services, which generates impacts to a greater or lesser extent on affected people.

The process of integrating leprosy control actions into primary healthcare has been underway in Brazil since the 1970s, gradually and progressively, although slowly. As a consequence, decentralization is still insufficient, and care is concentrated in specialized services in medium and large-size municipalities.^{3,19,20}

A study conducted in the municipality of São José do Rio Preto, SP, with the aim of assessing health services as to early detection of leprosy, revealed that people with the disease traveled 9.2km on average between their homes and the places where they got treatment, confirming the importance of decentralization for improving access, early diagnosis and treatment follow-up.^{20,21} A study conducted with the aim of characterizing the flow of people with leprosy from their municipality of residence to the municipality where they got treatment, in the states of Maranhão, Pará, Tocantins and Piauí, identified gaps in this process of decentralization. Standing out, in particular, are difficulties and challenges in follow-up during and after multidrug therapy (MDT).²²

The reality found in the contexts analyzed may be equal to that in other parts of the country. A study conducted with individuals with leprosy in Salvador, Bahia, revealed that affected people have to follow a long path before getting care, often with excessively long average time for diagnosis and, in many cases, only after having been referred to a reference center in the state capital.¹⁰ Another study

Table 2 – Operational aspects of leprosy control actions among contacts and index cases (n=233), by case occurrence in two or more generations of families assessed in municipalities in Bahia, Piauí and Rondônia, 2001-2014

Variables	Total n (%)	Two or more generations		p-value	PR ^a	95%CI ^b	p-value ^c
		No n (%)	Yes n (%)				
Index cases and contacts							
Household registered by ACS^e							
Yes	197 (84.5)	47 (23.9)	150 (76.1)	0.026 ^c	1.31	0.98;1.74	0.026
No	36 (15.5)	15 (41.7)	21 (58.3)		1.00	–	–
First service accessed upon suspicion							
UBS ^f	49 (21.0)	12 (24.5)	37 (75.5)	0.679 ^c	1.00	–	–
Municipal reference service	167 (71.7)	44 (26.3)	123 (73.7)		0.97	0.81;1.17	0.794
Other	17 (7.3)	6 (35.3)	11 (64.7)		0.86	0.58;1.26	0.389
Place of diagnosis							
UBS ^f	27 (11.6)	9 (33.3)	18 (66.7)	0.220 ^d	1.00	–	–
Reference unit	200 (85.8)	50 (25.0)	150 (75.0)		1.12	0.85;1.49	0.354
Other	6 (2.6)	3 (50.0)	3 (50.0)		0.75	0.32;1.74	0.443
Place of treatment							
UBS ^f	55 (23.6)	15 (27.3)	40 (72.7)	0.899 ^c	1.00	–	–
Reference unit	178 (76.4)	47 (26.4)	131 (73.6)		1.01	0.84;1.21	0.899
Ever heard of leprosy							
Yes	178 (76.4)	48 (27.0)	130 (73.0)	0.825 ^c	1.00	–	–
No	55 (23.6)	14 (25.5)	41 (74.5)		1.02	0.85;1.22	0.824
Contacts (n=110)							
Dermatology examination							
Yes	48 (43.6)	4 (8.3)	44 (91.7)	0.005 ^d	1.00	–	–
No	62 (56.4)	19 (30.6)	43 (69.4)		1.32	1.10;1.59	0.004
Neurology examination							
Yes	47 (42.7)	4 (8.5)	43 (91.5)	0.008 ^d	1.00	–	–
No	63 (57.3)	19 (30.2)	44 (69.8)		1.31	1.09;1.57	0.006
Advised about BCG^g							
Yes	77 (70.0)	22 (28.6)	55 (71.4)	0.002 ^d	1.36	1.16;1.58	0.003
No	33 (30.0)	1 (3.0)	32 (97.0)		1.00	–	–
BCGg vaccination administered^d							
Yes	28 (25.5)	1 (3.6)	27 (96.4)	0.007 ^d	1.00	–	–
No	82 (74.5)	22 (26.8)	60 (73.2)		1.32	1.14;1.53	0.009
Advice on mobilizing other contacts							
Yes	68 (61.8)	19 (27.9)	49 (72.1)	0.029 ^d	1.26	1.05;1.50	0.021
No	42 (38.2)	4 (9.5)	38 (90.5)		1.00	–	–
Guidance on returning to health services							
Yes	53 (48.2)	10 (18.9)	43 (81.1)	0.646 ^c	1.00	–	–
No	57 (51.8)	13 (22.8)	44 (77.2)		1.05	0.87;1.27	0.612
IntegraHans Score							
Excellent	38 (34.5)	3 (7.9)	35 (92.1)	0.017 ^d	1.00	–	–
Regular	10 (9.1)	1 (10.0)	9 (90.0)		0.98	0.78;1.22	0.830
Poor	62 (56.4)	19 (30.6)	43 (69.4)		1.33	1.10;1.61	0.008

a) PR: prevalence ratio.

b) 95%CI: 95% confidence interval.

c) Pearson's Chi-Square test.

d) Fisher's exact test.

e) ACS: community health agent.

f) UBS: primary healthcare center.

g) BCG: Bacillus Calmette-Guérin.

Table 3 – Operational aspects of leprosy control actions among contacts and index cases (n=233) by occurrence of three or more leprosy cases in household social networks (HSN) in municipalities in Bahia, Piauí and Rondônia, 2001-2014

Variables	Total n (%)	Three or more HSN cases		p-value	PR ^a	95%CI ^b	p-value ^c
		No n (%)	Yes n (%)				
Index cases and contacts							
Household registered by ACS^e							
Yes	197 (84.5)	65 (33.0)	132 (67.0)	0.492 ^c	1.09	0.83;1.44	0.492
No	36 (15.5)	14 (38.9)	22 (61.1)		1.00	–	–
Place of diagnosis							
UBS ^f	27 (11.6)	7 (25.9)	20 (74.1)	0.465 ^d	1.00	–	–
Reference unit	200 (85.8)	69 (34.5)	131 (65.5)		0.88	0.69;1.13	0.376
Other	6 (2.6)	3 (50.0)	3 (50.0)		0.67	0.29;1.55	0.246
Place of treatment							
UBS ^f	55 (23.6)	17 (30.9)	38 (69.1)	0.591 ^c	1.00	–	–
Reference unit	178 (76.4)	62 (34.8)	116 (65.2)		0.94	0.77;1.16	0.591
Contacts (n=110)							
Dermatology examination							
Yes	48 (43.6)	5 (10.4)	43 (89.6)	0.011 ^c	1.00	–	–
No	62 (56.4)	19 (30.6)	43 (69.4)		1.29	1.07;1.56	0.011
Neurology examination							
Yes	47 (42.7)	5 (10.6)	42 (89.4)	0.014 ^c	1.00	–	–
No	63 (57.3)	19 (30.2)	44 (69.8)		1.28	1.06;1.55	0.014
Advised about BCG^g							
Yes	33 (30.0)	1 (3.0)	32 (97.0)	0.001 ^d	1.00	–	–
No	77 (70.0)	23 (29.9)	54 (70.1)		1.38	1.18;1.62	0.002
BCG^g vaccination administered							
Yes	28 (25.5)	1 (3.6)	27 (96.4)	0.007 ^d	1.00	–	–
No	82 (74.5)	23 (28.0)	59 (72.0)		1.34	1.15;1.56	0.007
Advice on mobilizing other contacts							
Yes	42 (38.2)	5 (11.9)	37 (88.1)	0.048 ^c	1.00	–	–
No	68 (61.8)	19 (27.9)	49 (72.1)		1.22	1.02;1.47	0.048
Guidance on returning to health services							
Yes	53 (48.2)	9 (17.0)	44 (83.0)	0.236 ^c	1.00	–	–
No	57 (51.8)	15 (26.3)	42 (73.7)		1.13	0.93;1.37	0.236
IntegraHans Score							
Excellent	38 (34.5)	3 (7.9)	35 (92.1)	0.020 ^d	1.00	–	–
Regular	10 (9.1)	2 (20.0)	8 (80.0)		1.15	0.83;1.59	0.265
Poor	62 (56.4)	19 (30.6)	43 (69.4)		1.33	1.10;1.61	0.008

a) PR: prevalence ratio.

b) 95%CI: 95% confidence interval.

c) Pearson's Chi-Square test.

d) Fisher's exact test.

e) ACS: community health agent.

f) UBS: primary healthcare center.

g) BCG: Bacillus Calmette-Guérin.

conducted in a municipality in the state of São Paulo, revealed absence of active case tracing – despite it being necessary –, in order to obtain true knowledge of the epidemiological situation, as well as absence of health education actions, pointing to the need to reorganize care for leprosy in the primary healthcare network, especially with regard to diagnosis and treatment in these spaces.²³

There are therefore complex challenges to be overcome by primary healthcare professionals with regard to scaling up user access to health services.^{20,21} Certain issues stand out among these challenges: (i) health management quality in relation to regionalized networks; (ii) continuing education for health professionals; (iii) lack of empowerment of affected people and their families

with regard to their right to health; and (iv) insufficiency of systematic analyses in relation to epidemiological and operational indicators in the territories.^{3,8,14}

The high percentages of CPCs not approached adequately at the time the ICs were diagnosed, when they were contacts, illustrate real difficulties for timely diagnosis and contact follow-up, as well as for immunoprophylaxis, these being measures that have been made known for a very long time in Brazil.^{3,19,23} As a consequence, *Mycobacterium leprae* in the HSN continues to circulate actively, affecting individuals of more than one generation, which can favor the emergence of physical disabilities and continuance of stigma strongly associated with leprosy.²³⁻²⁵

A case study of situations related to leprosy in children concluded that active contact tracing revealed itself to be an important method for early leprosy diagnosis in childhood, principally because the clinical signs are not always easily identifiable.²⁶ Despite dermatology and neurology examinations being the main form of case diagnosis, it is also essential to promote skills and knowledge about the disease and its diverse manifestations.^{3,5,19}

Also worthy of note is the fact of CPCs seen by health professionals at the time ICs were diagnosed not having been given guidance on returning to the health services in the event of skin or neurological lesions. Because of this, the recommendation for longitudinal surveillance over a five-year period can get lost in the midst of the health service routine, or as a result of the weakness of health education actions for people and their HSN.²⁶⁻²⁸

Another study, aimed at characterizing standards of care involving household contacts of leprosy cases living in the Northern region of Brazil, revealed that 41.6% of contacts had not undergone a dermatology examination, and that 54.9% had not had a neurology examination. The same study found that 56.0% of contacts did not receive guidance on returning to the health service for new assessments/follow-up and 40.5% were not advised on mobilizing other contacts.²⁹ These findings point to possible health institution weaknesses in fulfilling their role of preventing leprosy,³⁰ with the possibility of increasing the susceptibility of some HSN and maintaining transmission sources.

A cause of concern with regard to the national leprosy control policy relates to the lack of indicators to enable not only monitoring of coverage, but also the quality of contact care.^{3,19} In this respect, the IntegraHans

score aimed to assess the extent to which six actions considered essential for contact surveillance occurred. Overall, care provided to less than 50.0% of CPCs was classified as 'excellent'; i.e., almost half the CPCs did not receive some form of care essential for prevention and/or early diagnosis in their HSN, as part of the actions planned nationally.³

Continuing education processes, aligned with well-established monitoring and evaluation systems, favor the accompaniment of leprosy control action decentralization in the SUS healthcare network.^{2,3,6} They are activities that have the potential to inform planning of comprehensive care for people with leprosy and their HSN. Incorporation of the score, associated with monitoring of HSN with 3 or more leprosy cases and/or two or more affected generations, should also be taken into account on the processes of prioritizing scenarios of integrated surveillance in health territories.

Development of health surveillance actions by primary healthcare and their integration with other care points within the network is strategic for the sustainability of these actions and their distribution with greater fairness and quality.^{19,29} Communication and education processes among the population must, therefore, be (re)signified so that there is greater inclusion and empowerment of SUS users.

Possible limitations of this study relate to the possibility of CPC memory recall bias with regard to surveillance actions performed at the time ICs were diagnosed, in addition to it not having been possible to interview all HSN CPCs, in many cases because of change of address or refusal. The fact of the study having been based on the existence of at least 2 leprosy cases per HSN may, in some way, have contributed to poorer results in comparison to more general contexts. Notwithstanding, having studied a significant number of HSN in three states with high endemicity in Brazil strengthens the findings.

The operational failures identified in the leprosy contact surveillance process reinforce the nature of programmatic vulnerability in the scenarios studied, even among contacts of HSN with overlapping cases. We stress once more the critical aspects relating to access to the SUS healthcare network, as well as the development of longitudinal surveillance actions. In addition to coverage, it is fundamental to develop new strategies aimed at improving the quality of these actions.

Contrary to the recommendations of the national leprosy control policy in Brazil, reference services continued to be the main National Health System space where leprosy contact surveillance, and leprosy diagnosis and treatment actions were undertaken. In the municipalities covered by this study, decentralization of primary healthcare was still not a daily health service practice. Use of the IntegraHans score was shown to be feasible for assessing the quality of care for leprosy contacts and should be considered as a possibility for use in health services.

In conclusion, we highlight the importance of structured processes, matrix-based support and monitoring of actions in the territory, especially in scenarios of HSN with overlapping of leprosy cases.

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Authors' contributions

Boigny RN, Souza EA e Ramos Jr. AF contributed to the concept of the project, data analysis and interpretation, drafting, relevant critical reviewing of the intellectual content and final approval of the article. Ferreira AF contributed to data analysis and interpretation, drafting, relevant critical reviewing of the intellectual content and final approval of the article. Cruz JR, Prado NMBL, Silva GV, García GSM, Barbosa JC, Silva RL, Oliveira MLW and Nobre ML contributed to relevant critical reviewing of the intellectual content and final approval of the article. All the authors have approved the final version of the manuscript and are responsible for all aspects thereof, including the guarantee of its accuracy and integrity.

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