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Primary Health care in Leprosy, Assessed by Users and Professionals Primary Health Care and leprosy

ORIGINAL

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Abstract

Objective: Evaluate the performance of primary health care in control of leprosy in Teresina, Brazil from the perspective of users and professionals.

Methods: This cross-sectional, descriptive study involved 25 healthcare users with leprosy and 34 professionals (physicians and nurses) working in 13 municipal health units within the urban area of Teresina. The data were collected from January to June, 2017, using the Instrument for Assessing the Performance of Primary Care in Leprosy Control Actions, a document based on the Primary Care Assessment Tool/PCATool Brasil which measures the presence and extension of essential and derived attributes from primary health care.

Results: The mean scores obtained for the essential, derived and global attributes, through the perception of the users, were lower than 6.6, indicating that the primary health services in Teresina are not sufficiently oriented to carry out leprosy control actions, mainly in terms of access, integrality of services provided, family orientation and community orientation. The professionals showed a contrasting view, with averages exceeding 6.6 for all attributes and scores. The difference in perception between the groups was significant for all attributes except for coordination (Mann-Whitney U test, p = 0.479). The overall evaluation of quality was not influenced by the user's clinical or socioeconomic variables, but rather by the organization/provision of services.

Conclusions: The municipal health units within the urban area of Teresina must be strongly guided by primary health care attributes in order to reach higher levels of user satisfaction.

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Leprosy; Primary Health Care; Health Services Assessment.

Introduction

Leprosy is an infectious, granulomatous, slow-evolving chronic disease associated with *Mycobacterium leprae*, an obligate intracellular parasite that leads to skin lesions, peripheral nerve damage, and involvement of the upper respiratory tract and eye mucosa, which may result in permanent physical disabilities that progress into deformities in some cases [1-2].

Data from the World Health Organization for the year 2015 show that 14 countries in the world have presented more than 1000 new cases of leprosy. These countries accounted for 95% of the global leprosy burden, with the remaining 5% reported by 92 other countries. India reported 127,326 new cases, accounting for 60% of new global cases of leprosy, Brazil reported 26,395 new cases (13%), and Indonesia reported 17,202 new cases (8%) [3].

As a signatory to the global commitment to eliminate leprosy, Brazil has developed and improved the National Leprosy Control Program (*Programa Nacional de Controle da Hanseníase*, PNCH), which involves a set of actions to guide services at all levels and complexities. Consequently, implementation of the PNCH has been important to establish a network for leprosy control actions (LCA) in primary health care (PHC), and has led to improvement in the national disease control indicators and elimination of the disease in most of Brazil. But even though the target has been reached in some areas, several regions of the country continue to be endemic areas [4-5].

In this context, the state of Piauí is significant as an area where leprosy continues to be highly endemic; it ranks second in the Brazilian northeast and sixth nationally in terms of prevalence, with 2.09 cases per 10,000 inhabitants in 2015. Within the state, the city of Teresina can be considered hyperendemic according to the coefficient of detection in the general population (40.75 cases/100,000 inhabitants in 2015) and in children under 15 years old (8.78 cases/100,000 inhabitants in 2014) [6].

To address this scenario, the Brazilian Ministry of Health has encouraged research that may indicate the determinants of this process and permit reorganization of health care in order to reach the goals of eliminating and controlling leprosy as a public health problem.

Evaluation of health services generally considers aspects related to quality, efficiency, equity, relevance, sustainability, quality of care, and physical structure indicators, among other factors [7-8]. Specifically with regard to leprosy, evaluation of service quality is critical, since this is a primary complaint in Brazilian health policy and requires actions to strengthen the performance of PHC. The use of suitable instruments permits situational analysis and makes it easier to plan actions for each individual service, thus directly impacting quality [9]. Consequently, this study investigated the performance of primary health care in controlling leprosy in the city of Teresina from the perspectives of users and professionals within the services; we looked for correlations between socioeconomic aspects and clinical characteristics of the disease, and investigated whether certain factors are related to better performance in leprosy control activities.

Methods

This cross-sectional, descriptive study involved 59 participants: 25 PHC users in therapeutic follow-up for leprosy, and 34 higher-level health professionals (doctors and nurses) from 13 municipal health units (MHU) in the urban area of Teresina, Piauí, where active leprosy cases were recorded in 2016 and 2017, according to data from the National Information System of Notifiable Diseases (*Sistema Nacional de Agravos de Notificação,* SINAN).

The study included patients of both sexes aged 18 years or older who received therapeutic leprosy control care in the units for at least 2 months, as well as the professionals responsible for their treatment. All the participants received an explanation of the

research objectives and signed a free and informed consent form.

Data was collected from January to June 2017 through application of the Instrument for Assessment of Performance of Primary Care in Leprosy Control Actions, which was developed by Lanza [9] and based on the Primary Care Assessment Tool/ PCATool Brasil; this tool measures the presence and extent of essential attributes (gateway, access, continuous care, integrality of available services, integrality of services provided, coordination) and derivatives (family orientation, community orientation and professional orientation) in primary care. The overall PHC score was obtained by dividing the total average score of the components of the essential and derivative attributes by the total number of components. Average scores above 6.6 indicate that the services are highly oriented toward conducting leprosy control actions.

The Mann-Whitney U test, Kruskal-Wallis test, and Fisher's exact test were used in the statistical analysis in order to verify the existence of an association between the study variables and the perception of primary health care quality in leprosy. A significance level of 5% and a 95% confidence level were estimated. The data were analyzed using the Statistical Package for Social Sciences for Windows version 20.0 and R Software (Project for Statistical Computing) version 3.4.0.

Ethical considerations

The present study was conducted according to the recommendations in the Brazilian National Health Council's Resolution 466/12, which addresses research involving human subjects, and was approved by the Research Ethics Committee of the Federal University of Piauí (register number 1.794.204) and the Teresina Municipal Health Foundation's Ethics Committee.

Results

Table 1 shows the socioeconomic and clinical profiles of the users we interviewed. They were mainly 50 years of age or older (60%; mean age 52.56 years, standard deviation [SD] 20.37 years, minimum of 18 years and maximum of 89 years) and predominantly male (68%), married or in a stable union (48%) with a low educational level (76.6% did not complete secondary education), and their average monthly family income was 2.04 times the minimum wage.

Table 1. Frequency distribution of the socioeconomic characteristics of patients receiving leprosy treatment in municipal health units within the urban area of Teresina, Piauí, 2017. (n=25).

Variable	n	%
Age group (years)		
18- 30	5	20
30- 40	3	12
40- 50	2	8
50- 60	4	16
60 years and over	11	44
Sex		
Male	17	68
Female	08	32
Marital status		
Single	9	36
Married/stable union	12	48
Divorced/separated	1	4
Education		
Illiterate	4	16
Incomplete basic education	11	44
Incomplete high school	4	16
Complete high school	3	12
Complete higher education	3	12
Family income (Minimum wage equivalents)		
1	8	32
2	6	24
3	3	12
4	2	16
5 and over	3	12
Social benefits (*Bolsa família*)	3	12

Variable	n	%
Operating disease class		
Paucibacillary	5	20
Multibacillary	20	80
Clinical Form of leprosy		
Undetermined	1	4
Tuberculoid	4	16
Dimorphic	14	56
Lepromatous	6	24
Leprosy reactions		
Yes	8	32
No	17	68
Leprosy reactions		
Grade 0	14	56
Grade 1	4	16
Grade 2	2	8
Not assessed	5	20
Total	25	100

Source: Interviews with users, 2017.

In terms of clinical profile, there was a high prevalence of multibacillary cases (80%) and more severe clinical presentations (24% were lepromatous and 56% were dimorphous). A significant percentage of participants had reactive episodes during treatment (32%), and 24% already had some degree of disability at diagnosis (16% grade 1 and 8% grade 2). Statistical analysis showed a significant correlation between grade 1 disability and male sex and grade 1 disability and female sex (Fisher's exact test, p = 0.014).

The professional groups we interviewed consisted of 19 nurses (55.9%) and 15 physicians (44.1%), nearly all of whom had postgraduate-level education (94.1%). The professionals had an average of 7.9 years of experience in the MHU (SD = 5.6 years, minimum = 2 months, maximum = 18 years). They had an average of 15.1 years of experience in primary healthcare (SD = 6.9 years, minimum = 2 months, maximum = 36 years); 85.3% of respondents had worked 10 years or more at this level of care. Most also had experience in LCA, with 82.3% of respondents reporting 10 or more years of experience, with an average of 14.2 years (SD = 6.4 years, minimum = 2 months, maximum = 30 years).

Table 2 presents the users' perceptions of the quality of PHC in LCA in the city of Teresina. Note that the average scores for the attributes were below 6.6 except for the following items: gateway (mean = 7.95), continuous care (mean = 8.22), integrality of available services (mean = 7.96), and coordination (mean = 8.45). As a result, the average evaluation scores were also low: essential score =

Table 2. Descriptive statistics for primary health care attributes in the perception of users with leprosy treated in municipal health units within the urban area of Teresina, Piauí, 2017.

PHC attribute users	Average	Median	SD	Min.	Max.
Degree of affiliation with primary health care	3.44	4	0.77	2	4
Degree of affiliation with primary health care in leprosy	2.84	3	0.69	2	4
Gateway	7.95	7.76	2.15	3.3	10
Access	6.15	6.25	1.63	2.36	9.1
Continued service	8.22	9.2	1.45	5.1	10
Integrality of available services	7.96	8.03	1.07	5.6	9.6
Integrality of services provided	4.93	5.06	2.6	0.5	9.46
Coordination	8.45	9.58	2.11	3.33	10
Family orientation	5.96	6.2	2.62	1.1	10
Community orientation	5.19	5	2.62	0.83	10
Essential Score	5.91	5.77	1.06	3.86	7.48
Derivative Score	5.62	6.2	1.96	1.46	9.16
Overall Score	5.82	5.74	1.24	2.01	7.32

SD: Standard deviation; **Source:** Interviews with users, 2017.

5.91, derived score = 5.62, and overall score = 5.82. These results indicate that in the users' opinions, PHC services in the urban area of Teresina are not sufficiently directed towards LCA.

Table 3 presents the perceptions of the professionals we interviewed about the quality of PHC. A divergence can be seen between the opinions of the users and the professionals, since all the mean scores from the latter group were above the cutoff point (6.6). This indicates that the professionals believe that PHC services in the urban area of Teresina are strongly oriented toward LCA.

Table 3. Descriptive statistics of primary health care attributes in the perception of health professionals who treat cases of leprosy in municipal health units within the urban area of Teresina, Piauí, 2017.

PHC attribute Health professionals	Average	Median	SD	Min.	Max.
Gateway	9.38	9.58	0.72	7.5	10
Access	7.05	7.03	0.82	5.16	8.13
Continued service	9.57	9.66	0.57	7.26	10
Integrality of available services	9.56	9.8	0.45	8.4	10
Integrality of services provided	9.68	10	0.57	7.76	10
Coordination	8.74	8.86	0.74	6.93	10
Family orientation	9.41	10	0.87	7.03	10
Community orientation	7.56	8.33	2.38	2.66	10
Professional orientation	7.37	7.76	2.01	2.2	10
Essential Score	8.99	9.04	0.34	8.1	9.54
Derivative Score	8.11	8.43	1.38	5.17	10
Overall Score	8.7	8.81	0.63	7.64	9.7

SD: Standard deviation;
Source: Interviews with health professionals, 2017.

Table 4 shows that the difference between the perceptions among both groups of the quality of PHC in treating leprosy, based on the PCATool Brasil, was significant for all items of the questionnaire, except for the coordination attribute (Mann-Whitney U test, p = 0.479).

Table 4. Comparison between mean scores for public health care attributes in evaluations by users and professionals participating in the study, 2017.

Category	Average	SD	Median	p-value
Access				
Patient	6.2	1.68	6	0.0144
Professional	7.05	0.83	7.03	
Coordination				
Patient	8.5	2.14	9.5	0.479
Professional	8.74	0.75	8.86	
Integrality of available services				
Patient	8	1.07	8	<0.001
Professional	9.56	0.46	9.8	
Integrality of services provided				
Patient	4.88	2.64	5	<0.001
Professional	9.68	0.57	10	
Family orientation				
Patient	6	2.68	6	<0.001
Professional	9.41	0.87	10	
Community orientation				
Patient	5.18	2.7	5	0.003
Professional	7.56	2.39	8.33	
Essential Score				
Patient	6.04	1.02	6	<0.001
Professional	9	0.35	9.05	
Derivative Score				
Patient	5.52	2	6	<0.001
Professional	8.11	1.39	8.43	
Overall Score				
Patient	5.88	1.24	6	<0.001
Professional	8.7	0.64	8.81	

SD: Standard deviation;
Source: Interviews with users and health professionals, 2017.

The determinants for better or poorer PCATool scores through statistical cross-over between the study variables were analyzed to verify that the variables were independent **(Table 5)**. To do so, a statistical significance test was performed between the following groups compared to the PCATool scores: sex, marital status, income, age group, reactional episodes, operational leprosy classification, clinical form, and degree of disability in diagnosis.

We found that individuals with higher incomes (above 1 minimum wage) generally assigned poorer scores to the PHC attributes in LCA in the MHU surveyed; however, the only statistically significant correlation was with the community orientation attribute (Mann-Whitney U test, p = 0.044).

Table 5. Comparison between socioeconomic and clinical variables for users and primary health care attribute evaluation, test applied, and statistical significance, 2017.

Compared groups	Statistical test	p-value
PCATool scores and sex	a: Mann-Whitney U Test	>0.05
PCATool scores and marital status	a: Kruskal-Wallis Test	>0.05
PCATool scores and income	a: Mann-Whitney U Test	0.044
PCATool scores and age group		>0.05
PCATool scores and leprosy reactions		>0.05
PCATool scores and operating disease class		>0.05
PCATool scores and clinical form of leprosy	a: Kruskal-Wallis Test	>0.05
PCATool scores and degree of physical disability at diagnosis		>0.05

Source: Interviews with users, 2017.

Discussion

Socioeconomic and clinical characteristics of study participants

Like the socioeconomic profile observed in this study, other authors of studies conducted in the state of Piauí found that leprosy cases were predominantly men with low levels of schooling, with at most middle school complete [10-11].

One study conducted in the city of Belém, Pará, which investigated sensory and physical limitations resulting from leprosy, also found that most patients were men (64.3%), married (52.4%), age 31-40 years (26.2%), with incomplete middle school (50%), and were independent laborers (36.9%) [12].

Although leprosy is more common in adults below 60 years of age, the predominance of cases in patients older than age 60 in this study (44%) was significant. We believe that this high prevalence can be explained by the expansion of the older population in Brazil, especially in the capital cities, and by the decrease in immunity in this age group, which increases susceptibility to infections [13]. It is important to note that the distribution of leprosy among the regions of Brazil is heterogeneous; the Northeast has long had higher rates of detection in the general population and in older adults [14].

In terms of clinical profile, studies in different regions of Brazil have also shown high proportions of multibacillary cases and more severe clinical forms of leprosy, as well as degrees I and II of physical disability at the time of diagnosis [15-16] This shows that the transmission dynamics of leprosy have remained in the evaluated areas, and also signals the occurrence of late diagnosis.

We found that the professionals we interviewed have extensive experience in PHC and generally utilize good follow-up behaviors in patients with leprosy. However, they still focus on medicalization rather than developing preventive activities such as routine periodic neurological evaluation or guideli-

nes on self-care, which can significantly impact the onset of disability and quality of life in these patients. Professionals in PHC must be more vigilant with regard to leprosy, reinforcing active search and health education in the community.

These professionals should encourage and value patient visits to the health unit to receive supervised doses of multidrug therapy, taking advantage of these visits to also include consultations for early identification of reactional states, side effects or adverse effects of the medications being used, development of physical disabilities, and onset of neural damage, as well as to promote health education [17].

Changes in human resources training in the health area, specifically for the family health strategy, are fundamental because the new assistance model requires a professional stance based on production of care and new work in health, with attitudes that extend beyond medicalization [18].

Perception of users and professionals with regard to the quality of PHC in treating leprosy

User evaluations of the attributes of PHC were general unsatisfactory **(Table 2)**. We should emphasize that several aspects were cited as difficulties and had a negative impact on the essential, derived, and overall scores, such as access, integrality of services provided, family orientation, and community orientation.

A study on the evaluation of PHC in elderly care made similar observations to those in this present study, with that the participants attributing scores below the 6.6 point cutoff for quality of services (5.7). While longitudinality of care was seen positively (7.3), the older adult patients in this study were critical in their assessments of integrality (4.7), family orientation (4.1), and accessibility (3.8) [19].

A worldwide systematic review that analyzed studies on performance evaluation of PHC services using the PCATool instrument from the user perspective found that the most positive evaluations were given for access of first contact/sub-item utilization, and longitudinality, while the worst evaluations were given for first contact access/sub-item accessibility, family orientation, community orientation, and integrality [20].

In this present study, the user complaints regarding access involved the fact that the MHU is not open any day of the week after 6 pm, transportation difficulties, and waiting time in the unit exceeding 30 minutes for the supervised dose. As for the integrality of the services provided, many users stated that important items in the dermato-neurological evaluation (sensitivity test, motor force evaluation, visual acuity assessment) are not routinely performed by the MHU professionals, and that contact examination and guidelines on self-care involving eyes, hands and feet were similarly neglected.

With regard to family orientation, some users stated that MHU professionals do not usually make home visits, and do not ask for information about illnesses among other family members or talk to family members about leprosy, self-care, or the possibility of leprosy reactions. And with regard to the community orientation attribute, users also indicated weaknesses such as a lack of information about leprosy in the media, absence of educational activities related to leprosy conducted by MHU professionals and active search activities for cases in the community.

Health education work for the community is essential to boost integration of leprosy care in PHC [21]. Studies suggest that a strategy for strengthening attributes such as family orientation could combine oral and written guidance with telephone follow-up [22-23].

The findings among the users show a number of gaps to be filled with regard to both the dynamics of MHU operations and conduct by the medical professionals. As a result, greater attention must be given to the difficulties faced by patients with leprosy, prioritizing their care in the health units.

In contrast, the perceptions of the professionals interviewed about PHC performance in LCA in the city of Teresina were positive, with satisfactory scores attributed for all attributes. We should stress, however, that although the professionals did not attribute negative scores, some questions regarding access, community orientation, and professional orientation deserve special attention since they received the lowest scores in this group.

Like the users, in the area of access many professionals also listed weaknesses including the fact that the MHU is not open after 6 p.m. any day during the week, the difficulties users face in getting to the MHU without having to miss work or other commitments, and waiting times exceeding 30 minutes for consultations with the health professional.

In the area of community orientation, some professionals pointed out that they generally do not analyze epidemiological data on leprosy for disease control activities and that they carry out few educational activities to inform the community about leprosy. For the professional orientation attribute, some professionals reported that they do not consider themselves fully qualified to care for cases of leprosy and that few trainings on this disease are available for PHC professionals.

Studies conducted in different Brazilian states using the PCATool as an instrument to evaluate PHC have concluded that a clear difference exists between evaluations by users and professionals, with users generally having a less positive opinion [24-25].

One study conducted in the state of Minas Gerais concluded that the performance quality in PHC reported by the professionals is not perceived or valued by users, and the authors concluded that actions and services may be inadequately conducted or to a degree which is insufficient for users to capture [26]. As a result, we conclude that health services must be strongly oriented by the attributes of PHC to reach high levels of user satisfaction.

Some researchers have indicated the lack of human and material resources and equipment as a major limit to the work of the health team, which in turn impacts user satisfaction with the services offered [27] Correspondingly MHU with wider material and human support, such monofilament kits, the BCG vaccine, and teams performing directly observed treatment as well as educational actions on leprosy, are more attractive to users and may have a better chance of diagnosing new cases of leprosy and performing recommended procedures.

Although this present study found that the professionals in the MHU are experienced and generally show adequate conduct for the work they carry out in PHC and LCA, we perceived that not all actions are being put into practice. This is due to either structural deficiencies or lack of inputs in PHC, or high levels of patient demand in routine care; the latter scenario does not allow time to conduct a complete physical evaluation and examination, orientation, or preventive educational activities.

Correlation between the main variables of the study and the highest and lowest scores from the PCATool

The results of this study showed that the evaluation of PHC quality in LCA generally did not depend on clinical or socioeconomic variables; in other words, user perception was not influenced by aspects related to the person affected or the severity of the disease, but rather by the organization/provision of services. This fact reinforces that the Instrument for Assessment of the Performance of Primary Health Care in Leprosy Control Actions used in this study is well-suited for this use.

Other studies did not find significant correlations between PCATool attribute scores and socioeconomic or clinical variables, although some have suggested that people with lower education levels and in lower social classes usually attribute better scores to attributes [28].

In the present study, individuals with higher incomes (exceeding 1 minimum wage equivalent) also assigned lower scores to the PHC attributes in LCA. However, the only statistically significant correlation was found with the community orientation attribute **(Table 5)**, which concerns educational activities and community awareness of leprosy, as well as active search for cases. This may be explained by the fact that people with higher incomes may be more demanding and consequently assess the quality of services offered in a more rigorous manner.

A study carried out in the city of Macaíba, Rio Grande do Norte, found that socio-demographic factors related to the vulnerability of older people such as lower income, rural area, and older age, were positively associated with different attributes of PHC. Older adults with lower incomes gave more positive evaluations for first contact access ($p = 0.019$) and coordination of care ($p = 0.034$) [19].

The strengthening of the community orientation attribute is highlighted by different authors, who argue that educational activities carried out by health professionals should become routine in a basic service, especially in endemic municipalities, to disseminate appropriate information and sustain the population's knowledge about leprosy [9, 21].

Conclusion

The findings of this present study clearly show the need to bring professionals and the community closer together, understanding that hearing the population's opinion about its real needs is extremely important for promoting improvements in the quality of services, and that these need to be more strongly guided by PHC attributes to achieve higher levels of user satisfaction. We also emphasize the importance of greater incentives for the structural improvement of MHU and the valorization and qualification of health professionals.

This study presents some limitations resulting from the small sample size in comparison with the total number of patients and professionals who interact routinely in the Teresina municipal health system. Nevertheless, we believe that careful analysis of the data may be an important tool for stimulating new studies and as a foundation for managers who plan leprosy control and surveillance strategies which are appropriate for the reality in the endemic area.

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