

# Reception of Patients with Leishmaniasis in Primary Health Care in the Federal District

Acolhimento de Pacientes com Leishmaniose na Atenção Primária à Saúde no Distrito Federal  
Acogida de Pacientes con Leishmaniasis en la Atención Primaria de Salud en el Distrito Federal

## RESUMO

**Objetivo:** Analisar possíveis falhas de encaminhamento de pacientes em tratamento para leishmaniose da Atenção Primária à Saúde (APS) para o Hospital Universitário de Brasília (HUB), no Distrito Federal. **Métodos:** Estudo descritivo com 40 pacientes atendidos no HUB. Os sujeitos responderam dois questionários: um sobre aspectos sociodemográficos e percepção do atendimento na APS, e outro foi o Primary Care Assessment Tool (PCATool) na versão reduzida usuário-adulto. Os dados foram analisados de forma descritiva. **Resultados:** A maioria dos participantes era do sexo masculino, pardos e com baixa escolaridade. O escore geral da APS, calculado pela média das respostas, não ultrapassou 6,6, revelando que as necessidades dos usuários não foram plenamente atendidas. As principais falhas identificadas ocorreram na comunicação entre profissionais e pacientes. **Conclusão:** O fortalecimento do fluxo de atendimento aos pacientes com leishmaniose pode reduzir a sobrecarga hospitalar e melhorar a adesão ao tratamento. Campanhas educativas podem contribuir para diminuir a transmissão e o atraso na busca por cuidados.

**DESCRIPTORIOS:** Serviços de Saúde. Atenção Primária à Saúde. Necessidades e Demandas de Serviços de Saúde. Leishmaniose.

## ABSTRACT

**Objective:** To analyze possible flaws in the referral of patients under treatment for leishmaniasis from primary health care (PHC) to the University Hospital of Brasília (HUB) in the Federal District. **Methods:** Descriptive study with 40 patients treated at HUB. Participants answered two questionnaires: one on sociodemographic aspects and their perception of PHC services, and the other was the reduced adult-user version of the Primary Care Assessment Tool (PCATool), validated in Brazil. Data were descriptively analyzed from the users' perspective. **Results:** Most participants were men, brown-skinned, with low schooling. The overall PHC score did not exceed 6.6, showing that patients' demands were not fully met. Gaps were mainly identified in communication between patients and health professionals. **Conclusion:** Strengthening PHC referral flow is essential to reduce hospital overload and improve treatment adherence. Health education campaigns could reduce transmission and delays in seeking care.

**DESCRIPTORS:** Health Services. Primary Health Care. Health Services Needs and Demands. Leishmaniasis.

## RESUMEN

**Objetivo:** Analizar posibles fallas en la derivación de pacientes en tratamiento de leishmaniasis desde la atención primaria de salud (APS) hacia el Hospital Universitario de Brasília (HUB), en el Distrito Federal. **Métodos:** Estudio descriptivo con 40 pacientes atendidos en el HUB. Los participantes respondieron dos cuestionarios: uno sobre aspectos sociodemográficos y percepción del servicio recibido en la APS, y otro fue la versión reducida del Primary Care Assessment Tool (PCATool) validada para adultos. Los datos fueron analizados de manera descriptiva según la perspectiva de los usuarios. **Resultados:** La mayoría eran hombres, pardos, con baja escolaridad. El puntaje global de APS no superó 6,6, indicando que las demandas de los pacientes no fueron plenamente atendidas, principalmente por fallas en la comunicación. **Conclusión:** El flujo de acogida de pacientes con leishmaniasis en el SUS debe fortalecerse para reducir la sobrecarga hospitalaria y mejorar la adherencia al tratamiento. Campañas educativas podrían disminuir la transmisión y el retraso en la búsqueda de atención.

**DESCRIPTORIOS:** Servicios de Salud. Atención Primaria de Salud. Necesidades y Demandas de Servicios de Salud. Leishmaniasis.

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## INTRODUCTION

Primary care for patients and the role of health professionals involved in their treatment have evolved significantly in recent years and should be available to the entire population, promoting health and well-being<sup>1</sup>. The Health Care Network (RAS) comprises a complete cycle of care ranging from primary to secondary and tertiary care. Understanding the importance of Primary Health Care (PHC) within the RAS contributes to the smooth running of the health system and, above all, to better patient care and treatment.

PHC is the gateway and the first level of patient care in the Unified Health System (SUS). There are pre-established flows according to the guidelines of the Ministry of Health or other bodies linked to management, and their adherence or non-adherence will result in successes or errors in patient care. Continuous and comprehensive accountability and the role of the multidisciplinary health team will result not only in economic gains but also in health gains with a major impact on public health<sup>2-5</sup>.

In this context, guidelines on the care of patients with leishmaniasis come into play. Leishmaniasis continues to be considered by the World Health Organization (WHO) as a neglected tropi-

cal disease that is growing mainly in underdeveloped and developing countries. This is mainly due to the relationship between the disease and poverty and lack of education<sup>6,7</sup>. Approximately 95% of cases reported in the Americas occur in Brazil, which is an alarming figure. From 2010 to 2022, Brazil reported 293,842 cases of leishmaniasis, 85.5% of which were tegumentary leishmaniasis (TL) and 14.5% visceral leishmaniasis (VL). Of this total, 39,942 cases (13.6%) were reported in the Midwest region. During the same period, the Federal District reported 1,153 cases of leishmaniasis, most of which were TL (60%)<sup>8</sup>. In order to adequately combat leishmaniasis, it is essential to constantly update health professionals, especially those in primary health care, so that they can identify suspected cases early on, in order to diagnose and treat them more quickly<sup>9,10</sup> and consequently improve patient well-being.

Basic Health Units (BHUs) would be strong allies in government initiatives to combat critical infectious and parasitic diseases in Brazil, such as leishmaniasis. Health workers could work with the most vulnerable populations to disseminate information about the cycle of contamination and methods of prevention. The population must be aware of the importance of seeking diagnosis and/or treatment in suspected

cases. Many studies report that poverty, low education, and lack of information are risk factors for leishmaniasis<sup>11-13</sup>.

The Federal District Health Secretariat (SES-DF) has a defined workflow<sup>14</sup> to facilitate the reception and provide adequate treatment to patients with suspected and/or diagnosed leishmaniasis. However, it is often not followed, either due to lack of knowledge or overload in the health system. Therefore, the objective of this study is to evaluate the main problems, from the users' perspective, in PHC using a questionnaire already validated by the Ministry of Health. In addition, it aims to point out solutions to reduce the transmission of leishmaniasis in socially vulnerable areas and improve the relationship between patients and health workers at the UBS in the Federal District.

## METHODS

### Design, Study Setting, and Recruitment

This is a descriptive cross-sectional study. Patients over 18 years of age diagnosed with and/or undergoing treatment for leishmaniasis, in addition to suspected cases, were included in the study. Subjects must have visited the UBS at least once during the period from January to June 2024. Patients under 18 years of age or who refused

to sign the informed consent form were excluded.

The research protocol was submitted to the Ethics Committee of the Faculty of Medicine of the University of Brasília on February 11, 2023, and approved on November 1, 2023, with CAAE: 68059123.2.0000.5558. The study was conducted at the dermatology outpatient clinic of the University Hospital of Brasília (HUB), a federal public institution that provides free care through the SUS. The HUB is a reference in the diagnosis and treatment of leishmaniasis and receives patients referred by the SES-DF (SIS-REGIII) regulation system.

## Instruments

Participants answered two self-administered questionnaires. The first questionnaire was structured with questions on sociodemographic aspects and the user's perception of the care provided by primary care health professionals. The choice to develop a structured questionnaire was to ensure the anonymity of participants, and pre-established objective questions provide standardization and easy interpretation. The second instrument applied was the *Primary Care Assessment Tool* (PCATool) in the reduced adult user version. This form was validated in Brazil in the early 2000s, with the objective of evaluating PHC services from the user's perspective. It evaluates the first contact and accessibility to the UBS, the continuity of consultations, the coordination of care within the multidisciplinary team, and access to information<sup>15,16</sup>. Each of these aspects is evaluated through blocks of questions that result in an overall score, indicating the quality of PHC. The instrument has been adopted by more than 20 countries, thus enabling comparisons to be made<sup>15</sup>. Responses are on a Likert scale, with "definitely yes" (value = 4), "probably yes" (value = 3), "probably no" (value = 2), "definitely no" (value = 1), and "don't know/can't remember" (value =

9). Responses marked "don't know/can't remember" were considered "probably no."

## Data analysis

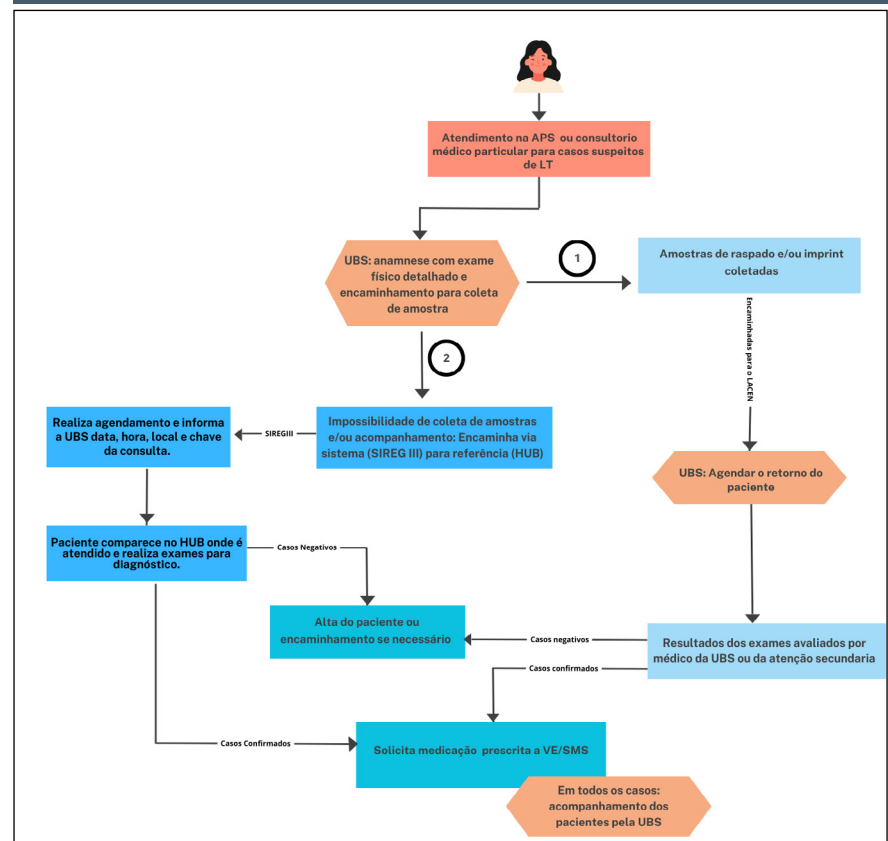
The Essential Score (ES) was obtained by averaging the essential attributes (access, longitudinality, coordination, and comprehensiveness), the Derived Score (DS) by averaging the derived attributes (family orientation and community orientation), and the General PHC Score by the average value of the two previous attributes. The results were dichotomized into two categories, representing Low Score (< 6.6) and High Score ( $\geq 6.6$ ). The information was manipulated in an Excel spreadsheet.

## RESULTS

### Sociodemographic and occupational characteristics

Participants diagnosed with and/or suspected of having leishmaniasis who were referred to the University Hospital of Brasília via SIREGIII were included in the study. Only one patient was suspected of having visceral leishmaniasis. There is a flow of reception and referral of patients with leishmaniasis who arrive at PHC (Figure 1). Patients are referred to the HUB if there is any problem with the diagnosis or if VL is suspected. In the routine flow, most patients should be followed up directly via the UBS.

**Figure 1: Flow of patients suspected of having leishmaniasis entering and leaving the Federal District. APS: Primary Health Care; LT: Tegumentary Leishmania; UBS: Basic Health Unit; LACEN: Central Health Laboratory; VE/SMS: Epidemiological Surveillance/Health Department**



The sociodemographic characteristics of the sample (n=40) are presented in Table 1. Most patients were men (n=23) with low levels of educa-

tion and brown skin, aged between 24 and 70 years. Among women (n=17), the average age was 51.58 years. According to the data obtained, most of

the interviewees did not have completed high school (n=33) and 37.5% had not even completed elementary school, with 5 being illiterate.

**Tabela 1 - Variáveis descritivas e sociodemográficas dos pacientes que aceitaram participar do estudo.**

Sociodemographic characteristics	Total	Women (%)	Men (%)
Total patients	40 (100)	17 (42,5)	23 (57,5)
Age	18-80	18-80	24-70
Education			
Illiterate	5 (12,5)	3 (7,5)	2 (5)
Incomplete elementary education	10 (25)	6 (15)	4 (10)
Complete elementary education	9 (22,5)	4 (10)	5 (12,5)
Incomplete secondary education	6 (15)	2 (5)	4 (10)
Complete secondary education	7 (17,5)	2 (5)	5 (12,5)
Higher	3 (7,5)	0	3 (7,5)
Skin color (Self-reported)			
Yellow	1 (2,5)	0	1 (2,5)
Brown	24 (60)	11 (27,5)	13 (32,5)
Indigenous	1 (2,5)	0	1 (2,5)
White	9 (22,5)	4 (10)	5 (12,5)
Black	5 (12,5)	2 (5)	3 (7,5)
Regional Health Authorities in the Federal District			
Center-South	1 (2,5)	1 (2,5)	0
North	8 (20)	3 (7,5)	5 (12,5)
South	4 (10)	1 (2,5)	2 (5)
East	3 (7,5)	2 (5)	1 (2,5)
West	4 (10)	2 (5)	2 (5)
Southwest	10 (25)	5 (12,5)	5 (12,5)
Central	3 (7,5)	1 (2,5)	2 (5)
Surroundings	3 (7,5)	2 (5)	1 (2,5)
Other states	4 (10)	0	4 (10)

The Federal District is divided into seven health regions, and 42.5% of patients were referred from the north and southwest regions, while 17.5% came from surrounding cities or other states. Only three patients (7.5%) came from the central region, considered to have the highest per capita income. Regarding the par-

ticipants' work activities, 13 are retired (32.5%), and 8 are unemployed (20%). Among women, 29.4% declared themselves to be housewives. The other activities declared were: aircraft pilot, merchant, carpenter, young apprentice, lawyer, administrator, cashier, logistics analyst, advertising executive, and civil servant.

### Users' perceptions of PHC care

Eight questions were asked to assess patient reception and perception of care at the UBS (Figure 2). The answers were yes or no, and what stood out was that the return to PHC, which should occur after care at the HR, is not happening. Of the 40 participants, 28 said they did not return

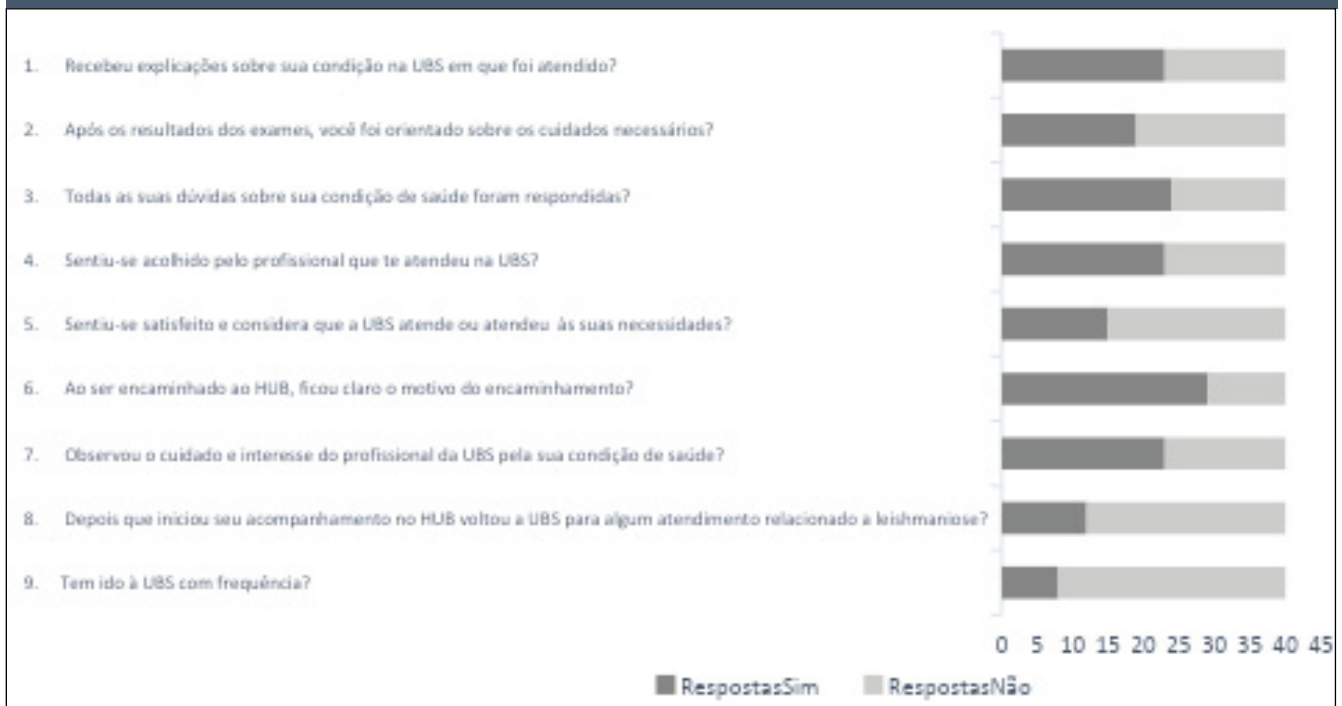
to their original UBS to continue the follow-up stages. The answers to the first three questions, about guidance and care for patients with leishmaniasis, show that there was no consensus, since half of the patients felt satisfied with the explanations before and after diagnosis, and the other half were not satisfied.

The answers to questions 4 (*"Did you feel welcomed by the professional*

*who attended you at the UBS?"*) and 5 (*"Did you feel satisfied and consider that the UBS fully meets or met your needs?"*) also show that the welcome to the service needs to be improved. People who arrive at the health service with infectious and parasitic diseases are usually in a vulnerable state and need to feel secure about their condition. Our study shows that this was not the case for half of the patients

seen. The sixth question, *"When you were referred to the University Hospital of Brasília (HUB), was the reason for the referral explained to you?"* was answered favorably by more than 70%, but 17 patients did not observe care and interest from the UBS professional regarding their health condition (question 7).

Figure 2: Users' responses about their perspectives on the care provided by health professionals.



### Evaluation of scores obtained in PCATool-Brazil

The PCATool adult user version questionnaire had not yet been applied to patients with leishmaniasis in Brazil. The data obtained with the assessment tool generated a PHC score for each participant. This score was calculated by averaging the responses to all items on the form. A high score indicates that most of the patients' needs were met, reflecting more PHC-oriented services. A score below 6.6 shows that the demands of users with leishmaniasis were not met

<sup>15</sup>. According to the results obtained, none of the questionnaires answered by the participants achieved a score classified as high performance, which characterizes low utilization of the components related to primary health care attributes.

For respondents who left 50% or more of the items blank, no score was calculated, and they were considered *missing*. The score ranged from 2.34 to 5.04 (Table 2), with the lowest score given by patients who came from the Sobradinho and Ceilândia RAs. The Planaltina RA received the

highest score from one of the users. The variations found in the scores within the same region occur because there is more than one UBS per RA, in addition to the fact that this study is based solely on user perception. This is a limitation of the study; it would be interesting to apply the PCATool health agent version for comparison purposes.

**Table 2: Average PCATool scores obtained for each referral health region.**

	CS	C	L	S	O	N	SE	E	OE
	-	3,08	2,65	2,52	2,34	2,34	2,52	2,73	2,73
		3,17	2,95	2,65	2,34	2,56	2,52	3,17	3,73
		-	3,65	2,91	2,69	2,69	2,65	4,04	3,86
				3,04	4,00	2,73	2,78		3,86
						3,08	2,78		
						3,17	2,91		
						5,04	2,91		
						-	3,17		
							3,73		
Average		3,125	2,95	2,78	2,515	2,73	2,78	3,17	3,79
Standard Deviation		0,045	0,41	0,20	0,683	0,840	0,355	0,54	0,47
Patients		3	3	8	4	9	4	3	4

CS: Center-South; C: Center; L: East; S: South; W: West; N: North; SW: Southwest; E: Surrounding area; OE: Other states; -: Missing

Each attribute was evaluated individually (Table 3), and the average scores show that the main complaint occurs

in the area of community orientation (J). The component “First contact access (B)” had the highest average score of 2.70. It can be seen that the main problems that led to low scores were, in

addition to Community Orientation, Degree of affiliation (A) and Care Integration (E), with averages of 1.85 and 1.93, respectively.

**Table 3: Mean and standard deviation of individualized scores for each PHC attribute obtained by the PCATool questionnaire**

Scores	Mean	Standard Deviation
Essential Score	2,29	0,41
Overall Score	2,23	0,41
Attributes		-
Degree of Affiliation (A)	1,85	1,144
First contact access (B)	2,70	0,72
First contact access – accessibility (C)	2,35	0,64
Longitudinality (D)	2,51	0,56
Coordination – integration of care (E)	1,93	1,52
Coordination – information system (F)	2,2	0,51
Comprehensiveness - available services (G)	2,30	0,63
Comprehensiveness - services provided (H)	2,50	0,68
Derivative		3
Family Guidance (I)	2,21	0,62
Community orientation (J)	1,80	0,64

## DISCUSSION

Leishmaniasis is endemic in 98 countries worldwide, affecting people living in poor areas of developing countries and placing additional stress on families already living in precarious conditions. Poor housing conditions, lack of basic sanitation, and low levels of education increase the risk of transmission. These factors favor the life cycle of sand flies and, consequently, the transmission of the parasite.

The sociodemographic data of the study subjects corroborate those found in the literature, with the majority being men of reproductive age<sup>17-19</sup>. One aspect pointed out by the participants that needs to be addressed is access to information about leishmaniasis. Due to their low level of education, they probably have little knowledge of how the disease is transmitted or where to seek treatment<sup>20</sup>. Patients responded that they did not receive information about the disease or that it was insufficient. Access to information can be a key factor in early diagnosis and treatment initiation. It is necessary for the UBS to carry out educational campaigns informing the population about the presence of the "straw mosquito" in forests or waterfalls, especially in places where leishmaniasis is endemic. This role, as a disseminator of knowledge, should be performed by health professionals in campaigns developed by the government<sup>20</sup>. However, the questionnaires revealed that most patients were not informed about the disease. In a survey conducted in an endemic area in the state of Maranhão, 76% of the 106 people interviewed, aged between 18 and 76, reported that Community Health Agents (ACS) never mentioned anything about leishmaniasis. Regarding the mode of transmission of the disease, 85 of the interviewees were unaware of how VL is contracted and 80 were unaware of the main symptoms<sup>21</sup>. The lack of information is also ob-

served during referral to the HR, since most patients report communication problems at that time. When referred via SIREGIII without proper clarification, many patients may abandon treatment, since the distance to the referral center is long and the public transportation system in the Federal District does not function well.

The PCATool was applied in the Federal District in 2015 to assess comprehensive child care and, as in our study conducted now in 2024, obtained scores below 6.6 in all attributes<sup>22</sup>. A study comparing the correlation of the reduced and complete versions of the PCATool observed that the scores are positively correlated, indicating that the reduced version of the instrument can be used to reliably assess PHC services<sup>23</sup>. Some limitations in our study should be taken into account when interpreting the results. Although the number of participants was reached (n= 40), it is still not a representative sample to assess the extent of care for individuals with leishmaniasis in primary care in the Federal District. Studies with a larger number of participants are needed to analyze care at this level of care.

The results shown in this study demonstrate the lack of importance given to the Federal District's public primary care services in relation to PHC attributes from the perspective of leishmaniasis users. Unfortunately, this problem is recurrent and has been described in other studies evaluating the user's view of PHC<sup>24-26</sup>. What we have noticed is that even with some improvements, 14 years after the launch of PCATool by the Ministry of Health, it has not yet been possible to correct some of the problems repeatedly pointed out by users of the system.

The mean EG and EE for PHC were low (EG=2.23 ± 0.41 and EE 2.29 ± 0.41). The lowest scores were from patients referred from the North, West, South, and Southwest regions.

One study showed a positive correlation between training health agents and better reception of the population with leishmaniasis treated<sup>20</sup>. This type of intervention should be carried out periodically with health professionals, with the aim of benefiting both sides. Among the regional health centers, homogeneity was observed in the evaluation of the overall Primary Health Care score and each of its individual attributes. The Central-South Region (EG 1.60 ± 0.79) had the lowest score, followed by the West Region (EG 1.85 ± 0.78). However, there is a bias here, since only one patient was referred from the Central-South Regional Health Center. The regions with the highest overall scores were Central (EG 2.45±0.55), followed by the East Region (EG 2.35±0.85).

Our results differed from those of the systematic review of the literature between 2007 and 2015, which evaluated the performance of PHC services using the PCATool instrument from the user's perspective<sup>25</sup>. In this study, the best-rated attribute was First Contact Access (B) and the worst were Affiliation (A), Care Integration, and Community Orientation. These results suggest that, although people use PHC, there are barriers to accessibility to services. Access does not only mean the user's entry into the health system or the availability of services and resources at a given time and place, but rather the fit between the needs of the population and those who provide the service.

The attribute that measures the relationship between patient and health professional, longitudinality, considered one of the most important attributes, received an average score of 2.51 ± 0.56. This attribute is a central and unique feature of PHC. A greater extent of longitudinality tends to produce greater diagnostic and therapeutic accuracy, reducing the number of unnecessary referrals, the performance of more complex procedures, and,

consequently, lower costs for public health<sup>27</sup>.

The other attributes, coordination of care, integration of care, and information system, obtained low scores. The attribute "Coordination-Information System" did not reach the statistical cutoff point in the publication of the manual, but was retained because of its conceptual importance. In our study, it was the question that more than half of the respondents did not remember. It is worth noting that patients with leishmaniasis, like all others, would benefit from actions to integrate the information system.

Regarding the comprehensiveness of care, both the available services (GE  $2.3 \pm 0.63$ ) and the services provided (GE  $2.5 \pm 0.68$ ) obtained low scores. The low score for comprehensiveness indicates that users did not feel fully served within PHC. The four aspects of this attribute are: promotion and prevention actions, care at the three levels of the RAS, coordination of promotion, protection, and prevention actions, and a comprehensive approach to individuals and families<sup>28</sup>. Finally, as seen in other

studies, the scores for family orientation (LO  $2.21 \pm 0.62$ ) and community orientation (LO  $1.8 \pm 0.64$ ) obtained a low overall PHC score<sup>24,29</sup>. This is evidence of the difficulty health professionals have in understanding the functioning and dynamics within families and recognizing the real needs of users.

Primary care plays a crucial role in the care of patients with leishmaniasis, and early identification of leishmaniasis is essential for effective treatment. Health professionals must be attentive to the signs and symptoms of the disease and perform appropriate diagnostic tests, initiate treatment or refer patients to a referral hospital, advise patients on care and transmission of the disease, and, above all, play their role in coordinating the care of patients with leishmaniasis. Therefore, the results of this research serve to initiate a broad discussion about the care provided by each member of the UBS team in caring for patients with leishmaniasis, raising awareness among these professionals regarding the deepening of knowledge about the disease, its form of transmission and

treatment, the responsibility to pass on information to the family and the patient, as well as guiding them to another level of care in an assertive manner, in addition to reinforcing guidelines for patient reception.

In conclusion, the authors believe that establishing strategies for horizontal cooperation between teams and health managers, institutional support for planning, and the periodic monitoring and evaluation of the presence and extent of PHC attributes can contribute to the reformulation and development of the quality of Primary Health Care in Brazilian municipalities. Other points to be raised at the end of this study were that the lack of information for users, referrals without proper reception by the health team, and lack of explanation of the treatment flow can have a negative impact, causing most patients not to return to the UBS. All these problems, together with the high demand from patients who arrive in an advanced stage of leishmaniasis, will result in a longer delay in diagnosis and appropriate treatment for each case.

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