

QUALITY OF LIFE IN PEOPLE WITH CUTANEOUS LEISHMANIASIS

Qualidade de vida em pessoas com leishmaniose cutânea

Calidad de vida de personas con leishmaniasis cutánea

Original Article

ABSTRACT

Objective: To assess the quality of life (QoL) of people with cutaneous leishmaniasis. **Methods:** Descriptive cross-sectional study conducted in Brasília, Distrito Federal, Brazil in 2013 with 44 patients with cutaneous leishmaniasis using sociodemographic and clinical questionnaires and the WHOQOL-bref. Data underwent descriptive analyses of frequency, central tendency and dispersion, and inferential analysis of comparison between domains. **Results:** Participants were mostly women (n=24; 54.5%), with a mean age of 51.8 years, married (n=23; 52.3%), had incomplete primary education (n=22; 50%), homemakers (n=11; 25%), and were from Distrito Federal (n=30; 68.2%). A total of 27 (61.4%) participants did not have any complaints; however, 10 (22.7%) complained of wounds and 6 (13.6%) complained of pain. The QoL of 36 (81.82%) participants was rated as positive, 30 (68.18%) were satisfied with their own health, better scores were found in the social relationships domain, in which personal relationships, social support and sexual activity facets had a median of 4. The lowest scores were obtained in the environmental domain, particularly in transport, financial resources and leisure activity facets, with a median of 3. **Conclusion:** Satisfaction in the social relationships domain represented a strategy for coping with the disease and had a positive effect on the QoL of interviewees.

Descriptors: Quality of life; Cutaneous Leishmaniasis; Adult.

RESUMO

Objetivo: Avaliar a qualidade de vida (QV) de pessoas com leishmaniose cutânea. **Métodos:** Estudo observacional transversal e descritivo realizado em Brasília, DF, Brasil em 2013 com 44 pacientes portadores de leishmaniose cutânea, por meio da aplicação de um questionário sociodemográfico e clínico e do WHOQOL-bref. Os dados sofreram análises descritivas de frequência, tendência central e dispersão e análise inferencial de comparação entre domínios. **Resultados:** Os participantes eram em sua maioria do sexo feminino (n=24; 54,5%), com idade média de 51,80, casados (n=23; 52,3%), com primeiro grau incompleto (n=22; 50%), do lar (n=11; 25%) e procedentes do Distrito Federal (n=30; 68,2%). Um total de 27 (61,4%) não possuíam queixas, embora 10 (22,7%) queixaram-se das feridas e 6 (13,6%) de dor. A QV de 36 (81,82%) foi positiva, 30 (68,18%) satisfeitos com a própria saúde, melhores escores observados no domínio relações sociais cujas facetas relações pessoais, apoio social e vida sexual obtiveram mediana 4. Os escores mais baixos foram obtidos no domínio meio ambiente, nas facetas transporte, recursos financeiros e atividade de lazer, com mediana 3. **Conclusão:** A satisfação no domínio relações sociais representou uma estratégia para o enfrentamento da doença, contribuindo positivamente para a QV dos entrevistados.

Descritores: Qualidade de Vida; Leishmaniose Cutânea; Adulto.

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RESUMEN

Objetivo: Valorar la calidad de vida (CV) de personas con leishmaniasis cutánea. **Métodos:** Estudio observacional, transversal y descriptivo realizado en Brasilia, DF, Brasil en 2013 con 44 pacientes portadores de leishmaniasis cutánea a través de la aplicación de un cuestionario socio demográfico y clínico y del WHOQOL-bref. Fueron realizados análisis descriptivos de frecuencia, tendencia central y dispersión y análisis inferencial para comparación de los dominios. **Resultados:** Los participantes eran en su mayoría del sexo femenino (n=24; 54,5%) con media de edad de 51,80 años, casados (n=23; 52,3%), con educación primaria incompleta (n=22; 50%), ama de casa (n=11; 25%) y procedentes del Distrito Federal (n=30; 68,2%). Veinte y siete (61,4%) no presentaban quejas aunque 10 (22,7%) se quejaban de las heridas y 6 (13,6%) del dolor. La CV de 36 participantes (81,82%) fue positiva, 30 (68,18%) estaban satisfechos con su propia salud y las mejores puntuaciones fueron observadas en el dominio de relaciones sociales cuyos aspectos de relaciones personales, de apoyo social y de vida sexual presentaron la mediana 4. Las puntuaciones más bajas fueron para los dominios de medio ambiente en los aspectos de transporte, recursos financieros y actividades de ocio con mediana 3. **Conclusión:** La satisfacción en el dominio relaciones sociales representó una estrategia de afrontamiento de la enfermedad contribuyendo positivamente para la CV de los entrevistados.

Descriptor: Calidad de Vida; Leishmaniasis Cutánea; Adulto.

INTRODUCTION

The leishmaniasis are tropical diseases of complex epidemiology and ecology and constitute a major public health problem. Approximately 1 to 1.2 million cases of its cutaneous form are estimated each year worldwide. Despite its high morbidity, mortality data are scarce and are generally related to hospital admissions⁽¹⁾.

Its incidence is particularly important in Latin America and Brazil is the country with the highest number of new cases, which occur in its regions, particularly in the North, Northeast and Central West⁽²⁾. Due to lack of efficient environmental sanitation, with deforestation on the rise, the disease has spread throughout Brazil⁽³⁾. In the Federal District, its occurrence relates to the building of houses near the woods and/or people's exposure in protected forest areas intended for leisure or occupational activities⁽⁴⁾.

Cutaneous Leishmaniasis (CL) is characterized by single or multiple skin lesions of several clinical spectra that will depend not only on genetic factors and immune response, but also on the Leishmania species involved⁽⁵⁾. Mucocutaneous lesions, even after healing, tend to leave atrophic and depressed scars with smooth surfaces, areas

of hypo or hyperpigmentation and fibrous traces, and may sometimes become hypertrophic⁽⁵⁾. Therefore, leishmaniasis may be destructive, disfiguring and incapacitating⁽⁵⁾.

Although it does not directly threaten life, leishmaniasis lesions may have a potential deformation capacity, affecting the social and psychological functions of affected individuals. These individuals may present anxiety attacks, depression, dissatisfaction with body image and decrease in quality of life. The disease and its treatment can have an impact on the physical, psychological, social and economic domains of those who experience them⁽⁶⁾.

Quality of life (QoL) is a concept that encompasses several meanings, theoretical approaches and measurement methods⁽⁷⁾. In the health context, the concept acquires valorization as a way to overcome the purely biomedical model. QoL conceptions seek to overcome the focus on issues such as the symptom-centered approach, the reduction in mortality or the increase in life expectancy. It considers an individual's perception of several aspects of life: physical, occupational, psychological, social and economic spheres⁽⁸⁻¹⁰⁾.

In an attempt to create a concept with a cross-cultural focus, the World Health Organization (WHO) created the WHOQOL Group, which defined QoL as "the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns." Such definition relates the environment to physical, psychological, independence level, social relations and personal beliefs aspects^(8,9). In short, it is a subjective multidimensional construction of an evaluation of positive and negative features. This conception is not immutable; it is under construction throughout life and is susceptible of global modifications or changes in only some aspects^(8,11).

Due to the epidemiological relevance and the impact of this disease, surveillance actions are necessary in order to reduce the number of cases by identifying and monitoring relevant territorial units and also by identifying and reporting cases. In addition, it is necessary to encourage the development of preventive and control actions to be carried out in endemic environments⁽⁵⁾.

Given the above, the present study aims to assess the quality of life of people with cutaneous leishmaniasis.

METHODS

This is a descriptive observational cross-sectional study conducted with people with Cutaneous Leishmaniasis (CL) undergoing treatment and follow-up at the Laboratory of Dermatomyology of the University Hospital of Brasilia (*Laboratório de Dermatologicologia do Hospital*

Universitário de Brasília – HUB) from December 2012 to March 2013. The HUB is the reference center for diagnosis and treatment of tegumentary leishmaniasis in the Federal District, Brazil⁽⁵⁾.

Interviews were carried out in a reserved room of the laboratory for the application of two instruments. The first one aimed to collect data on the sociodemographic and clinical aspects of the study sample and was developed based on a questionnaire used in a study with a similar objective⁽¹¹⁾. The second one, the World Health Organization Quality of Life Instrument Brief (WHOQOL-bref), validated in Brazil⁽¹²⁾, is used to assess the quality of life of adult populations.

The convenience sample was composed of 44 people with CL who were contacted during the four months of data collection and informed about the research objective and methodology. They were also informed about the secrecy and anonymity of answers and had their doubts clarified. Interviews were carried out with men and women over 18 years old who agreed to participate in the study after understanding the study guidelines and signing the Free and Informed Consent Form, as established in resolution CNS/MS No. 466, of December 12, 2012⁽¹³⁾.

The WHOQOL-bref⁽¹⁴⁾ is an abbreviated version of the WHOQOL-100, which arose from the need for a shorter instrument with a shorter filling time and with satisfactory psychometric characteristics. It consists of 26 questions: two general questions about QoL and health and other 24 questions representing each facet of the original instrument grouped into four domains: physical, psychological, social relationships and environment. The issues take into account the respondent's values, aspirations, pleasures and concerns over the last 15 days. The answers are given on a Likert-type scale by using four types of sequence: intensity (not at all-extremely), capacity (not at all-completely), frequency (never-always), and evaluation (very dissatisfied-very satisfied and very poor-very good)⁽¹⁴⁾.

Data were analyzed using SPSS version 17 and descriptive analysis of simple frequency, central tendency and dispersion and inferential analysis for comparison between domains.

Median values of responses, that is, the value separating 50% of the responses when they are ordered, were obtained from the values found in each of the twenty-four facets that compose the domains. The values show 1 as the worst response and 5 as the best response, which allowed to verify which facets were positively or negatively evaluated. In order to ensure standardization and allow comparison, the values obtained in the facets related to pain

and discomfort, dependence on treatments or medications, and negative feelings were inversely analyzed according to WHO guidelines⁽¹⁴⁾.

QoL scores were calculated separately for each of the four domains since a global QoL score is not conceptually predicted in the instrument. The raw score was transformed to a 0 to 100 scale (transformed score TS 0-100) according to SPSS syntax file proposed by the WHO. Therefore, each domain must have a minimum value of 0 and a maximum value of 100 so that the higher the score, the more positive is the evaluation of the domain⁽¹⁴⁾. The paired sample t-test was used to compare domains and check for statistically significant differences.

The research project was approved by the Research Ethics Committee of the Faculty of Health Sciences of the University of Brasília (*Faculdade de Ciências da Saúde da Universidade de Brasília*) under No. 149/2012 at the 10th Ordinary Meeting held on November 13, 2012.

RESULTS

Regarding sociodemographic data, the study included 44 people: 20 men (45.5%) and 24 women (54.5%). Age ranged 30 to 80 years, with a mean age of 51.80 ± 11.62 . As for education, 22 (50%) interviewees had incomplete primary education or were illiterate and 7 (15.91%) had complete secondary education. In all, 23 (52.3%) individuals were married and 11 (25%) were single. Divorced, living as married, widowed and separated individuals totaled 10 (22.7%). With regard to occupation, 11 (25%) participants were domestic workers and 10 (22.7%) were agricultural, forestry and hunting and fishing workers – these were the most relevant occupations. Of the interviewees, 30 (68.2%) were from the Federal District (Portuguese: *Distrito Federal or DF*).

As for clinical data, 27 (61.4%) interviewees presented no complaints while 10 (22.7%) complained of wounds, 6 (13.6%) of pain and only 1 (2.3%) reported extreme tiredness.

In the two initial questions of the WHOQOL-bref, which assess the general perception about QoL and health, 36 (81.82%) participants rated their QoL as good or very good. Regarding health, 10 (22.73%) participants were neither satisfied nor dissatisfied and 30 (68.18%) reported being satisfied or very satisfied.

The scores obtained in the four domains and the two general questions (overall assessment) of the WHOQOL-bref are summarized in Figure 1.

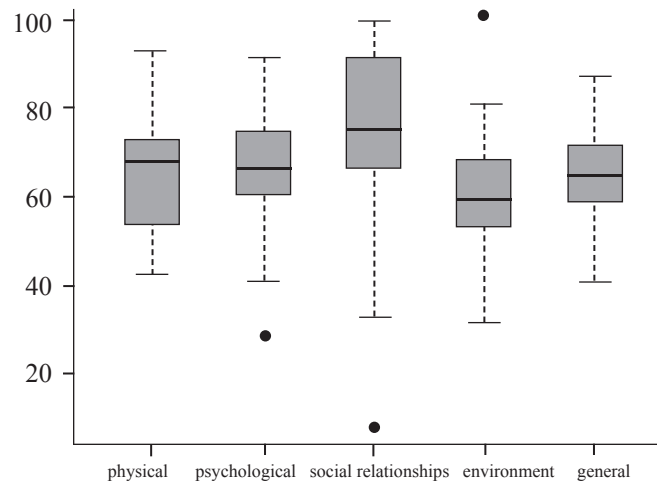


Figure 1 - Scores in the domains of the quality of life assessment in patients with cutaneous leishmaniasis that make up the WHOQOL-BREF. Brasília, Distrito Federal, 2013.

The raw data of the domains presented the following means and standard deviations: social relationships 3.98 ± 1.09 , psychological 3.65 ± 1.13 , physical 3.59 ± 1.12 and environment 3.39 ± 1.22 .

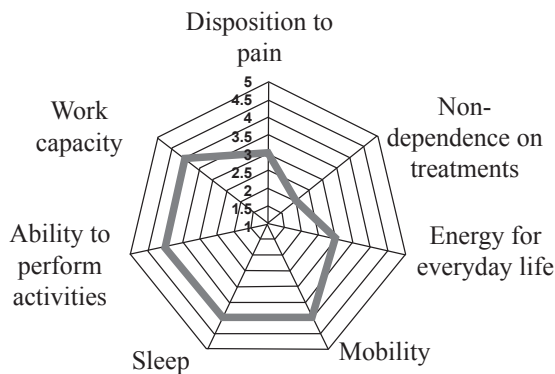


Figure 2 – Median of interviewees' evaluation of the facets in the physical domain of the WHOQOL-bref in the period from December 2012 to March 2013. Brasília, DF, 2013.

The scores transformed to 0-100 (TS 0-100) revealed the following means in the four domains: social relationships 74.62, psychological 70.55, physical 61.85 and environment 59.80.

In order to compare the domains and check for statistically significant differences between them, the paired sample t-test was employed. The test found differences between domains. However, considering a significance level

of 5%, it is not possible to affirm that there is a difference between the social relationships and the psychological domains and between the physical and the environment domains. Social relationships was the best rated domain and environment was the worst rated one.

The analysis of the median value of the responses in each of the questions (facets) of each domain showed that the physical domain, represented by Figure 2, is composed of seven questions that refer to work capacity, activities of daily living, sleep and rest, mobility, energy and fatigue, pain and discomfort and dependence on medical treatment. The median 4 occurred in four questions (capacity for work, ability to perform daily living activities, sleep, and mobility), showing that at least half of the respondents were satisfied with these issues. The items energy for everyday life and pain obtained median 3, that is, half of the ratings are neither good nor bad. Dependence on treatments obtained median 2; in this item, 25 (56.82%) interviewees reported needing not at all or a little medical treatment to function in their daily lives.

In the psychological domain, all the six facets obtained a satisfactory evaluation, with a median 4. With regard to the frequency of negative feelings (blue mood, anxiety, despair, depression), 40 (90.9%) interviewees presented these feelings. Of these, 8 (18.18%) reported experiencing such feelings always, 19 (43.18%) very often, 9 (20.45%) quite often, and 4 (9.09%) seldom (Figure 3).

Figure 4 presents the social relationships domain, which obtained median 4 in the three items evaluated: personal relationships, social support, and sex life. This

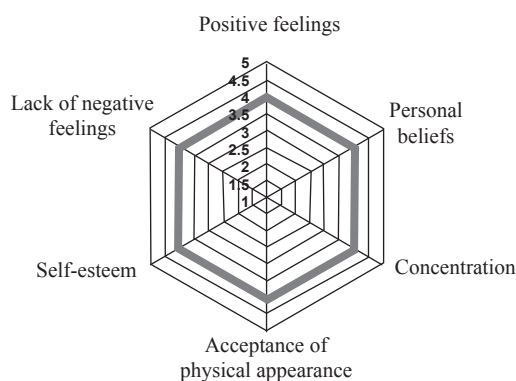


Figure 3 - Median of interviewees' evaluation of the facets in the psychological domain of the WHOQOL-bref in the period from December 2012 to March 2013. Brasília, DF, 2013.

result indicates that 22 (50%) participants were satisfied with the support received from family and friends and with their intimate lives.

The environment domain, represented by Figure 5, has eight facets and presented the worst scores. Five items – physical safety, physical environment, access to health services, home environment and opportunity for acquiring new information – obtained median 4, revealing that 22 (50%) respondents were satisfied with these issues. Transport, financial resources and leisure activities obtained median 3, that is, half of the participants were neither satisfied nor dissatisfied with these items. Of the interviewees, only 6 (13.64%) stated that they had enough

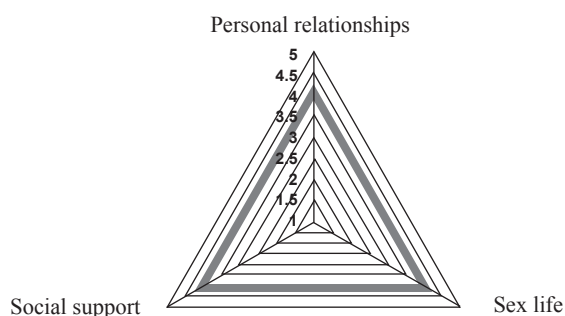


Figure 4 - Median of interviewees' evaluation of the facets in the social relationships domain of the WHOQOL-bref in the period from December 2012 to March 2013. Brasília, DF, 2013.

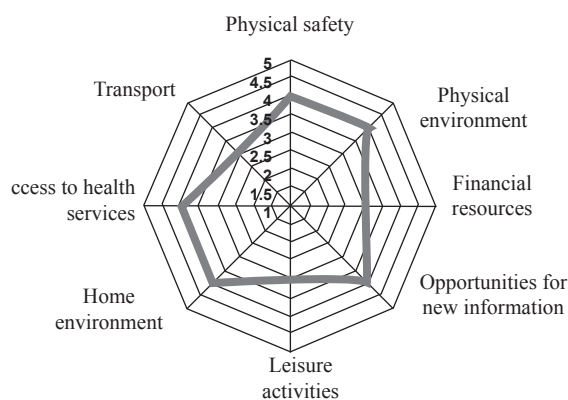


Figure 5 – Median of interviewees' evaluation of the facets in the environment domain of the WHOQOL-bref in the period from December 2012 to March 2013. Brasília, DF, 2013.

financial resources to fully satisfy their needs and only 5 (11.36%) felt completely satisfied or very satisfied with their leisure opportunities and their transport.

DISCUSSION

The sample analyzed in the present study, constituted of 54.5% of women, does not corroborate the Brazilian profile of the disease, which predominantly affects men (74%)⁽⁵⁾. Other studies on quality of life in this population, in Brazil⁽¹⁵⁾ and in Turkey⁽¹⁶⁾, also showed a predominance of men. Studies in Iran⁽¹⁶⁾ and in Morocco⁽¹⁷⁾ showed a higher number of women in the samples studied.

The main occupations found in the present study – domestic workers (25%) and agricultural, forestry and hunting and fishing (22.7%) workers – relate to changes in the disease transmission profile and represent two of the epidemiological profiles: occupational or leisure and rural or peri-urban. The first is associated with the disorderly clearing of forests and agricultural and tourism activities, and the latter is related to colonization areas near residual forests⁽⁵⁾.

Studies in Iran⁽⁶⁾ and Turkey⁽¹⁶⁾ found that gender, marital status, occupation and educational level did not affect QoL. However, appearance and the type of lesion had an effect on life and QoL, with ulcerative lesions as the ones that significantly affected it the most⁽⁶⁾.

In the present study, with regard to the clinical aspects, the main complaints were also related to lesions and pain. The psychosocial influence of skin diseases is directly linked to how visible they are. CL lesions occur particularly

in exposed areas of the body and can often be deforming. These particularities of the location and severity of the lesion can lead the individual to feel stigmatized, affecting not only their self-esteem but also their social well-being⁽¹⁶⁾.

Negative feelings (blue mood, anxiety, despair, depression) in the psychological domain were present in 90.9% of the interviewees of the present study. Skin lesions are often associated with depression, anxiety, low self-esteem, personal satisfaction, and suicidal ideation⁽¹⁶⁾. A pioneer study on the influence of CL on QoL showed an increase in depressive and anxiety symptoms in this population⁽¹⁸⁾. Later research demonstrated higher levels of depression in children and adolescents with CL⁽¹⁶⁾. As they are not a direct life threat, the psychological consequences of dermatological diseases are often neglected⁽¹⁶⁾. However, early recognition of the onset of symptoms and the development of health actions to minimize them are important in improving quality of life in addition to ensuring a better response to treatment⁽¹⁶⁾.

The results obtained in the social relationships domain show that the interviewees of the present study receive family and social support and have a satisfactory sex life. The social relationships of patients with CL in other studies also had a positive effect on quality of life^(6,15).

In the present study, the high number of participants who were dissatisfied with their financial resources, access to leisure activities and transport reflects their socioeconomic difficulties. Neglected diseases prevail in people with low socioeconomic status and aggravate inequalities in Brazil^(5,19).

Surveillance and control actions are necessary to reduce cases of CL and their impact on the quality of life of affected individuals⁽⁵⁾. The prevention of CL has been a problem in endemic regions given its correlation to ecological, environmental, socioeconomic, cultural and behavioral factors⁽²⁰⁾.

Developing health policies to improve appropriate prevention, diagnosis and treatment is critical. These actions should actively involve the community^(5,21). As each region has particular epidemiological characteristics, it is fundamental that actions are developed on the basis of these peculiarities⁽²¹⁾.

Lack of information on transmission and treatment hinders prevention strategies. Knowledge about the disease is often restricted to those who have had the disease or to those with a history of the disease in their family or in people close to them⁽²¹⁾. Early diagnosis and appropriate treatment of human cases should be prioritized^(5,20). Therefore, health education should be focused on epidemiology, transmission,

recognition of clinical signs and treatment^(5,21). In order to do so, joint actions should be developed involving the political, academic and management fields in the process of health care and work and in social control⁽²⁰⁾.

Pentavalent antimonials have been used for CL treatment for more than five decades. Despite their efficacy, these drugs have significant side effects and high costs. In addition to requiring intravenous use, the healing time of the lesions is prolonged, which interferes with the life and quality of life of the people who develop the disease. The literature suggests the development of further studies to evaluate new therapeutic regimens in order to find a drug as effective as antimonials but of easy administration and low toxicity. Since CL is a disease of developing countries, there is no commercial incentive for the pharmaceutical industry to develop cheap and effective drugs for its treatment⁽²²⁾.

Leishmaniasis surveillance actions include not only the recognition and reporting of cases, but also the identification of areas of transmission and the recognition of and control of phlebotomine sand flies⁽⁵⁾. A study carried out in Morocco⁽¹⁷⁾ showed a reduction in the incidence of the disease after the bodies responsible – at the national level – for health and agriculture were involved in the development of strategies for vector control in affected areas.

Preventive measures should be encouraged. They include individual protection in areas of transmission and environmental management to control vectors. The main measures of individual protection in endemic areas consist in using repellents, avoiding exposure during the hours of peak biting activity for vector, using thin mesh mosquito net and window and door screens⁽⁵⁾.

More detailed studies on this issue are needed. A limitation of the present research was the use of a generic instrument for the assessment of quality of life. The instrument captures general issues (physical, psychological, social and environmental) but it does not provide a deep analysis of the effect of health-disease issues, in the case of cutaneous leishmaniasis, on the assessment of quality of life. Other studies could build and validate a specific instrument for assessing quality of life in people with the disease. One aspect to be explored is the comparison during and after treatment/follow-up of the pathology in order to check for changes in the perception of quality of life. In parallel, it is possible to use qualitative methodologies given that quality of life is a subjective theme and the methodologies could be complementary. It is hoped that this knowledge will allow the valorization of the perceptions of this population regarding the different areas of their life so that priority aspects for the prevention, treatment and follow-up of the disease can be identified and achieved.

CONCLUSION

The present study allowed to know the assessment of the quality of life of people with cutaneous leishmaniasis undergoing treatment and follow-up at the University Hospital of Brasília (*Hospital Universitário de Brasília*). Satisfaction in the social relationships domain represented a strategy for coping with the disease, contributing positively to the interviewees' QoL. The environment domain had a negative influence on the participants' perception of QoL, mainly due to financial resources, leisure activity and transport facets, which highlighted the vulnerable condition of this population affected by a neglected disease.

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