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REVIEW ARTICLE

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## QUALITY OF LIFE OF PEOPLE LIVING WITH LEISHMANIASIS: AN INTEGRATIVE LITERATURE REVIEW

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### ABSTRACT

Although common in the tropics, leishmaniasis is a neglected disease. It is caused by the intracellular protozoan species *Leishmania*. The disease is transmitted by a phlebotomine vector and presents different clinical manifestations: cutaneous and visceral. The latter poses an imminent risk of death depending on the clinical condition of the affected person. This research is a descriptive, integrative review about the quality of life of people living with leishmaniasis. The following steps were followed: elaboration of the question; methodological description of the selection of studies; retrieval, analysis and judgment of data; data collection; and description of the resulting synthesis. The search in the Capes journal platform resulted in 37 articles, while in the Brazilian Digital Library of Theses and Dissertations resulted in one thesis. Ten studies were initially selected for this manuscript, and after reading the texts in full length, 13 publications were selected to compose the sample, considering the eligibility criteria and reverse search. It was evident that there are few publications on the theme, taking into account the magnitude of the impact of this problem on public health. No studies used the mixed method in their investigations. Regarding the dimensions of quality of life affected by leishmaniasis, it was observed that there was a negative impact on the quality of life of people affected by the disease. The psychological dimension of human health and overall health as well as the physical dimension were affected, and especially when related to the pharmacological treatment. Given this, further research addressing the quality of life of these individuals in a more thorough way, providing comprehensiveness through the various dimensions of the human being.

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## INTRODUCTION

Leishmaniasis is a neglected and common health and disease condition in tropical areas and is characterized by a group of diseases caused by at least 20 intracellular protozoan species of the genus *Leishmania*. The parasites are transmitted by the bites of the vector, which is known as the straw mosquito, infected by the promastigote form of the protozoan (Khatami, 2019). It is a clinical entity with different manifestations, ranging from cutaneous lesions to visceral disease. The later incurs imminent risk of death and the prognosis is determined by the interaction between parasitic characteristics, vector biology, and host immune factors (Burza, 2018). Visceral leishmaniasis (VL) can be lethal in individuals who are malnourished and/or ineffectively treated. In addition, it is considered emerging in people living with HIV and AIDS, thus calling attention to the importance of this clinical situation (Silva, 2017). Cutaneous leishmaniasis (CL) is manifested as an ulcer that can lead to scarring, deformation and stigmatization, as a result of physical and dermatological deficiency. Depending on the parasite species, patients with CL may achieve spontaneous healing over time. However, up to 10% of them can progress to more severe manifestations known as mucocutaneous leishmaniasis, diffuse cutaneous leishmaniasis, or disseminated cutaneous leishmaniasis, as well as present recurrence of the disease (Azeredo-Coutinho, 2016). Visceral leishmaniasis is caused by *L. donovani* in Asia and Africa and *L. infantum* in the Mediterranean Basin, Middle East, Central Asia, South America, and Central America. It is the most severe, systemic form and usually fatal if not properly treated. Post-calazar dermal leishmaniasis is a skin manifestation that occurs in healthy people after VL treatment (Showler, 2015). The disease is endemic in 98 countries, especially in developing countries. It is estimated today that about 350 million people worldwide are at risk of contracting different types of leishmaniasis, with 1.5-2 million new cases estimated every year. In Brazil, 18,185 cases of CL and 3,987 cases of VL were reported in 2017, thus demonstrating the high number of people affected by the disease (Brasil, 2019 and Brasil, 2017).

The diagnosis of this condition and the therapy adopted may interfere with the quality of life (QOL) of the patients, so that their daily life activities and future aspirations can be seriously and negatively affected. Social stigma, depression and anxiety may be associated with these factors (Refai, 2018). Quality of life is a subjective, multidimensional entity, because it receives (quantitative and qualitative) influences from physical, psychological, environmental, social and spiritual dimensions, and may differ from one individual to another and even change in an individual over time (Soares, 2019). In a study conducted in 2013 in Brazil, it was said that CL interferes with the QOL of patients in the domains related to the environment and also in the facets transport, financial resources and leisure activity, thus demonstrating the importance of social relations as a method for coping with the disease (Honório, 2016). Regarding VL, a pioneering research investigated the impact of the disease on people living with HIV and AIDS in Ethiopia. According to this study, in these individuals, in particular, the disease interferes negatively in all dimensions of human health, with strong (Alemayehu, 2017). Therefore, despite the high incidence of leishmaniasis worldwide, the morbidity and possible mortality resulting from the disease and the negative effects that the injuries may cause to the individuals, there is little scientific production on this subject.

Given the above, this review seeks to answer the following question: What is the impact of leishmaniasis on the QOL of people affected by the disease?

In order to answer the proposed question, the present work aims to contextualize the state of the art of the impact of leishmaniasis on the QOL of people affected by the disease.

## METHOD

This research is a descriptive, integrative review about the quality of life of people living with leishmaniasis. Literature review is a method that gathers studies with different methodological approaches for a systematic analysis, with methodological rigor in relation to objectives, materials and methods, allowing the reader to analyze the pre-existing knowledge about the subject in evidence (Rocha, 2017). A review study should support the discussion of the compilation of existing scientific data in given science, thus demonstrating the "state of the art", as well as making it possible to draw possible controversies and gaps in the knowledge produced.<sup>13</sup> For the development of this research, the following steps of construction of the integrative literature review were followed: 1 - Elaboration of the question for the development of the integrative review, 2 - Methodological description of the selection of the studies to compose the sample, 3 - Retrieval, analysis and judgment of data listed in the studies included in the integrative literature review; and 4 - Data extraction and description of the synthesis built from the constructed and published knowledge (The Joanna Briggs Institute reviewers' manual, 2014). Initially, the search for studies was conducted in May 2019 using the Portal of Journals of the Coordination for the Improvement of Higher Education Personnel (Capes) and the Brazilian Digital Library of Theses and Dissertations (BDTD). For the search of the studies, the following English Health Sciences Descriptors (DeCS/MeSH) were used: "Quality of Life", "Leishmaniasis, Cutaneous" and "Leishmaniasis, Visceral".

To systematize the search, the Boolean operator AND was applied to search the Capes portal. The search with the descriptors "Quality of Life" AND "Leishmaniasis, Cutaneous" resulted in 26 studies. In turn, the search with the descriptors "Quality of Life" AND "Leishmaniasis, Visceral" found 11 studies. At BDTD, only one doctoral dissertation was found. As for the search period, the time frame was delimited between 1995 - 2019. Although the concept of expanded health was described in 1945 by the World Health Organization (WHO), it was only after the late twentieth century that comprehensive human health based on measures of the impact of the disease on people's QOL was addressed (Fleck, 2000). Then, eligibility criteria were adopted to select the sample: studies addressing the QOL of people with CL or VL, that were available online in full length, and published in any language were considered. Studies presenting only speech categorization or that did not use validated instruments to assess QOL were excluded from the analysis, as they did not present rigor and statistical accuracy in their evaluations. It is noteworthy that the scientific works were accessed online through the Internet software Mozilla Firefox, from the Federal University of Paraíba, which allows access to journals available exclusively to journal subscribers, which is the case of the referred higher education institution. The pre-selected studies were translated from English to Portuguese, in order to enable the cataloging of the sample variables. After a thorough

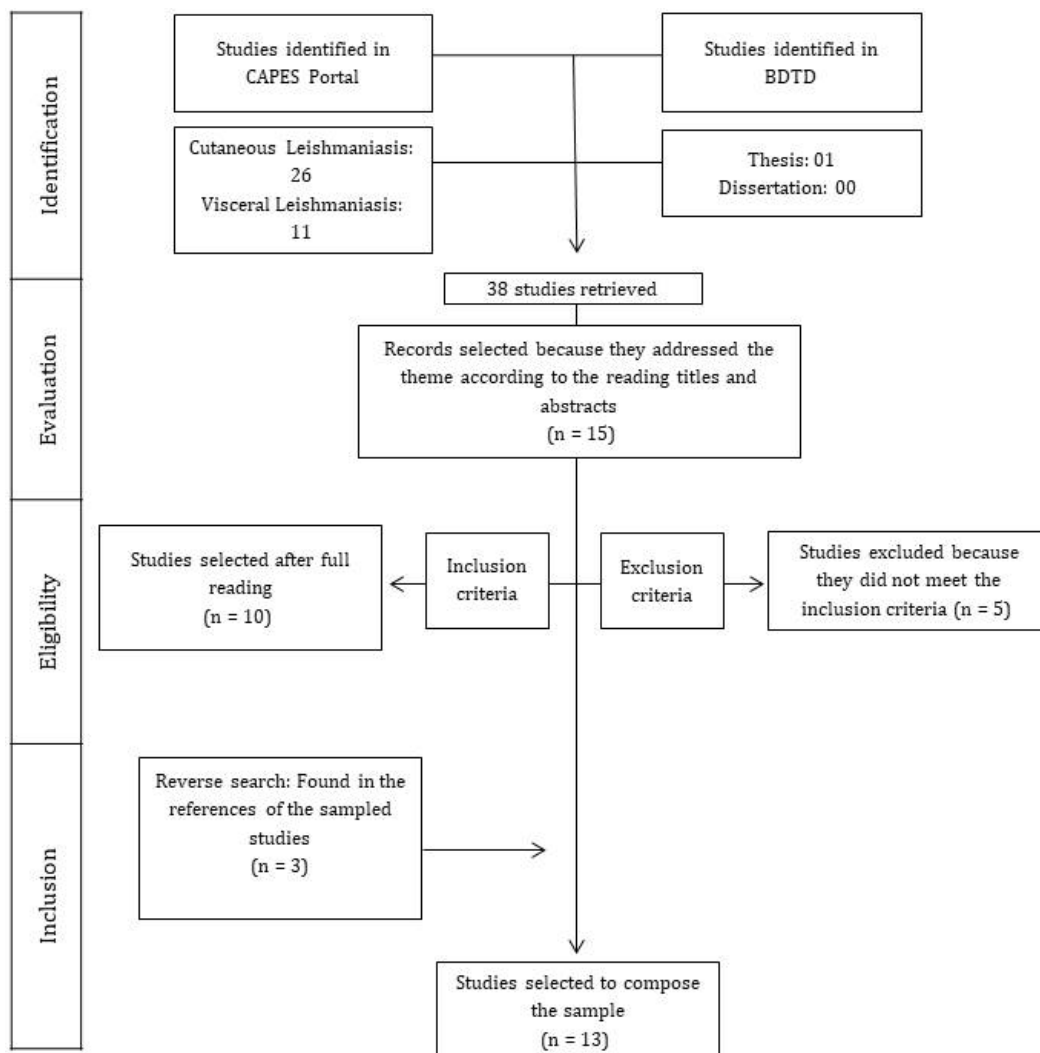
reading of titles, abstracts and methods, according to the eligibility criteria, the sample first comprised 10 studies published in journals and were organized and grouped in a file folder in the Microsoft Windows 10 operating system. To broaden the search, aiming at data saturation, a reverse search was performed, consisting of checking the bibliographic references of the studies selected to compose the sample.<sup>16</sup> Three other articles were included so that the a sample of the present investigation was composed by a total of 13 studies.

The reading of the articles during the stages of sample selection was performed in pairs, concerning the recommendation of the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) method, respecting the protocol for conducting reviews and the inclusion and exclusion criteria (Moher, 2009). Then, the data contained in the empirical material were surveyed with aid of an instrument prepared by the authors in Microsoft Word 2010, covering the following information of the studies: characteristics (author, year of publication and country of development of the primary study and journal of publication) and methodological approach (place of recruitment of participants, and type of leishmaniasis approached, affected dimensions of QOL, and recommendations for further studies). In the next step, the quantitative treatment of the statistical data was performed by calculating the simple and relative frequencies of the variables, with frequency distribution in absolute numbers and percentages.

The results were analyzed in the light of the literature relevant to the investigated theme. There was no analysis by a Research Ethics Committee because the study addresses public domain data. However, all ethical prerogatives regarding the citation of the authorship of the documents were strictly followed (Costa, 2017).

### RESULTS

The search in the CAPES journal portal resulted in 37 articles, while only one thesis addressing the theme was found in the BDTD database. After the reading of titles and abstracts, 10 studies were selected, and after reading in full length, 13 publications were selected to compose the sample, considering the eligibility criteria (Figure 1). Regarding the characteristics of the publications included in this integrative literature review, the following were presented: authorship, year of publication, country of origin of the research, and journal of publication of the work, shown in Table 1. The empirical material gathered in this integrative review showed the following findings: Brazil was the leader of the scientific production on the QOL of people with leishmaniasis with three studies, followed by Iran, Ethiopia, India and Turkey, with two studies each, and lastly, Sri Lanka and Tunisia, with one publication each. Regarding the year of publication of the studies, it was noted that in 2004, 2010, 2015 and 2019 there was one publication in each year; in 2013, 2016, 2017, two



Source: Direct Search, 2019.

Figure 1. Retrieval algorithm of studies in the CAPES Journal Portal and BDTD databases. Brazil, 2019

**Table 1. Distribution of works according to author, year of publication, and country of development of the primary study, and journal of publication. Brazil, 2019**

Authorship	Year of publication and country of development of the study	Journal of publication of the works
1 Yanik, Gurel, Simsek <i>et al.</i>	2004- Turkey	Clinical and Experimental Dermatology
2 Nilforoushzadeh, Roohafza, Jaffary <i>et al.</i>	2010 - Iran	Journal of Skin& Leishmaniasis
3 Vares, Mohseni, Heshmatkhahe <i>et al.</i>	2013 - Iran	Archives of Iranian Medicine
4 Toledo Jr, Silva, Carmo <i>et al.</i>	2013-Brazil	Transactions of the Royal Society of Tropical Medicine and Hygiene
5 Turan, Kandemir, Yeşilova <i>et al.</i>	2015 - Turkey	Postepy Dermatologii I Alergologii
6 Chahed, Bellali, Jema <i>et al.</i>	2016 - Tunisia	PLOS Neglected Tropical Diseases
7 Honório, Cossul, Bampiet <i>et al.</i>	2016 - Brazil	Revista Brasileira em Promoção da Saúde
8 Alemayehu, Wubshet, Mesfin <i>et al.</i>	2017 - Ethiopia	Health and Quality of Life Outcomes
9 Pal, Murti, Siddiqui <i>et al.</i>	2017 - India	Health and Quality of Life Outcomes
10 Galvão, Pedras, Cota <i>et al.</i>	2018 - Brazil	PlosOne
11 Refai, Madarasingha, Sumanasena <i>et al.</i>	2018 - Sri Lanka	International Journal of Dermatology
12 Alemayehu, Wubshet, Mesfin, <i>et al.</i>	2018-Ethiopia	The American Society of Tropical Medicine and Hygiene
13 Veeri, Gupta, Pal <i>et al.</i>	2019- India	Health and Quality of Life Outcomes

Source: Direct Search, 2019.

**Table 2. Distribution of studies included in the integrative review according to type of study, quality of life assessment instruments, affected quality of life dimensions, and proposals for further investigations. Brazil, 2019**

Study Type	QOL Assessment Instruments used	QOL dimensions affected	Factors associated with the impact of leishmaniasis on the participants' QOL	Proposals for new investigations
1 Cross-sectional study with a quantitative approach.	1- Instrument for collection of demographic data ; Hospital Anxiety Depression Scale (HAD), Body Image Satisfaction Scale (BIS); Dermatology Life Quality Index (DLQI).	People with cutaneous leishmaniasis had higher anxiety and depression scores than control group participants (healthy people). It was also observed that they had lower body satisfaction and QOL when compared to those in the control group. Those with skin lesions had worse QOL than those without lesions. Lesions on exposed body parts, permanent scarring, and stigmatization appeared to be the cause of social anxiety, depressive symptoms, decreased body satisfaction and lower QOL in people with cutaneous leishmaniasis.	The study points to a significant association of depression and anxiety with cutaneous leishmaniasis.	There is no explicit mention of the development of new studies.
2 Randomized clinical trial	Dermatology Life Quality Index (DLQI).	The study showed that people with cutaneous leishmaniasis, who received pharmacological treatment associated with psychotherapy, had a better QOL.	Impact of cutaneous leishmaniasis on participants' QOL was associated with self-conscious shame and changes in habits (wearing clothes or going shopping), as well as problems related to sexuality resulting from dermal involvement.	The study points to the importance of psychotherapeutic follow-up of leishmaniasis patients, which would result in decreased depression and improved QOL.
3 Cross-sectional study with a quantitative approach.	Instrument for collection of demographic data and Dermatology Life Quality Index (DLQI).	The greatest impact on the QOL of people with cutaneous leishmaniasis was observed in the domains of symptoms and feelings assessed by the instrument. There was lower impact on the QOL of these patients in the treatment domain.	In this investigation, there was an association with the negative impact of QOL due to cutaneous leishmaniasis, and the appearance and type of lesion (whether nodular or plaque).	Studies are needed to evaluate the impact of cutaneous leishmaniasis treatment on different aspects of QOL, particularly in patients with ulcerated lesions.
4 Cross-sectional and quantitative study.	Instrument for collection of demographic data and Dermatology Life Quality Index (DLQI).	There was a significant effect of cutaneous leishmaniasis on the participants' QOL. The domain work and school had the highest average impact scores, followed by symptoms and feelings. The smallest impact was evidenced in the domain of personal relationships.	The study does not show factors associated with the impact of cutaneous leishmaniasis on the participants' QOL.	Studies with larger numbers of patients are needed to evaluate the effects on QOL related to the site, number, size, and duration of cutaneous lesions, as well as the effects of treatment and residual scarring.
5 Cross-sectional, quantitative and descriptive study.	Child Depression Inventory (CDI); Pediatric Quality of Life Inventory Parent and Child Versions (PedQL-P and C).	The study demonstrated psychological (anxiety, anguish, self-esteem, among others) and psychosocial (stigma, rejection, discrimination in the social and professional environment) impacts, resulting from scars caused by cutaneous leishmaniasis among women and girls.	The correlations between QOL scores and the domains of the instrument were non-significant except for social perception and knowledge about the disease. There was significant correlation between being affected by cutaneous leishmaniasis and having over 12 years of age.	Further studies using a larger sample size and participants from different cultures are suggested to better identify the relationship between cutaneous leishmaniasis and the psychological state of people with the disease.
6 Quantitative, cross-sectional and descriptive study.	Revised Illness Perception Questionnaire (IPQ-R); Psoriasis Life Stress Inventory (PSLI); World Health Organization Quality of Life-26 (WHOQOL-26) scale.	Negative impacts on the QOL of patients with cutaneous leishmaniasis were observed, especially on the environmental and mental domains. The disease had a greater negative impact on the environmental domain of QOL, involving availability of financial resources, freedom, security, access to quality housing, opportunities to acquire new information and skills, opportunities for recreation and leisure.	Emotional representations of leishmaniasis were associated with loss of self-esteem, feelings of inferiority, and the idea that the disease causes social disorders. There was a correlation between social QOL and total knowledge of the the participants, showing that the greater the knowledge of a person with cutaneous leishmaniasis, the lower their negative perception of QOL.	It was considered important to carry out studies to establish a holistic support system for the management of cutaneous leishmaniasis, and to address the psychological challenges and barriers that interfere with the social and professional integration of women affected by the infection.

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7	Observational study with cross-sectional, descriptive, and quantitative approach.	Instrument for collection of demographic data and World Health Organization Quality of Life Instrument short form (WHOQOL-Bref).	The results pointed to the negative impact on QOL related to the psychological domain, because of the presence of negative feelings (moodiness, anxiety, despair, depression) and the environmental domain, mainly related to the facets of financial resources, leisure activities and transportation, highlighting the vulnerable condition of this population affected by a neglected disease.	After applying statistical tests to evaluate the correlation between the dimensions affected by cutaneous leishmaniasis, it was found that there was a difference between the dimensions. However, the difference between the social relations and psychological domains, and between the physical and environmental domains, was not confirmed through the applied statistical tests.	The study recommends the development of research to address aspects related to infection prevention, the need for validation of a specific instrument to measure QOL of people living with leishmaniasis, and the importance of using qualitative techniques to collect subjective information regarding the QOL of the participants that cannot be evidenced through quantitative research.
8	Quantitative, cross-sectional and descriptive study.	Instrument for collection of demographic data and World Health Organization QoL Instrument for HIV infected patients (WHOQoL HIV-Bref).	It was evidenced that people with visceral leishmaniasis living with HIV/AIDS had a lower average score in all evaluated domains, indicating a worse QOL.	Males living in urban centers were more likely to be affected by visceral leishmaniasis. There was a strong correlation between physical health, independence level and spiritual health in people with visceral leishmaniasis. The high level of education of people living with HIV was associated with higher HRQoL in the psychological, social, level of independence and environmental domains.	New approaches aimed at a comprehensive perspective of health of people with visceral leishmaniasis living with HIV and AIDS, related to the psychological dimension, are suggested in order to improve their QOL.
9	Quantitative and cross-sectional study using a control group.	Instrument for collection of demographic data and clinical characteristics of the lesions; Dermatology Life Quality Index (DLQI); Short Form Health Survey (SF-36).	The study shows the negative impact of cutaneous leishmaniasis on the QOL of the affected people, particularly in the psychological dimension, assessed by the DLQI; and mental health, social functioning, body pain and overall health assessed by the SF-36.	Patients with nodular lesions had lower QOL when compared to those with macular or papular lesions. The participants who presented longer-lasting lesions in many parts of the body experienced a greater negative impact on their QOL. The study says that the more severe the leishmaniasis involvement, the greater the negative impact on the individual's QOL.	Development of new investigations to better understand the natural history, pathogenesis and long-term impact of the infection.
10	Descriptive study of the questionnaire validation type	Validation Version of the Cutaneous Leishmaniasis Impact Questionnaire (CLIQ).	There was a negative impact on the QOL of people with cutaneous leishmaniasis undergoing intravenous and intraleisional pharmacological treatment related to adverse drug effects and need to buy the medication, and also due to the need to miss work because of the infection.	Adverse events arising from pharmacological therapy against cutaneous leishmaniasis and work absenteeism due to the disease were found to be significantly associated with the negative impact on the QOL of people with cutaneous leishmaniasis.	It is recommended to conduct investigations using self-administered questionnaires that allow emerging questions from respondents about the object investigated. Further studies with longitudinal approach as well as involving other health care levels are encouraged.
11	Quantitative, cross-sectional and descriptive study.	Instrument for collection of demographic data and Dermatology Life Quality Index (DLQI).	The study showed that the disease had no effect on the QOL of about half of the participants, being the symptoms and feelings domain the most affected.	It was shown that the QOL of patients with ulcers, plaques and nodular ulcers was worsened.	The study points to the importance of developing studies to assess the QOL of people with cutaneous leishmaniasis after treatment.
12	Quantitative, longitudinal study.	World Health Organization QoL Instrument for HIV infected patients (WHOQoL HIV-Bref).	All domains of QOL improved at the sixth month of follow-up when compared to baseline scores in both patient groups. Lack of social support and income were associated with low QOL in most domains in both groups. Compared with patients with severe acute malnutrition, patients with moderate acute malnutrition and normal nutritional status had better QOL scores in most domains in both groups. Pharmacological treatment (antiretroviral and antileishmaniasis) caused improvement in all dimensions of QOL. Income, social support and nutritional status were the predictors of low QoL for most domains.	The study points out that lack of income negatively impacted the health-related QOL of research participants in the psychological, independence and environmental levels. Similarly, lack of social support was associated with lower HRQoL in all domains but the spiritual domain of patients living with HIV and AIDS. Lack of social support has a negative impact on the psychological, social and environmental domains of patients with HIV and VL co-infection.	There is no explicit mention of further studies. However, there is a need for testing the association between psychosocial, financial integration, and nutritional support with existing national visceral leishmaniasis and HIV / AIDS health care programs to improve patients' HRQoL.
13	Quantitative, cross-sectional and descriptive study using a control group (healthy individuals).	World Health Organization Quality of Life Instrument short form (WHOQOL-Bref).	All QOL domains of patients with visceral leishmaniasis were highly impaired when compared to control (healthy) subjects. The participants received pharmacological treatment with Liposomal amphotericin B 10 mg/kg body weight. After one month of treatment, the QOL score was significantly improved in the physical, psychological and environmental domains. The maximum score (best QOL) was found in the social relationship domain and the minimum score (worst QOL) in the physical domain.	The physical and environmental domains were significantly more affected when correlated with sociodemographic variables. It was evidenced that married individuals, living in rural areas, over 40 years old, with low schooling, and working activities had a worse QOL.	New studies using the QOL assessment tool World Health Organization Quality of Life Instrument short form (WHOQOL-Bref).

publications in each year; and in 2018, three publications. Concerning the journals, the *Health and Quality of Life Outcomes* stood out with three articles on the subject. Regarding the application of QOL assessment instruments in the studies analyzed in this integrative review, as shown in Table 2, the distribution of the instruments used showed that six studies used instruments classified as generic (Hospital Anxiety Depression - HAD Scale; Body Image Scale - BIS; Child Depression Inventory - CDI; Pediatric Quality of Life Inventory Parent and Child Versions - PedQL-P and C; Revised Illness Perception Questionnaire - IPQ-R; Psoriasis Life Stress Inventory - PSLI; World Health Organization Quality Of Life-26 - WHOQOL-26; Short Form Health Survey - SF36; World Health Organization Quality of Life Instrument short form - WHOQOL-Bref). Eight articles used specific instruments for the population with skin conditions: the Dermatology Life Quality Index - DLQI and the Psoriasis Life Stress Inventory - PLSI. It is noteworthy that two of the studies<sup>11,19</sup> used a specific instrument for people living with HIV and AIDS (WHOQoL HIV- Bref) because they addressed this unique population (co-infection with human immunodeficiency virus and visceral leishmaniasis). Regarding the assessment of QOL of people with leishmaniasis, a study (Galvão, 2019), validated in Brazil a specific assessment instrument for Cutaneous Leishmaniasis (Cutaneous Leishmaniasis Impact Questionnaire - CLIQ).

Table 2 also shows that among the studies that comprised the sample there was no one with qualitative or mixed (quantitative and qualitative) approach and that most primary studies (10) developed research based on a temporal follow-up of the cross-sectional type. According to the articles that were included in the sample of this review, it was observed that leishmaniasis negatively impacts the QOL of people who are affected by the disease, especially in the psychological dimension of human health (Refai, 2018; Honório, 2019; Alemayehu, 2017; Alemayehu, 2019; Yanik, 2019; Nilfroushzadeh, 2010; Vares, 2013; Toledo, 2009; Turan, 2015; Chahed, 2019; Pal, 2017 and Veeri, 2019), overall health (Alemayehu, 2017; Alemayehu, 2017; Nilfroushzadeh, 2010; Toledo, 2013; Turan, 2015; Veeri, 2019), and the physical dimension of these people (Refai, 2018; Honório, 2016; Alemayehu, 2017; Vares, 2013; Toledo, 2013; Veeri, 2019), accentuated when related to pharmacological treatment (Alemayehu, 2017 and Galvão, 2019). Among the 13 publications analyzed, 10 evaluated the QOL of people with CL, while the QOL of people with VL was the object of three articles. It is noteworthy that in two of the studies (Alemayehu, 2019 and Alemayehu, 2017) the participants also lived with HIV and AIDS.

## DISCUSSION

Despite the presence of one study published in 2004<sup>21</sup>, the number of works increased from 2010 onwards, with subsequent publications on the impact of leishmaniasis on the QOL of people. Although the understanding of health as improvement in all dimensions of the human being was adopted by the World Health Organization many years ago, soon after the end of World War II in 1946<sup>29</sup>, the comprehensive approach to providing health care to users with a less curative approach, based on diminishing inequities and perceived impact of the disease on people's QOL, was only decisively emphasized after the Ottawa Charter was published during the International Conference on Health Promotion

(1986)<sup>30</sup>, based on the proposal of the WHO to develop an instrument capable of measuring people's QOL (The WHOQOL Group 1995). The higher number of publications about the impact of leishmaniasis on the QOL of people in recent years may have as a possible explanation the dissemination in this period of the need for a comprehensive approach to human health, coupled with the high rate of people with this disease and the scarce scientific productions related to the theme (Pal, 2017). It was observed that Brazil was the leader in the production of studies on the theme. This demonstrates the importance of stimulating research at the national level and encouraging the continuity of scientific activity through financial and technological support, so as to effectively go against the budget cuts instituted in recent years by national legal amendments (Silva, 2017 and Brasil, 2016). Data from DATASUS (Brasil, 2017), reveal that, in Brazil, there is a high incidence of leishmaniasis, in agreement with the findings of this review in showing that this country stood out as the largest producer of knowledge on the subject. Besides Brazil, leishmaniasis occurs in Africa, Asia and India, which also explains the scientific production coming from these countries (Burza, 2018). Regarding the follow up of the studies, it is observed that most of the works were based on a cross-sectional and quantitative approach, which is considered in situations where the disease-inducing factor is permanent, since in this case the researcher does not have a delimited time interval. The use of this method is justified by the immediate possibility of response to a phenomenon, as well as by its low financial cost during the investigation (Hochman, 2005). This type of follow up has some limitations, because the cross-sectional temporal method may not necessarily refer to the impact of the disease, but rather to other associated factors at the time of the interview, such as lack of therapeutic or financial resources. Another limitation is that it is developed based on the prevalence of the observed outcome, and the collection of data about exposure and outcome is made in a single time period (Bastos, 2007). The present review showed that the quantitative studies used widely disseminated and accepted instruments to measure QOL. As QOL is a subjective and peculiar phenomenon of each person, studies using general instruments to assess QOL should be carried out, because they encompass various dimensions of the individual and provide a basis for decision-making and therapeutic implementation regarding the domains affected in populations with health problems.

The QOL of people affected by leishmaniasis is affected in several dimensions; the general instruments of QOL measurement used alone are not efficient in capturing the particularities of this phenomenon. The development and applicability of instruments for assessment of QOL specific to this condition is important (Galvão, 2019). This review pointed out that, until the moment the studies were retrieved, there was one specific instrument, validated in Brazil in 2018, to measure the QOL of people with leishmaniasis, but the instrument presented as particularity the need to be applied only to individuals with the clinical cutaneous form of the disease. Despite the magnitude of the disease in several countries<sup>5</sup>, there is no instrument capable of measuring the QOL of people with different forms of leishmaniasis (visceral and cutaneous). This finding points to the importance of validating a specific questionnaire for this population, especially for people with visceral leishmaniasis, due to the absence of such a scientific tool. Even though leishmaniasis does not represent a potentially fatal problem, it interferes with

the life of the affected people, causing social and family problems, because dermal eruptions and injuries can cause psychological discomfort due to embarrassment, leading the individual to have less social participation and causing emotional damage (Pal, 2017). In a study conducted in Sri Lanka (Refai, 2019) the family and social life of patients was a likely protective factor against the interference of leishmaniasis on the QOL of people. Lower QOL of soldiers affected by the disease (who would be far from their family and social constellation) than that of civilians with their constituted social activities was observed, thus demonstrating that social support can improve human self-esteem and consequently preserve the psychological dimension. It is important to highlight that people affected by leishmaniasis may suffer psychological interference during pharmacological treatment, leading to poor adherence, especially if this psychiatric morbidity is neglected (Turan, 2015). Therefore, it is necessary that health professionals, especially those who participate in drug therapy (doctors and nurses) also direct treatment to the psychological dimension, promoting a comprehensive view of the human being and the interdisciplinarity of care, to achieve better results in the treatment of this parasitic infection.

It is observed that adolescents near adulthood present lower QOL when compared to active adult individuals (Pal, 2017). This may explain the fact that the overall health related to QOL can suffer negative interference in cases of leishmaniasis. Patients are exposed to social limitations regarding aesthetics, as skin lesions turn this a source of stigmatization. In addition, people affected by leishmaniasis have lower chances of getting a paid work activity, because in capitalist societies appearance is a preponderant factor for insertion of individuals in the labor market (Nascimento, 2019). This problem is even more intense among women because, despite the need for financial income and insertion in the labor market, there is also the home tasks, especially in patriarchal cultures, as is the case in some countries of the tropics (Santos, 2017). Such domestic tasks can be interrupted due to the diagnosis and treatment of leishmaniasis, resulting in decreased overall health of the affected person and her family. Negative impact on QOL and overall health of patients with leishmaniasis was also evidenced when compared to healthy individuals (Toledo, 2013). This factor corroborates the idea that, although this is not a disease with imminent threat of death, it may lead to the interruption of activities of daily living, especially in its cutaneous form, due to stigma, lack of family and social support, and the need for hospitalization to receive pharmacological treatment (Pal, 2017).

Among the studies that comprised the present synthesis of publications regarding the QOL of people affected by leishmaniasis, there were three that addressed the impact of VL, and in two of them there was the particularity of participants being affected also by HIV and AIDS (Alemayehu, 2017 and Alemayehu, 2017). Leishmaniasis is a serious health problem in people living with HIV and AIDS. It is considered an opportunistic disease with low therapeutic response and high chances of inducing death, especially in the case of the visceral form. This points to the need for treatment and assistance from a multidisciplinary team (Burza, 2018). It is noteworthy that leishmaniasis is aggravated when it occurs in an individual living with HIV and AIDS because cutaneous leishmaniasis can be present in the disseminated form and still in the visceral form, with species that are found in

dermatological situations of the disease (Zijlstra, 2019 and Griensven, 2014).

## Conclusions

In order to answer the question established for this systematic method, which makes it possible to synthesize the existing knowledge about the impact of leishmaniasis on the QOL of people infected and presenting the cutaneous and visceral clinical forms, a survey of available material in the published articles and gray literature from stricto sensu graduate studies (theses and dissertations) was carried out. Despite the magnitude of the impact of this problem on public and collective health worldwide, with high rates of global incidence, there were few publications on the subject. No study used mixed methods, although they could have been significant, because they would allow to address qualitative aspects that may not be grasped by exclusively quantitative methods. Regarding the dimensions of QOL affected by leishmaniasis, it was observed that there was a negative impact on the QOL of people affected by the disease. The psychological dimension of human health and overall health and the physical dimension were affected, and especially when related to the pharmacological treatment. With regard to the psychological impact of the illness, spirituality can be explored to improve the health of individuals with leishmaniasis. However, any approach or mention to spiritual aspects related to human health was observed in the studies, although such an approach could promote improved pharmacological and psychological treatment. Given this, we recommend that further research be conducted to address the QOL of these individuals in a broad way, promoting a comprehensive appreciation of the human being through his various dimensions, especially when evidenced by the mixed method of investigation, as well as the approach of spirituality as part of treatment. The present study is timely, making information about the QOL of people with leishmaniasis available. Based on this perspective and this knowledge, it is possible to support the decision making of professionals from the health area and related areas, preventing and enabling the effective control of factors that may affect the QOL of people infected by leishmaniasis.

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