



Leprosy patients quality of life: a scoping review*

Qualidade de vida de pacientes com hanseníase: uma revisão de escopo

Calidad de vida de los pacientes con lepra: una revisión de alcance

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ABSTRACT

Objective: To explore the scientific evidence regarding the leprosy patients quality of life. **Method:** Scoping review according to the Joanna Briggs Institute methodology, with articles indexed in PubMed, Cochrane, LILACS, Embase, CINAHL, Scopus, Web of Science, PsycINFO, INFOLEP, and Google Scholar databases, published in full in Portuguese, English, or Spanish. **Results:** Seventy-four studies were identified, with 71 of quantitative approach and 3 with a mixed method. There was a predominance of studies published in Brazil (58.1%), with an adult population, (97.3%) and recruited in reference centers for the treatment of leprosy (52.7%). There was greater use of the WHOQOL-bref (50%) and SF-36 (18.9%) instruments to assess quality of life. The study showed that the greatest impairment in quality of life was related to the delay in the diagnosis of the disease, to leprosy reactions, physical disabilities, neuropathic pain, and stigma. **Conclusion:** Most studies were developed in endemic countries, with adults, and based on observational studies, and the worst scores obtained were associated with physical domain impairment.

DESCRIPTORS

Leprosy; Quality of Life; Neglected Diseases; Review.

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INTRODUCTION

Leprosy is a neglected and stigmatizing tropical disease. Advances in treatment and the implementation of strategies for its control have significantly reduced its prevalence worldwide. However, its magnitude and high disabling power keep it as a public health problem in 123 countries⁽¹⁾.

In 2019, 202,185 new cases of leprosy were reported worldwide, with 14,981 (7.4%) of these being detected in children under 15 years of age. In addition, of the total number of new cases registered in the world in that same year, 29,936 (93%) occurred in the region of the Americas and 27,863 in Brazil, a figure that places this country as the only one on the continent that remains endemic for the disease⁽¹⁾.

Given the epidemiological scenario of leprosy, which is a condition that represents a priority problem for the health of the individual and his family, there are other challenges to be overcome, such as stigma, social reintegration, and improvement in the patients' quality of life scores⁽²⁻⁵⁾.

Leprosy can affect the skin and peripheral nerves and cause deformities and physical incapacities with relevant social⁽³⁾, emotional⁽⁴⁾, and psychological⁽⁵⁾ impact and, consequently, impairment in the Quality of Life (QoL) of patients affected by the disease^(2,6-8).

According to the World Health Organization (WHO), QoL is defined 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⁽⁹⁾.

The health area, by providing a debate on QoL from the perspective of patient's health, consolidates it as an important thematic axis to be considered both in the context of care practices and in the production of knowledge and public policies. This discussion shows how important it is to assess the impact of diseases on the population's living conditions, contributing to the overcoming of the biomedical model with reference to socioeconomic, psychological, cultural aspects, and actions for health promotion, treatment, and rehabilitation⁽¹⁰⁻¹²⁾.

Quality of life in the health field can be assessed with general or specific instruments. The instruments considered general cover different clinical conditions, allowing the analysis of the disease involvement in the patient's life, and are indicated to assess larger groups. The specific ones, in their turn, measure the QoL of a given disease in a one-time manner^(10,13-14).

Analyzing QoL through validated instruments with reliable psychometric properties allows measuring to what extent the condition relates to daily life, identifying what is not visible, such as feelings of pain and anguish⁽¹⁴⁾.

Leprosy patients may have compromised QoL, with damage mainly in the physical and psychological domains. The physical domain has a direct predominance in the patient's work and daily activities, and this can lead to segregation, isolation, and depressive manifestations, while the psychological domain depicts the way patients see

themselves and relate to the interactional aspects in the environment where they live^(2,6-7,15-26).

In recent years, studies on the assessment of QoL in the health area have become more relevant in the scientific community as they, in addition to data from biomedical measures, also included psychosocial issues, which helped to better measure QoL. This turns to be a relevant process, because the medical condition brings personal and social consequences, requiring the expansion of public policies aimed at strengthening the quality of care provided, especially aspects related to the QoL of these patients and their families^(12,27-28).

Although there is significant scientific production on leprosy, studies assessing the QoL of patients with the disease still need to be expanded, as they are essential for directing attention and health policies. In this regard, the present study aimed to explore the scientific evidence related to the assessment of the quality of life of leprosy patients aiming to characterize the scientific production, find the instruments and domains used in this assessment, synthesize the main findings, as well as identify gaps in knowledge.

METHOD

DESIGN OF STUDY

The scoping review was conducted according to the methodology by the Joanna Briggs Institute (JBI)⁽²⁹⁾, which allows mapping the main concepts, clarifying research areas, and identifying knowledge gaps. The methodological procedures of this method are based on five steps: 1 – Identification of the research question; 2 – Identification of relevant studies; 3 – Study selection; 4 – Data tabulation; 5 – Conference, summary, and reporting of results⁽²⁹⁾.

POPULATION

The mnemonic PCC (Population, Concept, and Context)⁽²⁹⁾ was adopted, with the definitions of P – studies including patients of any age and sex, with a current or previous diagnosis of leprosy; C – since the terms 'quality of life' (QoL) and 'health-related quality of life' (HRQoL) are commonly used interchangeably in the literature⁽³⁰⁾, to avoid unnecessary exclusion of relevant studies, we considered all studies that aimed to assess QoL or HRQoL; C – any environment where the study was developed, such as community, health units of primary, secondary, and tertiary levels, reference in leprosy treatment, or social environments such as former colonies of patients living with the disease. Then, the following research question was elaborated: what evidence is available in the literature on the QoL of patients with leprosy? In addition, more specifically: what are the characteristics of scientific productions, the instruments and domains used in the assessment of these patients, and the gaps in the knowledge produced?

SELECTION CRITERIA

Relevant studies were selected based on the following eligibility criteria: primary studies with a quantitative/qualitative approach or with a mixed method (quali-quantitative); and

published with full text in Portuguese, English, or Spanish, from the beginning of the first publications available in the databases until October 19, 2020. Those who did not answer the research question or who evaluated and/or reported the results of only one domain of QoL were excluded.

DEFINITION OF SEARCH AND INCLUSION STRATEGY

The identification of relevant studies was developed in three stages, starting in July 2018 and updated in October 2020.

A preliminary step of research was taken in the PubMed and Lilacs databases with the descriptors “quality of life” AND “leprosy”, to identify primary studies on the topic and possible descriptors in the titles and abstracts, to expand the research.

In the next step, the search strategy was developed according to the specificity of each database (Chart 1): MEDLINE/PubMed, Cochrane Central, LILACS, Embase, CINAHL, Scopus, Web of Science, PsyINFO, INFOLEP, and Google scholar. Finally, in the third step, the reference lists of the studies selected were accessed for additional research. The Mendeley Desktop software, version 1.19.2, was used as a reference manager.

The process of selection and inclusion of studies (title, abstract and full reading) was carried out by two independent reviewers and by a third one when there was disagreement among peers.

DATA EXTRACTION

An adaptation of a standardized questionnaire⁽³¹⁾ was used to extract data regarding the identification of the

publication (title, authors, country, language), as well as methodological characteristics of the studies (research design, study objectives, population characterization, results, conclusions), criteria used to assess QoL (instruments used and QL domains evaluated), and significant results regarding the impact of the disease on QoL (variables associated with lower QoL indexes and recommendations).

DATA ANALYSIS AND TREATMENT

The selection process of the studies included in this review is presented in the flowchart of preferred report items for systematic reviews and meta-analyses (PRISMA)⁽³²⁾. The findings on the leprosy patients QoL in each publication were identified and extracted considering the objectives of the review, being organized in tables and charts and synthesized in a narrative form.

As this is a systematic scoping review, and according to the adopted methodology, it is exempt from assessment of the methodological quality of the included studies⁽²⁹⁾.

ETHICAL ASPECTS

Regarding the ethical aspect, the reliability and fidelity of the information contained in the selected publications were ensured through proper referencing and rigor in data treatment and presentation.

RESULTS

The search strategy identified a total of 4,876 publications. After excluding 405 duplicates and 4,395 due to

Chart 1 – Search strategy according to the informational resource used in the review – Cuiabá-MT, Brazil, 2019–2020.

Information resource	Search strategy
MEDLINE (PubMed)	((leprosy[mesh terms] or leprosy[tiab] or leprosius[tiab] or “hansen disease”[tiab] or “hansen’s disease”[tiab] or “mycobacterium leprae”[tiab] or “mycobacterium infections”[tiab])) OR “Leprosy, Multibacillary”[Mesh] OR “Leprosy, Paucibacillary”[Mesh] OR “Leprosy, Tuberculoid”[Mesh] OR “Leprosy, Lepromatous”[Mesh] OR “Leprosy, Borderline”[Mesh] and (((((((quality of life[mesh terms] or “quality of life”[mesh major topic] or “qol” [tiab] or “health related quality of life”[tiab] or “health-related quality of life”[tiab] or “hrqol”[tiab] or quality of life[tiab]))
COCHRANE LIBRARY	(lepr* or “hansen disease” or “hansens disease” or “hansen’s disease” or “leprosius”) and (“quality of life” or “health related quality of life” or “health-related quality of life”) limite: trials
LILACS (BVS)	((hanseníase or leprosy or lepra or leprosius) and (“qualidade de vida” or “qualidade de vida relacionada à saúde” or “quality of life” or “health related quality of life” or “health-related quality of life” or “calidad de vida” or “calidad de vida relacionada con la salud”)
EMBASE	‘leprosy’:ti,ab,kw and ‘quality of life’:ti,ab,kw
CINAHL	(mh “leprosy” or ti “leprosy” or ab “leprosy” or ti “hansen disease” or ab “hansen disease” or ab “hansens disease” or ab “hansen’s disease” or ti “leprosius” or ab “leprosius”) and (mh “quality of life” or ti “quality of life” or ab “quality of life” or ti “health related quality of life” or ab “health related quality of life” or ti “health-related quality of life” or ab “health-related quality of life”
SCOPUS	title-abs-key (“leprosy” or “hansen disease” or “hansens disease” or “hansen’s disease” or “leprosius”) and (“quality of life” or “health related quality of life” or “health-related quality of life”)
WEB OF SCIENCE	topic: (“leprosy” or “hansen disease” or “hansens disease” or “hansen’s disease” or “leprosius”) and (“quality of life” or “health related quality of life” or “health-related quality of life”)
PSYINFO	any field: (leprosy or “hansen disease” or “leprosius” or “hansens disease” or “hansen’s disease”) and any field: (“quality of life” or “health related quality of life” or “health-related quality of life”)
INFOLEP	“quality of life”
GOOGLE SCHOLAR	strategy 1: “paucibacillary leprosy” “quality of life”
	strategy 2: “lepromatous leprosy” “quality of life”
	strategy 3: “quality of life” “leprosy patients”

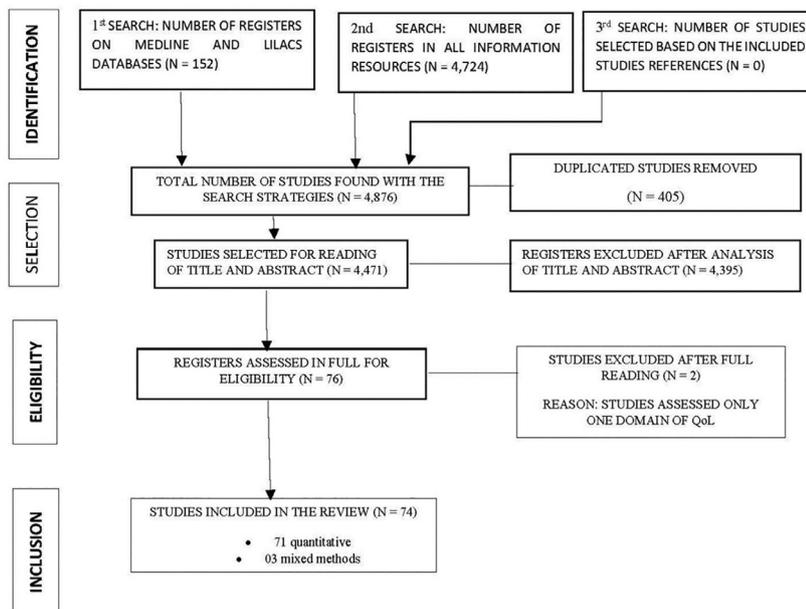


Figure 1 – Flow diagram of the selection of studies included in the review according to PRISMA⁽³²⁾ – Cuiabá-MT, Brazil, 2019–2020.

established eligibility criteria, 76 studies were selected for full reading. Of these, 2 were excluded for reporting only one QoL domain, resulting in a total of 74 studies included in the review. The description of the searches and the selection of articles were based on the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA)⁽³²⁾ (Figure 1).

The 74 studies included in the scoping review were published mainly in English (n = 49; 66.2%), and carried out in 13 different countries, with Brazil presenting the highest number of publications (n = 43; 58.1%). The surveys were predominantly of the observational quantitative type (n = 64; 86.5%), and the mixed method (Questionnaire + Focus Group and Questionnaire + In-depth Interview) was the least cited in the studies included in the review (n = 3; 4.1%). Participants in the studies analyzed in the review were essentially older than 15 years (n = 72; 97.3%), mostly recruited from reference centers for leprosy treatment (n = 39; 52.7%) (Table 1).

As for the year of publication, it was found that the first studies published in the databases on the subject date back to 1999⁽³³⁾ and those with the highest records between the years 2015 (n = 12) and 2019 (n = 11).

There was a higher frequency of the validated instrument with general questions, the World Health Organization Quality Of Life-Bref – WHOQOL-BREF (n = 37; 50.0%), and the Medical Outcome Study – Short form-36 – SF-36 (n = 14; 18.9%), followed by the specific one for skin diseases Dermatology Life Quality Index – DLQI (n = 11; 14.9%). It was also found that 2.7% of the studies included in the review used both the general and the specific instrument to assess QoL (Table 2).

Regarding the results of the studies selected, the grouping of coincident themes allowed the construction of four categories that summarize the main findings and are

Table 1 – Characterization of scientific production on leprosy patients Quality of Life – Cuiabá-MT, Brazil, 2019–2020.

Variables	n	%
Studied population		
>15 years	72	97.3
<15 years	2	2.7
Context		
Reference centers for leprosy treatment	39	52.7
Hospitals	16	21.6
Community/primary health care	12	16.2
Former isolation colonies	7	9.5
Country		
Brazil	43	58.1
India	14	18.9
Indonesia	3	4.1
China	2	2.7
Bangladesh	2	2.7
Nigeria	2	2.7
Others*	8	10.8
Language		
English	49	66.2
Portuguese	14	18.9
Portuguese/English	11	14.9
Approach quantitative		
Observational	64	86.5
Experimental	7	9.5
Mixed method		
Questionnaire + Focus Group	2	2.7
Questionnaire + In-Depth Interview	1	1.4

*Countries with only one study published: Ghana, Ecuador, Malawi, Nepal, Ethiopia, Malaysia, Egypt and Vietnam.

Table 2 – Distribution of studies included in the scoping review according to the instruments and domains used to assess leprosy patients Quality of Life – Cuiabá-MT, Brazil, 2019–2020.

Instrument	Domains evaluated	n	%
WHOQoL-Bref ^(5-7,15-22,24-26,34-55)	Physical; Psychological; Social relationships; Environment	37	50,0
SF-36 ^(2,10,56-67)	Functional capacity; Physical aspects; Pain; General health status; Mental health; Emotional aspects; Social aspects; Vitality	14	18,9
DLQI ^(8,68-77)	Symptoms and feelings; Daily activities; Leisure activities and sports practices; Work and school; Interpersonal relationships; Treatment	11	14,9
WHOQoL-100 ^(33,47)	Physical; Psychological; Level of independence; Social relationships; Environment; Spirituality/Personal Beliefs	2	2,7
DLQI** and SF-36 ⁽⁷⁸⁻⁷⁹⁾	Functional capacity; Physical aspects; Pain; General health status; Mental health; Emotional aspects; Social aspects; Vitality	2	2,7
PedsQL 4.0 ⁽⁸⁰⁾	Physical; Emotional; Social; Educational	1	1,4
NeuroQoL ⁽⁸¹⁾	Pain, Loss/Reduced sensitivity, Diffuse sensory-motor symptoms, Limitations of activities in daily life, Disorder in social relationships and distress Emotional	1	1,4
CDLQI ⁽⁸²⁾	Symptoms and feelings; Leisure; School or vacation; Personal relationships; Sleep and treatment	1	1,4
W-QLI ⁽⁸³⁾	Level of satisfaction; Psychological well-being; Mental symptoms; Physical health; Finances; Activities of daily living	1	1,4
RAND-36 ⁽⁸⁴⁾	Functional capacity; Physical aspects; Pain; General health status; Mental health; Emotional aspects; Social aspects; Vitality	1	1,4
SF-20 ⁽⁸⁵⁾	Physical ability; Limitation due to illness; Mental health; Health perception; Social aspects; Pain	1	1,4
Standardized instrument ^{(86)***}	Does not specify	1	1,4
Not mentioned ^{(87)****}	–	1	1,4
Total		74	100

*general validated instrument: World Health Organization Quality of Life-Bref (WHOQOL-bref); Medical Outcome Study – Short form-36 (SF-36); World Health Organization Quality of Life-100 (WHOQoL-100); Pediatric Quality of Life Inventory™ version 4.0 (PedsQL 4.0); Short Form Health Survey (RAND-36); Short Form-20 (SF-20); Wisconsin-Quality of Life Index (W-QLI).

**specific validated instrument: Dermatology Life Quality Index (DLQI); Quality of Life in Neurological Disorders (Neuro-QoL); Children’s Dermatology Life Quality Index (CDLQI).

***Instrument not validated.

****no information.

presented in Chart 2: 1) Interventions and the impact on leprosy patients QoL; 2) Comparison of leprosy patients QoL and that of other populations; 3) Leprosy patients QoL characterization, and 4) Impact of leprosy on the QoL of children and adolescents with leprosy.

In category 1, only seven of the reviewed studies used the assessment of QoL as an outcome investigated following interventions. These studies included surgical⁽⁸⁴⁾ interventions, as well as those of self-care oriented health education⁽⁵⁸⁾, therapeutic workshops⁽⁴³⁾, stretching-specific physical therapy⁽⁵⁶⁾, medication with emphasis on the treatment of type 1 leprosy reaction⁽⁶⁰⁾, and neuropathic pain⁽⁵¹⁾.

In category 2, on the comparison of the QoL of patients with leprosy with other populations, the studies showed worse QoL scores when compared to patients with other dermatoses and the general population.

Findings presented in category 3 indicated that QoL was frequently related to disease progression (time of treatment, multibacillary forms, leprosy reactions, disabilities, deformities, stigma, and neuropathic pain), and the physical domain had the worst scores in the assessment.

The findings in category 4 indicated that among the 74 studies included in the review, only two (2.7%)

investigated the child-juvenile population regarding the assessment of quality of life related to leprosy. Such evidence indicates moderate impairment of QoL in this age group⁽⁸²⁾ and also lower HRQoL scores when children presented musculoskeletal manifestations, mainly in the domains of physical capacity and school activities⁽⁸⁰⁾.

DISCUSSION

Quality of life has established itself as a significant concept in the health area, both in research and in care practice. In the present review, it was identified that, in recent years, a significant number of studies have focused on investigating leprosy patients QoL. As a result, it brought a better understanding of the disease, of treatment and, consequently, of decision-making at different levels of care⁽⁸⁸⁾.

The review showed Brazil as the country with the largest number of published studies from reference centers for leprosy treatment. These findings confirm the hyperendemicity of the disease in the country⁽¹⁾, related to factors regarding social, demographic, and economic aspects, among others. These factors can interfere with the population’s access to health services, resulting in late diagnosis and, consequently, in physical disability, observed in advanced clinical forms of the disease, which would justify the fact that

Chart 2 – Synthesis of evidence on the assessment of the leprosy patients Quality of Life – Cuiabá-MT, Brazil, 2019–2020.

Category	Main findings
(1)	There was no significant difference in quality of life between the group treated for leprosy-related neuritis on an outpatient basis and those that were hospitalized ⁽⁴⁷⁾ .
	The performance of surgical intervention for nerve decompression in patients with leprosy-related neuropathy resulted in a significant improvement in QoL ⁽⁸⁴⁾ .
	The use of a manual containing guidelines on self-care for the prevention of disability showed a statistically significant improvement in the domains of pain and social aspects of QoL ⁽⁵⁸⁾ .
	The performance of therapeutic workshops (arts, music and recreation/games) showed a statistically significant improvement in the physical, psychological, and environment domains of QoL ⁽⁴³⁾ .
	The application of passive static stretching exercises in the treatment of leprosy sequelae provided significant gains in quality of life ⁽⁵⁶⁾ .
	Those with type I leprosy reaction treated with cyclosporine® and prednisolone®, as well as those treated only with prednisolone, showed a significant improvement in quality of life, although without significant difference between the two groups ⁽⁶⁰⁾ .
	Botulinum toxin type A proved to be a good therapeutic option for pain relief with improved quality of life for leprosy patients ⁽⁵¹⁾ .
(2)	Leprosy patients had worse QoL scores when compared to those with other dermatoses ^(35,71) .
	Leprosy patients indicated worse QoL scores when compared to the general population ^(15,22,24,33,37,40,66) .
(3)	Paucibacillary leprosy showed better QoL scores ^(2,8,74,76,78-79) .
	Leprosy patients residing in the Brazilian Southeast region indicated better QoL scores ⁽⁷⁰⁾ .
	Better QoL scores were observed among leprosy patients who completed the treatment ⁽³⁴⁾ .
	Leprosy compromises mainly the physical component of QoL ^(2,6-7,10,15-20,22-23,34,44,48-49,52,56-58,60-61,63-65,84) .
	There is QoL impairment in leprosy reactions patients ^(8,16,66,76) , with greater effect in patients with Erythema Nodosum Leprosum ^(2,61-62,66,73) .
	Patients with isolated neuritis had significantly lower mean in all QoL domains compared to individuals without reaction ⁽⁶⁶⁾ .
	The presence of pain has a negative impact on the assessment of the QoL of leprosy patients ^(15,17,42,49,52,63) .
	Disability due to leprosy is related to greater impairment of quality of life ^(2,4,26,35,48,57,76) , being higher among those with visible disability ^(34-36,38-39,54,56,77) .
	Stigma has a negative impact on the leprosy people QoL ^(7,36,38,52) .
	The combination of neuropathy and stigma significantly increases QoL impairment ⁽⁵²⁾ .
	Leprosy patients with altered psychological health had low QoL scores ⁽²⁴⁻²⁶⁾ .
	The greater the limitation of activity in individuals affected by leprosy, the lower the QoL, mainly affecting the physical and environmental domains ^(6,48) .
	There was no significant association between physical activities and quality of life in individuals with leprosy ⁽⁵⁴⁾ .
	There was a significant difference in the domain of social, physical and psychological relationships among leprosy patients with symptoms of testicular dysfunction and patients without these symptoms ⁽⁵³⁾ .
	There was a relationship between family support and quality of life in leprosy patients, and the greater the family support, the better the quality of life ⁽⁵⁵⁾ .
The longer the duration of the disease, the greater the impact on QoL ^(26,39,77) .	
Leprosy negatively impacts QoL even after treatment is completed ⁽⁶⁹⁻⁷⁷⁾ .	
(4)	There is moderate impairment of the quality of life in leprosy patients under 15 years of age ⁽⁸²⁾ .
	Children and adolescents with leprosy and musculoskeletal manifestations had lower HRQoL scores in the domains of physical capacity and school activities when compared to those without these manifestations ⁽⁸⁰⁾ .

the population, in most studies, was recruited from reference units for the disease⁽⁸⁹⁾.

Leprosy remains a disease of difficult control for public health in endemic countries⁽¹⁾. Recently, the Ministry of Health of Brazil launched the National Strategy for Coping with the disease and, for the first time, patients' subjectivity and the specificity of each region of the country were respected, with different strategies being presented for each of them, according to geographic characteristics⁽⁸⁹⁾. In this context, the need to consider the subjectivity of each individual and the lifestyle in the society in which they live to reduce the impact of the disease on their QoL⁽⁹⁰⁻⁹²⁾ is highlighted.

The studies included in the current review were predominantly cross-sectional studies of quantitative approach. It should be noted that quantitative data on QoL assessment, despite reflecting the multidisciplinary nature of the human focus on their domains, may not capture their subjectivity, so the inclusion of qualitative approaches is essential. Qualitative studies allow capturing valuable information about the experiences and needs of patients in specific contexts, in addition to facilitating the understanding and interpretation of the meaning of quality of life, as well as the aspects that most affect it^(12,93-94).

As for the population characteristics, the surveys essentially included adults and/or the elderly, during or after

treatment. None of the retrieved studies specifically investigated patients being retreated, with treatment resistance, or even assessed the individuals' QoL over time. Thus, the current review failed to adequately address QoL among some groups whose experience may substantially differ from that of other leprosy patients.

Furthermore, only 2.7% of the total number of studies included in the review assessed the leprosy children and adolescents QoL. It is believed that the knowledge gap identified in this age group may be related to the lower prevalence of leprosy in this group than in adults, making it difficult to gather findings, as well as to the challenges of assessing children and adolescents QoL, such as the need for specific tools to measure it, interpretation of evaluated QoL measures, as a proxy, including children and their guardians, as well as ethical issues involving the participation of this population in research^(82,95). The increase in the number of cases of this disease in children and adolescents is an important epidemiological indicator and is intrinsically linked to the deficit in detecting the disease, which significantly increases its transmission rates⁽⁹⁶⁾.

Studies on leprosy in children and adolescents in Brazil demonstrate the need for better orientation of public health policies for its continuous and systematic surveillance, which also includes intra-household and social contacts, contributing to the understanding of the endemic behavior of the disease. Leprosy in this population, when diagnosed late, can lead to psychological sequelae that are difficult to treat and directly impact their quality of life and family^(80,82,97-99).

Studies have shown that QoL assessment is complex, and requires multiple measures to capture its subjectivity and multidimensionality, so that several instruments were developed to measure it⁽⁹¹⁾. As highlighted above, instruments with general questions provide a broader assessment and can be used for comparisons among different types of diseases and their degree of severity and treatments, as well as different demographic groups. The specific ones, on the other hand, propose to measure particular aspects of certain conditions in QoL, which may be exclusive to a special disease, condition, function or population^(10,13,14,91).

Regarding the instruments used to assess leprosy patients QoL, the review identified three validated instruments that were most frequently applied, the WHOQolbref (50%), the SF-36 (18.9%), and the DLQI (14.9%). The WHOQol-bref is a general instrument – short version of the WHOQOL-100, consisting of 26 items divided into 4 domains (physical, psychological, social relations, and environment)^(14,100). The SF-36, an instrument that also includes general health-related aspects, is intended to detect relevant clinical and social differences in health status, both in the general population and in individuals affected by any disease, as well as changes in health over time. The SF-36 questions are divided into two major components: the physical one, which includes the functional capacity, general health, pain, and physical aspects domains; and the mental one, which covers mental health, vitality, social, and emotional aspects⁽¹¹⁾. The specific QoL questionnaire for skin diseases, DLQI, consists of ten items that are divided

into six domains: 1 – Symptoms and feelings; 2 – Daily activities; 3 – Leisure; 4 – Work/school; 5 – Interpersonal relationships; and 6 – Treatment⁽¹⁰¹⁾.

The literature indicates that instruments addressing general QoL issues, such as the WHOQolbref and the SF-36, despite allowing the assessment of different areas or domains of different populations with different diseases, have the disadvantage of not incorporating all factors relevant to the QoL of groups with specific diseases⁽⁹³⁾; it is possible that some aspects inherent to leprosy have been under-evaluated by this type of instrument^(47,65-66).

Specific questionnaires for a particular group of diseases, such as the DLQI, focus on common aspects of different diseases, allowing comparisons among related but distinct populations, being particularly important for infrequent diseases, as they help to overcome the limitations associated with small samples^(88,101).

It should be noted that the association of a general and specific instrument⁽⁹⁵⁾ is recommended, as this ensures a more comprehensive view when evaluating different aspects of QoL, producing both general data, which facilitate comparisons between different health problems, and related data, specifically, the impact of a given disease on QoL. However, this association is uncommon in studies on leprosy people QoL, and was observed in only 2.7% of the studies included in this review⁽⁷⁸⁻⁷⁹⁾.

The findings of this study showed that physical domain – which mainly covers the assessment of pain and discomfort, dependence on medication or treatment, energy and fatigue, sleep and rest, mobility, daily activities and work capacity – often had lower scores in the QoL assessment in studies with leprosy patients^(10,15-23,44,56-61,63-65). However, it is highlighted that the change in people's lives, based on the symptoms and signs of the disease, the reactions and the development of disabilities, can lead to social isolation, work losses, difficulty in accepting the disease process and self-care; therefore, reaching not only the physical component, but also the emotional, social, and environmental component, as demonstrated in some studies^(7,24,34-43,45,72).

The studies included in this review showed that leprosy individuals had significantly lower QoL when compared to populations with other dermatoses^(35,71) and the general population^(15,22,24,33,37,40,66), which is corroborated by other studies that indicate that factors such as delayed diagnosis^(2,8,43,74,76,78-79), the presence of leprosy reactions^(2,8,16,61-62,72), disability^(5,8,39,72), neuropathic pain^(7,17-18,63,86), and stigma^(2,41,54) are often associated with greater losses in QoL.

Other studies, in their turn, show that early diagnosis and treatment^(2,5,25,39,47,70,76-77), the multidisciplinary approach to the patient^(10,12,15,33,41,59,65,73,81-82,86), the fight against social stigma^(15,25,40,63,82,86), the development of actions aimed at the prevention and appropriate management of disabilities^(5-6,8,28,64,71,85), health education for patients affected by leprosy^(39,54,77), and adequate follow-up in the post-discharge period^(22,38,70) are critical to improve the QoL of these individuals.

The study has its limitations because the evidence from observational research identified in the review shall be interpreted taking into account the possible biases inherent to the methodological design, which in itself weakens the analysis of results. In addition, other aspects such as variation in the instruments used, and the different ways of reporting QoL results, made comparison difficult. Another issue is the population selected in the surveys, mostly from reference centers for the treatment of leprosy, that is, patients in an advanced stage of the disease and often with physical disabilities already installed, which may have indicated the greater negative impact on the physical aspects of QoL.

CONCLUSION

The assessment of QoL was more frequently developed in hyperendemic countries, in adults, with late disease progression, and mostly through instruments that assessed general QoL issues. Evidence indicated impairment of the physical domain related to delayed diagnosis, leprosy reactions, physical disabilities, neuropathic pain, and stigma as the main aspects linked to the worst scores in the assessment of QoL. However, the review identified that the improvement in the QoL of patients was related to early diagnosis

and treatment, health education, a multidisciplinary approach, prevention of physical disabilities and stigma.

One can point out as knowledge gaps, evidenced in this review, the lack of research with children and adolescents, studies that used general and specific instruments together for the assessment of QoL, as well as those with a qualitative approach.

Greater investments in future research with the children and young population are recommended to investigate the perception that this group has of their health status, using parameters and instruments appropriate to this age group, as well as studies that demonstrate the effectiveness of evaluative interventions, as well as the proposition of validated instruments that include information from both general and specific domains and directed to each population. The development of studies with a qualitative approach or a mixed method are also suggested.

It is thought that the insertion of a Care Model for Leprosy Care in care practice could ensure more qualified care directed to the prevention, rehabilitation of physical disabilities, and management of stigma. In this regard, the need to include systematized care protocols that are applied in a multidisciplinary way, at all levels of care, supported by scientific evidence, is also highlighted.

RESUMO

Objetivo: Explorar as evidências científicas relativas à qualidade de vida de pacientes com hanseníase. **Método:** revisão de escopo segundo a metodologia do Instituto Joanna Briggs, com artigos indexados nas bases de dados PubMed, Cochrane, LILACS, Embase, CINAHL, Scopus, Web of Science, PsYINFO, INFOLEP e Google Scholar, publicados na íntegra em português, inglês ou espanhol. **Resultados:** identificaram-se 74 estudos, sendo 71 de abordagem quantitativa e 3 com método misto. Houve predominância de estudos publicados no Brasil (58,1%), com população adulta (97,3%) e recrutada em centros de referência para tratamento de hanseníase (52,7%). Verificou-se maior utilização dos instrumentos WHOQOL-bref (50%) e SF-36 (18,9%) para avaliação da qualidade de vida. O estudo evidenciou que o maior comprometimento da qualidade de vida se relacionou ao atraso no diagnóstico da doença, às reações hanseníase, às incapacidades físicas, à dor neuropática e ao estigma. **Conclusão:** as pesquisas foram desenvolvidas em sua maioria em países endêmicos, com adultos e a partir de estudos observacionais, sendo que os piores escores obtidos se associaram ao comprometimento do domínio físico.

DESCRITORES

Hanseníase; Qualidade de Vida; Doenças Negligenciadas; Revisão.

RESUMEN

Objetivo: Explorar las evidencias científicas con relación a la calidad de vida de pacientes con lepra. **Método:** revisión de alcance según la metodología del Instituto Joanna Briggs, con artículos indexados en las bases de datos PubMed, Cochrane, LILACS, Embase, CINAHL, Scopus, Web of Science, PsYINFO, INFOLEP y Google Scholar, publicados integralmente en portugués, inglés o español. **Resultados:** se identificaron 74 estudios, entre los cuales 71 fueron de abordaje cualitativo y 3 con método mixto. Predominaron estudios publicados en Brasil (58,1%), con población adulta (97,3%) y convocada en centros de referencia para tratamiento de lepra (52,7%). Se verificó mayor utilización de los instrumentos WHOQOL-bref (50%) y SF-36 (18,9%) para evaluación de la calidad de vida. El estudio mostró que los factores que más afectaron la calidad de vida fueron el retraso en el diagnóstico de la enfermedad, las reacciones leprosas, las discapacidades físicas, el dolor neuropático y el estigma. **Consideraciones Finales:** las investigaciones fueron desarrolladas en gran parte en países endémicos, con adultos y a partir de estudios de observación, por lo que los peores resultados obtenidos se asociaron a las complicaciones del dominio físico.

DESCRIPTORES

Lepra; Calidad de Vida; Enfermedades Desatendidas; Revisión.

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