



## QUALITY OF LIFE OF PEOPLE WITH LEPROSY SEQUELAE AND SELF-CARE: AN INTEGRATIVE REVIEW

Rayla Maria Pontes Guimarães Costa\*  
Layza Castelo Branco Mendes\*\*

### RESUMO

**Objective:** To identify the scientific literature on the quality of life of people with leprosy sequelae and its relation to self-care. **Method:** An integrative literature review was conducted in July 2018. The databases PubMed, LILACS, EMBASE, and Google Scholar were used. Nine articles that met the following inclusion criteria were analyzed: published between 2008 and 2017, free full-text available online, written in Portuguese or English, and addressing the themes quality of life, self-care, and leprosy. For data extraction, the selected articles were read in full. Data analysis was descriptive. **Results:** By discussing the quality of life of people with leprosy sequelae, the studies showed that the physical domain was the most affected, causing a self-care deficit. Few data have been published on quality of life and its relation to self-care. **Conclusion:** Thinking through self-care is a need due to the lack of studies on the theme, which has been emerging, as it is known that self-care may favor a significant improvement in the quality of life of people with leprosy sequelae.

**Palavras-chave:** Leprosy. Self-care. Quality of life. Disabled persons.

### INTRODUCTION

Leprosy is a chronic infectious disease that has one or more clinical manifestations, namely: skin lesion with altered thermal sensitivity, painful or tactile, peripheral nerve thickening, associated with sensory, motor, or autonomic changes and presence of the *Mycobacterium leprae* bacillus, requiring treatment with multidrug therapy (MDT)<sup>(1)</sup>, in addition to being a compulsory notification disease that is included in the list of neglected tropical diseases<sup>(2)</sup>.

Due to the involvement of peripheral nerves, the prevalence of physical disability in leprosy patients is high (64.4%), mainly due to late diagnosis<sup>(3)</sup>.

These disabilities may be classified into degrees (physical disability grade [PDG]), according to neural impairment of eyes, nose, hands, and feet: grade 0 – absence of motor-sensory impairment; grade 1 – sensory impairment; and grade 2 – motor impairment and/or presence of sequelae<sup>(4)</sup>. Disabilities that most affect the daily lives of leprosy patients are related to difficulty closing their eyes, decreased sensitivity, muscle weakness, ulceration, and hand and foot deformities<sup>(5)</sup>.

Leprosy generates sequelae – chronic conditions that permanently interfere with the persons' lives – that compromise the performance of daily life activities and the quality of life (QoL) of these individuals. It is noteworthy that the PDG is responsible for major consequences of disease, as it directly affects labor productivity, daily life activities, and interpersonal relationships, and it also triggers psychosocial disorders and decreases QoL in patients, with social, economic, and psychological impacts<sup>(6)</sup>.

In this context, QoL has been the focus of many studies in recent years, as it affects the evolution of disease and people's self-esteem<sup>(7)</sup>. According to the World Health Organization (WHO)<sup>(8)</sup>, health-related quality of life (HRQoL) is defined as a person's perception of her/his life, in the domain of culture and value system, considering her/his life goals, expectations, standards, and concerns. Therefore, the deployment of self-care actions to improve HRQoL in these individuals is timely, since decreased HRQoL is related to loss of functional ability, compromising self-care actions<sup>(9)</sup>.

These actions include the execution of practices performed individually or collectively and they can be managed by the

\*Nurse. Ph.D. student, Piauí State University, Parnaíba, Piauí, Brazil. E-mail: rayla.guimaraes@hotmail.com ORCID ID: <https://orcid.org/0000-0002-1794-1419>.

\*\*Psychologist. Ph.D., Ceará State University, Fortaleza, Ceará, Brazil. E-mail: layza.mendes@uece.br ORCID ID: <https://orcid.org/0000-0003-1729-5768>

multiprofessional team, in order to stimulate the empowerment of patients as protagonists in relation to their health needs. The actions that people take on a daily basis to prevent, control, or reduce the impact of chronic conditions characterize self-care, while health team interventions that help people to improve their skills are named as supported self-care<sup>(10)</sup>.

Thus, this article shows to be relevant in order to provide a stronger theoretical basis on the theme, with compilation of scientific evidence about self-care and QoL. The objective of this study was:

- To identify the scientific literature on the quality of life of people with leprosy sequelae and its relation to self-care.

## METHOD

An integrative literature review was carried out, a methodology that aims to identify, analyze, and synthesize research results on a given theme, in a systematic and orderly manner, producing a broad panorama of concepts<sup>(11)</sup>. The process to prepare an integrative review has 6 steps<sup>(12)</sup>: 1) formulation of the guiding question – identification of the theme and problem, as well as the study descriptors; 2) literature search – determination of the inclusion and exclusion criteria; 3) data collection – definition of the subjects, methodology, and concepts according to the descriptors; 4) critical analysis of studies – determination of the information extracted from selected studies; 5) discussion of results – interpretation and synthesis; and 6) presentation of the integrative review – synthesis of the data found.

This study has been guided by the question based on the pico (p = participants; i = phenomenon of interest; co = study context) strategy:

- What are the benefits of supporting self-care on the quality of life of people with leprosy sequelae?

In this review, the pico strategy was adopted to formulate the guiding question based on scientific evidence<sup>(13)</sup>: *participant* = person with leprosy sequelae; *phenomenon of interest* = supporting self-care; and *study context* = quality

of life.

Articles within the following inclusion criteria were considered eligible: published between 2008 and 2017, free full-text available online, written in portuguese and english, and addressing the themes quality of life, self-care, and leprosy. Full articles must be published and indexed in the databases pubmed, lilacs, embase, and google scholar. Articles that had only the abstract available online, duplicate articles, editorials, letters to the editor, theses, dissertations, and monographs were excluded.

The survey was conducted in July 2018. To do this, terms from the structured vocabularies “health sciences descriptors” (descritores em ciências da saúde [decs]) or “medical subject headings” (mesh) were used, by crossing the descriptors between themselves, through the boolean operation. In english, we used: quality of life and leprosy and self care. In portuguese, we used: qualidade de vida and hanseníase and autocuidado. It is noteworthy that data search, selection, and extraction were conducted by a single researcher.

Having the descriptors as a basis, 73 articles were found, which were assessed through analysis of titles and abstracts. However, 56 were excluded, because they did not meet the inclusion criteria. When the titles and abstracts were not enough to define the initial selection, the full publication was read, where 8 articles were excluded, because they did not meet the inclusion criteria defined for this study, too. After this step, 9 articles that met the inclusion criteria were selected.

The data extraction step considered the full reading of eligible articles to confirm their permanence in the sample. After this step, the presentation of results emerged, where tables and boxes were prepared. Data analysis was performed descriptively, allowing us to evaluate the available literature on the theme under study.

## RESULTS

To consolidate the results of this study, only 9 articles, out of the 73 found, constitute the sample because they meet the inclusion criteria (Table 1).

**Table 1.** Distribution of articles found, excluded, and selected. Parnaíba, Piauí, Brazil, 2018.

Database	Found	Excluded	Selected
LILACS	04	00	04
PubMed	12	10	02
EMBASE	15	14	01
Google Scholar	42	40	02
<b>Total</b>	<b>73</b>	<b>64</b>	<b>09</b>

**Source:** Prepared by the authors.

Box 1 details the main results found in the database, year of publication, research design, articles that constitute the sample: authors, title, objectives, and main results.

**Box 1.** Distribution of selected articles. Parnaíba, Piauí, Brazil, 2018.

Authors	Titles	Database/year	Design/number of participants	Objectives	Main results
Reis, Gomes, and Cunha.	Avaliação da limitação das atividades diárias e qualidade de vida de pacientes com hanseníase submetidos a cirurgia de neurólise para tratamento das neurites.	LILACS/2013	Cross-sectional study N = 36	To identify the activity limitation degree and the quality of life of leprosy patients undergoing neurolysis to treat neuritis.	Six patients had disability grade 0, 18, grade 1; and 12, grade 2. Many members had activity limitations which are higher in those with physical disabilities. The highest dissatisfaction in quality of life concerned the physical domain, mainly related to pain and health care needs obtained from the WHOQOL-BREF analysis.
Santos, Oliveira, Castro, Gois-Santos, Lemos, and Ribeiro.	Functional activity limitation and quality of life of leprosy cases in an endemic area in Northeastern Brazil.	PubMed/2015	Cross-sectional study N = 104	To identify the association between physical activity limitations and quality of life in patients during and after leprosy treatment.	Functional limitations are associated with poor quality of life in leprosy patients, with low scores for the physical and environmental domains, in the WHOQOL-BREF questionnaire evaluation.
Castro, Veloso, Matos Filho, Coelho, Pinto, and Castro.	Avaliação do grau de incapacidade física de pacientes com hanseníase submetidos ao Dermatology Quality Life Index em centro de referência e unidades básicas de saúde.	Google Scholar/2009	Observational, clinico-epidemiological cross-sectional study N = 54	To assess the physical disability degree in leprosy patients by correlating it to quality of life impairment.	Most patients (31%) had high quality of life impairment; 28%, moderate impairment; 24%, little compromise; 13%, extreme impairment; and only 4% did not report quality of life impairment. Regarding the disability degree, most (61.1%) had grade 1.
Silva, Guisard, Metello, Ferreira, Marziak, and Clemente.	Sonhos interrompidos, caminhos desviados, marcas amenizadas por pensões.	EMBASE/2013	Population-based health survey, with quantitative approach N = 485	To conduct a population survey with leprosy patients receiving State pensions as a compensatory policy.	The importance of pension income on the survival of pensioners and their families, as well as the impact of leprosy and compulsory isolation on the lives of leprosy patients, is confirmed.
Rodini, Gonçalves, Barros, Mazzer, Elui, and Fonseca.	Prevenção de incapacidade na hanseníase com apoio em um manual de autocuidado para pacientes.	LILACS/2010	Evaluative study N = 26	To assess the physical and functional status of eyes, hands, and feet of leprosy patients in relation to the onset and evolution of sensory-motor disabilities, the disability degree, and the quality of life.	The most affected nerves were the ulnar and posterior tibial nerves, causing a disability degree and deformities. However, there was significant improvement in the pain and social aspects domains of the SF-36 questionnaire, as well as in the muscular function of hands and feet and in feet dryness.

Continua.

Budel, Costa, Pedri, Raymundo, and Gerhardt.	Perfil dos pacientes acometidos pela hanseníase atendidos no ambulatório de dermatologia.	PubMed/2011	Observational, clinico-epidemiological, cross-sectional study N = 22	To profile leprosy patients treated at the Outpatient Clinic of the Evangelical University Hospital of Curitiba; to assess how leprosy affected the quality of life in these patients; to correlate the scores to the variables sex and disease form (paucibacillary and multibacillary).	The scores obtained by applying the Dermatology Life Quality Index ranged from 1 to 25 points, with a mean of 10.23. 50% of the patients had a severe or very severe score; 31.8% of the patients, from mild to moderate; and 18.25% of the patients reported that there was no quality of life impairment.
Finez and Salotti.	Identificação do grau de incapacidade em pacientes portadores de hanseníase através da avaliação neurológica simplificada.	LILACS/2011	Descriptive exploratory study, with a quantitative approach N = 19	To assess the disability degree in leprosy patients after drug treatment discharge, by means of the simplified neurological assessment instrument.	Grade 2 was the most prevalent, with several disabilities that may be indicative of late diagnosis.
Lima, Simpson, and Cabral.	Limitação de atividades e participação social em pacientes com hanseníase.	Google Scholar/2014	Descriptive and exploratory study, with a quantitative approach N = 22	To describe changes in daily life activities and interpersonal relationships of a leprosy patient.	10 patients had no limitations; 11 had mild limitation; and only 1 had moderate limitation in their daily life activities. Regarding social participation, only 3 respondents had social restrictions.
Souza, Ayres, Meneguín, and Spagnolo.	Autocuidado na percepção de pessoas com hanseníase sob a ótica da complexidade.	LILACS/2014	Descriptive, exploratory, with a qualitative approach N = 15	To grasp the perception of leprosy patients in relation to self-care, from the complexity viewpoint.	The study showed the hegemonic model and its concern to treat only the disease, disregarding the complex relationships that surround it.

**Source:** Prepared by the authors.

This study had predominance of articles published in Portuguese (8) and only 1 in English, with a concentration of publications in the years 2011, 2013, and 2014. As for the design, there were 4 cross-sectional studies, 3 descriptive studies, 1 evaluative study, and 1 health survey.

The instruments used to assess QoL, which supported data collection, were: “World Health Organization Quality of Life – Short Form–26” (WHOQOL-BREF)<sup>(15-16)</sup>, the “SF-36” questionnaire<sup>(20)</sup>, which has been translated to and validated in Portuguese, and the “Dermatology Life Quality Index,” developed in the United Kingdom<sup>(17,21)</sup>, translated to and validated in Portuguese (DLQI-BRA). Also, data were collected through structured and semi-structured interviews<sup>(19,26)</sup>.

To assess activity limitations, we used the instrument “Screening Activity Limitation and Safety Awareness” (SALSA), which was based on the “International Classification of Functioning, Disability, and Health” (ICF),

validated for Brazilian Portuguese<sup>(15-16,24)</sup>. The simplified assessment of neural functions and complications of the Brazilian Ministry of Health<sup>(23)</sup> was also used.

## DISCUSSION

By discussing the qol of people with leprosy sequelae, studies showed that the physical domain was the most affected, followed by the environment, psychological, and social relationship domains<sup>(15-16)</sup>.

Pain, discomfort, and drug dependence were identified as the most compromised in the physical domain<sup>(15-17)</sup>. In the environmental domain, the financial resources and transportation facets showed greater dissatisfaction<sup>(15-16)</sup>. These 2 domains contribute to decrease quality of life in people who have some severe restriction or limitation due to leprosy<sup>(18)</sup>.

In the psychological domain, feelings of unconformity, sadness, shame, insecurity, and

worthlessness were the most mentioned<sup>(15-19)</sup>. In social and emotional relationships, dissatisfaction with sexual activities and friendships reflect the impact of leprosy on social and family life<sup>(15-17)</sup>. However, it was found that there was a significant improvement in the pain and social aspects domains among literate patients, when compared to illiterate patients<sup>(20)</sup>. It is believed that this occurs because literate patients have more access to and information on health information. Moreover, it is known that the higher the education level, the more knowledge a person has about the disease and, consequently, more access to health services, thus enabling an earlier diagnosis and, as a result, less disability<sup>(3)</sup>.

Regarding qol, the scores obtained by applying the dlqi-bra showed that 50% of the patients had severe or very severe qol impairment; 31.8% of the patients, from mild to moderate, and 18.2% of the patients reported no injury<sup>(21)</sup>. It is also claimed that 31% of the patients had high qol impairment; 28%, moderate; 24%, low impairment; 13%, extreme impairment; and only 4% reported no qol impairment<sup>(17)</sup>.

These QoL impairments in people with leprosy sequelae cause major physical and mental damage, preventing them from having a full life, requiring constant support in their daily life activities, especially with regard to self-care actions. Thus, it is expected that self-responsibility among these people towards their lives fosters self-care actions that contribute to improve QoL. In this way, it is a must to prevent complications and to put into practice a self-care routine that enables health education actions aimed at knowledge and development of the skills needed to cope with their health conditions<sup>(22)</sup>.

Furthermore, deploying preventive measures, such as health education and monitoring of leprosy control actions, implies higher education level and more information about the disease, providing a more effective self-care<sup>(3)</sup>.

As for daily life activity limitations, 1 study conducted with 36 patients found that 6 of them had grade 0 disability, 18 patients, grade 1; and 12 patients, grade 2<sup>(15)</sup>. However, 2 other studies identified predominance of patients with grade 2 disability<sup>(16,23)</sup>, and in another study half of the

participating patients had grade 1 disability<sup>(17)</sup>.

In one study, the SALSA Scale was used and it was found that 10 patients had no limitations; 11 had a mild limitation, and only 1 had moderate limitation in their daily life activities<sup>(24)</sup>. Skin lesions, neural involvement, and late diagnosis are responsible for these limitations. It is noteworthy that neural involvement can occur in all forms of leprosy<sup>(25)</sup>.

It is also worth emphasizing that the development and onset of physical, emotional, and social limitations and disabilities in these people is one of the obstacles involved in disease morbidity and chronicity, requiring effective actions to control and monitor the cases<sup>(18)</sup>.

Furthermore, it was found that the QoL domains affected by leprosy could be mitigated or avoided through early diagnosis and treatment, since many patients discover the disease late, already with deformities and disabilities<sup>(26)</sup> and, consequently, with daily life activity limitations.

This fact leads us to infer that self-care is significant to overcome daily life activity limitations, as it stimulates people with leprosy sequelae to learn more about themselves, their bodies, and their needs. These people may be advised by the multiprofessional team, in order to meet their needs for support, daily inspection skills, and procedures to protect the skin and structures affected by disease (which include recognition of signs and symptoms of reactions and neuritis, use of daily protective instruments, practice of prescribed exercises, and use of adapted instruments, when recommended)<sup>(4)</sup>.

It was evidenced that people do not benefit from self-care because they do not grasp how to put it into practice autonomously and do not know the disease and the readjustments needed after diagnosis. Thus, they believe that their actions do not interfere with their lives and self-care and must be advised to know themselves, to be aware of their chronic condition and, therefore, to manage self-care<sup>(27)</sup>. This is where the importance of self-care support lies.

In this context, it is worth noticing that this study has some constraints, among them the search by a single researcher and the collection process in only four databases stand out, something which contributes to the scarcity of articles found.

## FINAL CONSIDERARIONS

It was found that the qol of people with leprosy sequelae was significantly compromised. So, the adoption of strategies to minimize the damage resulting from this millenary disease is a must. Among such strategies, it is worth mentioning those that raise awareness of self-care or supported self-care actions – on the part

of health professionals – along with the patients who, due to leprosy sequelae, show physical and psychological losses. There is a need to highlight the poor knowledge on supported self-care, which could be an intermediate stage for self-care awareness and practice. Overcoming these losses requires a collective effort on the part of health professionals and institutions and people with leprosy sequelae.

## QUALIDADE DE VIDA DOS SUJEITOS COM SEQUELAS PELA HANSENÍASE E AUTOCUIDADO: UMA REVISÃO INTEGRATIVA

### RESUMO

**Objetivo:** Identificar a produção científica acerca da qualidade de vida dos sujeitos com sequelas pela hanseníase e sua relação com o autocuidado. **Método:** Realizou-se, em julho de 2018, uma revisão integrativa da literatura. Foram utilizadas as bases de dados PubMed, Lilacs, EMBASE e Google Acadêmico. Analisaram-se 9 artigos que atenderam aos seguintes critérios de inclusão: publicados entre 2008 e 2017, disponíveis na íntegra *on-line* e gratuitamente, escritos em língua portuguesa ou inglesa e que abordassem as temáticas qualidade de vida, autocuidado e hanseníase. Para extração dos dados, fez-se a leitura na íntegra dos artigos selecionados. A análise dos dados foi descritiva. **Resultados:** Ao discutir a qualidade de vida dos sujeitos com sequelas pela hanseníase, os estudos mostraram que o domínio físico foi o mais comprometido, ocasionando déficit no autocuidado. Poucos dados foram publicados sobre qualidade de vida e sua relação com o autocuidado. **Conclusão:** Refletir sobre o autocuidado é uma necessidade diante da carência de estudos sobre o tema, que se torna emergente, na medida em que se sabe que o autocuidado pode favorecer a melhora significativa da qualidade de vida dos sujeitos com sequelas pela hanseníase.

**Palavras-chave:** Hanseníase. Autocuidado. Qualidade de vida. Pessoas com deficiência.

## CALIDAD DE VIDA DE LOS SUJETOS CON SECUELAS POR LA LEPRO Y AUTOCUIDADO: UNA REVISIÓN INTEGRADORA

### RESUMEN

**Objetivo:** identificar la producción científica acerca de la calidad de vida de los sujetos con secuelas por la enfermedad de Hans o lepra y su relación con el autocuidado. **Método:** se realizó, en julio de 2018, una revisión integradora de la literatura. Fueron utilizadas las bases de datos *PubMed*, *Lilacs*, *EMBASE* y *Google Acadêmico*. Se analizaron 9 artículos que atendieron los siguientes criterios de inclusión publicados entre 2008 y 2017, disponibles en su totalidad *on-line* y gratuitamente, escritos en lengua portuguesa o inglesa y que tratasen las temáticas calidad de vida, autocuidado y lepra. Para la recolección de los datos, fue hecha la lectura en su totalidad de los artículos seleccionados. El análisis de los datos fue descriptivo. **Resultados:** al discutir la calidad de vida de los sujetos con secuelas por la lepra, los estudios demostraron que el dominio físico fue el más perjudicado, ocasionando déficit en el autocuidado. Pocos datos fueron publicados sobre calidad de vida y su relación con el autocuidado. **Conclusión:** reflexionar sobre el autocuidado es una necesidad ante la carencia de estudios sobre el tema, que se vuelve prioritario, en la medida que se sabe que el autocuidado puede favorecer la mejora significativa de la calidad de vida de los sujetos con secuelas por la lepra.

**Palabras clave:** Lepra. Autocuidado. Calidad de vida. Personas con discapacidad.

## REFERENCES

1. Brasil. Diretrizes para vigilância, atenção e eliminação da hanseníase como problema de saúde pública: manual técnico-operacional. Brasília (DF): Ministério da Saúde; 2016. Disponível em: [http://www.saude.pr.gov.br/arquivos/File/Manual\\_de\\_Diretrizes\\_Eliminacao\\_Hanseníase.pdf](http://www.saude.pr.gov.br/arquivos/File/Manual_de_Diretrizes_Eliminacao_Hanseníase.pdf).
2. Segurado AC, Cassenote AJ, Luna EA. Saúde nas metrópoles: doenças infecciosas. *Estud Av* [on-line]. 2016 [citado em 2019 Jul]; 30(86):29-49. doi: <http://dx.doi.org/10.1590/S0103-40142016.00100003>.
3. Franciely PSB, Ivy FM, Jéssica CBP, Thalita CM, José LRSJ, Cristiane FS. Incapacidades neurológicas provocadas pela hanseníase em uma unidade de saúde do município de Anápolis-GO, entre 2011 e 2013. *Rev Educ Saúde* [on-line]. 2016 [citado em 2019 Out]; 4(2):3-10. doi: <https://doi.org/10.29237/2358-9868.2016v4i2.p%25p>.
4. Brasil. Guia de vigilância em saúde: volume único. 3. ed. Brasília (DF): Ministério da Saúde; 2019. Disponível em: <http://portal.arquivos2.saude.gov.br/images/pdf/2019/junho/25/guia-vigilancia-saude-volume-unico-3ed.pdf>.
5. Organização Mundial da Saúde. Estratégia Global para Hanseníase 2016-2020: acelerar a ação rumo a um mundo sem hanseníase. Brasília (DF): OMS; 2016. Disponível em: <https://apps.who.int/iris/bitstream/handle/10665/208824/9789290225201-pt.pdf>.
6. Gaudenci EM, Nardelli GG, Almeida Neto OP, Malaquias BSS, Carvalho BT, Pedrosa LAK. Qualidade de vida, sintomas depressivos e incapacidade física de pacientes com hanseníase. *Hansen Int* [on-line]. 2015 [citado em 2019 Out]; 40(2):48-58. Disponível em: [http://www.ils.br/revista/detalhe\\_artigo.php?id=12363](http://www.ils.br/revista/detalhe_artigo.php?id=12363).
7. Fayers PM, Machin D. Quality of life: assessment, analysis and

interpretation. Chichester: John Wiley; 2016.

8. The WHOQOL Group. The world organizations quality of life assessment (WHOQOL): position paper from the World Health Organization. *Soc Sci Med* [on-line]. 1995 [citado em 2018 Ago]; 41(10):1403-9. doi: [https://doi.org/10.1016/0277-9536\(95\)00112-K](https://doi.org/10.1016/0277-9536(95)00112-K).

9. Costa VB, Camargo CR, Santos PHF, Lima LR, Stival MM, Funghetto SS. Evaluation of quality of life and functional capacity of cancer patients in chemotherapy. *Ciênc Cuid Saúde* [on-line]. 2017 [citado em 2018 Set]; 16(3):1-8. doi: <http://dx.doi.org/10.4025/ciencucuidsaude.v16i3.35663>.

10. Mendes EV. O cuidado das condições crônicas na atenção primária à saúde: o imperativo da consolidação da Estratégia da Saúde da Família. Brasília (DF): Organização Pan-Americana da Saúde; 2012. Disponível em: <https://apsredes.org/o-cuidado-das-condicoes-chronicas-na-atencao-primaria-a-saude-o-imperativo-da-consolidacao-da-estrategia-da-saude-da-familia/>.

11. Mendes KDS, Silveira RCCP, Galvão CM. Use of the bibliographic reference manager in the selection of primary studies in integrative reviews. *Texto & Contexto Enferm* [on-line]. 2019 [citado em 2019 Out]; 28:e20170204. doi: <https://dx.doi.org/10.1590/1980-265X-TCE-2017-0204>.

12. Whitemore R, Chao A, Jang M, Mingos KE, Park C. Methods for knowledge synthesis: an overview. *Heart Lung* [on-line]. 2014 [citado em 2019 Out]; 43(5):453-61. doi: <https://doi.org/10.1016/j.hrtlung.2014.05.014>.

13. Joanna Briggs Institute. Reviewers' manual: methodology for JBI mixed methods systematic reviews [on-line]. JBI Rep. 2014 [citado em 2019 Out]. Available from: [http://joannabriggs.org/assets/docs/sumari/ReviewersManual\\_Mixed-Methods-Review-Methods-2014-ch1.pdf](http://joannabriggs.org/assets/docs/sumari/ReviewersManual_Mixed-Methods-Review-Methods-2014-ch1.pdf).

14. Pinho AB, Borghesan FHP, Lotufo MN, Allet MA. Avaliação dos tratamentos cirúrgicos das sequelas de hanseníase pelas escalas Salsa e Dash. *Rev Bras Ortop* [on-line]. 2014 [citado em 2018 Set]; 49(3):292-6. doi: <https://doi.org/10.1016/j.rbo.2013.06.001>.

5. Reis FJJ, Gomes MK, Cunha AJLA. Evaluation of the limitations in daily-life activities and quality of life in leprosy patients submitted to surgical neurolysis to treat neuritis. *Fisioter Pesqui* [on-line]. 2013 [citado em 2018 Set]; 20(2):184-90. doi: <http://dx.doi.org/10.1590/S1809-29502013000200014>.

16. Santos VS, Oliveira LS, Castro FDN, Gois-Santos VT, Lemos LMD, Ribeiro COM et al. Functional activity limitation and quality of life of leprosy cases in an endemic area in Northeastern Brazil. *PLoS Negl Trop Dis* [on-line]. 2015 [citado em 2018 Set]; 9(7):1-8. doi: <https://doi.org/10.1371/journal.pntd.0003900>.

17. Castro RNC, Veloso TC, Matos Filho LJS, Coelho LC, Pinto LB, Castro AMNC. Avaliação do grau de incapacidade física de pacientes com hanseníase submetidos ao Dermatology Quality Index em Centro de Referência e Unidades Básicas de Saúde de São Luís, MA. *Rev Bras Clín Med* [on-line]. 2009 [citado em 2018 Ago]; 7:390-2. Disponível em: <http://files.bvs.br/upload/S/1679-1010/2009/v7n6/a007.pdf>.

18. Silva PMF, Pereira LE, Ribeiro LL, Santos DCM, Nascimento

RD, D'Azevedo SSP. Evaluation of the physical limitations, psychosocial aspects and quality of life of people affected by leprosy. *Rev Pesqui* (Univ Fed Estado Rio J, Online) [on-line]. 2019 [citado em 2018 Ago]; 11(1):211-5. doi: <http://dx.doi.org/10.9789/2175-5361.rpcfo.v11.6975>.

19. Silva RCP, Guisard PCLM, Metello HN, Ferreira ME, Marzliak MLC, Clemente TMG. Sonhos interrompidos, caminhos desviados: marcas amenizadas por pensões. *Hansen Int* [on-line]. 2013 [citado em 2018 Set]; 38(1-2):3-13. Disponível em: <http://www.ils.br/revista/imageBank/v38n1-2a02.pdf>.

20. Rodini FCB, Gonçalves M, Barros ARSB, Mazzer N, Elui VMC, Fonseca MCR. Prevenção de incapacidade na hanseníase com apoio em um manual de autocuidado para pacientes. *Fisioter Pesqui* [on-line]. 2010 [citado em 2018 Out]; 17(2):157-66. doi: <http://dx.doi.org/10.1590/S1809-29502010000200012>.

21. Budel AR, Raymundo AR, Costa CF, Gerhardt C, Pedri LE. Profile of patients affected by Hansen's disease seen at the Outpatient Clinic of Dermatology at Hospital Evangélico de Curitiba. *An Bras Dermatol* [on-line]. 2011 [citado em 2018 Ago]; 86(5):942-6. doi: <http://dx.doi.org/10.1590/S0365-05962011000500012>.

22. Pinheiro MGC, Silva SYB, Silva FS, Ataíde CAV, Lima IB, Simpson CA. Knowledge on prevention of disabilities in a hanseniasis self-care group. *REME Rev Min Enferm* [on-line]. 2014 [citado em 2019 Out]; 18(4):895-900. doi: <http://www.dx.doi.org/10.5935/1415-2762.20140066>.

23. Finez MA, Salotti SRA. Identificação do grau de incapacidades em pacientes portadores de hanseníase através da avaliação neurológica simplificada. *J Health Sci Inst* [on-line]. 2011 [citado em 2018 Nov]; 29(3):171-5. Disponível em: [https://www.unip.br/presencial/comunicacao/publicacoes/ics/edicoes/2011/03\\_jul-set/V29\\_n3\\_2011\\_p171-175.pdf](https://www.unip.br/presencial/comunicacao/publicacoes/ics/edicoes/2011/03_jul-set/V29_n3_2011_p171-175.pdf).

24. Lima IB, Simpson CA, Cabral AMF. Limitação de atividades e participação social em pacientes com hanseníase. *Rev Enferm UFPE On Line* [on-line]. 2014 [citado em 2018 Nov]; 8(4):994-1001. doi: <http://www.dx.doi.org/10.5205/reuol.5829-50065-1-ED-1.0804201427>.

25. Uchôa REMN, Brito KKG, Santana EMF, Soares VL, Silva MA. Perfil clínico e incapacidades físicas em pacientes com hanseníase. *Rev Enferm UFPE On Line* [on-line]. 2017 [citado em 2018 Nov]; 11(Supl 3):1464-72. doi: <http://www.dx.doi.org/10.5205/reuol.10263-91568-1-RV.1103sup201719>.

26. Denise CT, Kelyanne SP, Claudio SB, Anderson BL, Gabriel PC, Maria CG, Sarah TRFC. Comparação da qualidade de vida de indivíduos com e sem hanseníase. *Revista Ceuma Perspectivas* [on-line]. 2017 [citado em 2018 Nov]; 30(2):64-77. doi: <https://doi.org/10.24863/rccp.v30i2.152>.

27. Souza IA, Ayres JA, Meneguín S, Spagnolo RS. Hansen's disease patients' perception of self-care from the complexity perspective. *Esc Anna Nery Rev Enferm* [on-line]. 2014 [citado em 2018 Out]; 18(3):510-4. doi: <http://dx.doi.org/10.5935/1414-8145.20140072>.

**Corresponding author:** Rayla Maria Pontes Guimarães Costa. Rua Felicidade Veras Neves, 265, Bairro: Reis Veloso. Parnaíba-Piauí- Brasil. E-mail: [rayla.guimaraes@hotmail.com](mailto:rayla.guimaraes@hotmail.com)

**Submitted:** 03/12/2018

**Accepted:** 19/11/2019