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Article/Artigo

The impact of leprosy on health-related quality of life

O impacto da hanseníase na qualidade de vida relacionada à saúde

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ABSTRACT

Introduction: Leprosy is a potentially disabling infectious disease that evolves into emotional issues due to the prejudice that persists about the illness. The endemic has declined substantially with multidrug therapy (MDT) in the 80's; however, new demands associated with the reduction of stigma and the improvement of the affected people's quality of life have emerged. In Brazil, leprosy is still a public health problem. Piauí is the second state in the Northeast in prevalence and detection, and Teresina is a hyperendemic city. This study aimed to analyze the health-related quality of life (HRQoL) of people in treatment for leprosy in Teresina/PI. **Methods:** An observational study was conducted using the SF-36 (a specific questionnaire for assessing quality of life), which sought the determinants of poor quality of life among people with leprosy, outlining the sociodemographic, clinical, and epidemiological characteristics of the 107 patients interviewed. **Results:** The correlations between the variables showed five determinants of HRQoL: late diagnosis, multibacillary forms, reactions, disability diagnosis grade II, and prejudice. The profile of the participants showed that leprosy still affects the lower social classes in historically endemic areas, causing high percentages of secondary injuries that compromise the work capacity and quality of life of the affected people, perpetuating the stigma associated with the disease. **Conclusions:** The study reinforces the need to implement more effective strategies of disease control, due to the development of severe and disabling forms of leprosy is directly related to poor HRQoL in the same cured patient.

Keywords: Leprosy. Quality of life. Stigma.

RESUMO

Introdução: A hanseníase é uma doença infecto-contagiosa, potencialmente incapacitante, que evolui com elevada carga emocional em função do preconceito que persiste sobre os acometidos. A endemia declinou substancialmente com a poliquimioterapia (PQT), na década de 80; entretanto, surgiram novas demandas associadas à redução do estigma e melhoria da qualidade de vida dos acometidos. No Brasil, a hanseníase ainda é um problema de saúde pública. O Piauí é o 2º estado do nordeste em prevalência e detecção, sendo que Teresina é hiperendêmica. Objetivou-se analisar a qualidade de vida relacionada à saúde (QVRS) de pessoas em tratamento da hanseníase em Teresina/PI. **Métodos:** Estudo observacional realizado com a aplicação do SF-36 (questionário específico para avaliação da qualidade de vida) que buscou os determinantes da piora na qualidade de vida das pessoas com hanseníase, delineando o perfil sóciodemográfico, clínico e epidemiológico dos 107 pacientes entrevistados. **Resultados:** A correlação entre as variáveis demonstrou cinco determinantes para QVRS: diagnóstico tardio, formas multibacilares, reações, grau II de incapacidade no diagnóstico e preconceito. O perfil dos participantes revelou que a hanseníase continua acometendo as classes sociais menos favorecidas em áreas historicamente endêmicas provocando percentuais elevados de lesões secundárias que comprometem a capacidade de trabalho e a qualidade de vida dos acometidos, perpetuando o estigma associado à doença. **Conclusões:** O estudo reforça a necessidade de implementação de estratégias mais efetivas de controle da doença, uma vez que o estabelecimento de formas graves e incapacitantes de hanseníase está diretamente relacionada à baixa QVRS mesmo no paciente curado.

Palavras-chaves: Hanseníase. Qualidade de vida. Estigma.

INTRODUCTION

Leprosy is an infectious chronic granulomatous disease that evolves slowly, manifesting itself through dermato-neurological signs and symptoms: skin and peripheral nerve lesions, especially in the eyes, hands, and feet[1, 2]. Over the millennia, the coping strategies for the disease have been based on compulsory isolation and social exclusion, leading to an entire process of building stigmas that negatively affect the quality of life of affected people until today[3].

In the 80's the World Health Organization (WHO) introduced multidrug therapy (MDT) for leprosy treatment, bringing the possibility of healing and breaking the chain of transmission of the disease and leading to a substantial improvement in the endemic global indicators[4]. However, new demands related to reducing stigma, promoting social reintegration, and improving quality of life have emerged, prompting the consideration of humanitarian questions and the human rights of people affected by leprosy in public policies related to the disease[5].

The WHO defines quality of life as *an 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*; this definition considers one's physical and psychological aspects, independence, social relationships, environment, and spirituality/religion/personal beliefs[6, 7].

The term health-related quality of life (HRQoL) also incorporates the multidimensional nature and perception of overall quality of life but often cites the impact of an illness/injury on the quality of life[8]. Thus, HRQoL represents the value given to the life span altered by the deficiency, functional status, perception of health, and social opportunity brought about by an illness, accident, treatment, or determined policy[9].

From the perspective of these new demands, this study aimed to examine the HRQoL of persons in treatment for leprosy in the City of Teresina/PI through the application of the *Medical Outcomes Study 36-Item Short-Form Health Survey* (SF-36),

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outlining the sociodemographic, clinical, and epidemiological characteristics of the participants and seeking to identify the major determinants of poor quality of life.

In this context, Brazil has demands related to the improvement of both the indicators and the quality of life of people affected by leprosy. Leprosy is still a public health problem in the country (prevalence of 2.19/10,000 inhabitants in 2007)[10], accounting for 92.9% of new leprosy cases in the Americas in 2009. Brazil is also the only country in the world with a prevalence coefficient greater than two cases per 10,000 inhabitants[11].

Piauí, the seventh state in the country, ranks second in the Northeast in terms of prevalence and detection of new cases; the latter had 4.7 cases per 10,000 inhabitants in 2007[10]. In Teresina the detection rate in children under 15 years was 39 per 100,000 inhabitants in 2008, an indicator that rendered the city hyperendemic[12].

The disease control strategies have long prioritized the biomedical aspect of leprosy (curing, breaking the chain of transmission, preventing secondary injuries, etc.); however, in recent years some important measures have been adopted in response to demands that go beyond the biomedical aspect of leprosy[5].

These measures aim at reducing stigma, promoting social reintegration, and improving the quality of life of affected people; their highlights include encouraging the political participation of social movements, using media to help reduce stigma and improve public recognition of signs/symptoms of the disease, health education programs, rehabilitation programs, the inclusion of tools to identify difficulties in daily living activities and in social inclusion from the perspective of the people involved (participation and SALSA scales)[10].

The political and social movements in the leprosy control global context point to a unique opportunity to break the traditional model of segregation/exclusion in the fight against leprosy and to the emergence of a new, humanized/full model. Moreover, the study of the quality of life of people affected by leprosy is incipient in Brazil and represents a major gap in the construction of policies for the integral care of this clientele, from which the main motivation of this study arose.

METHODS

This is a cross-sectional observational study that was conducted among 107 people in treatment for leprosy in eight health units in the Northern area of Teresina/PI (the area of highest endemicity in the city). Male and female patients aged 15 years or more who signed the consent form were interviewed. Patients with a cognitive deficit or doubtful diagnosis and those leaving the treatment or having irregular treatment were excluded.

The clinical and epidemiological characteristics of the study participants were collected from the SINAN database and through patient charts. Personal and socioeconomic data were collected through the application of a semi-structured questionnaire. To assess the impact of leprosy on HRQoL, the SF-36 was administered. The patients were approached according to their schedule for receiving the supervised dose of MDT.

Statistical analysis was carried out through the Kolmogorov-Smirnov (K-S) test, rejecting the normality hypothesis and implying the choice of nonparametric tests to verify the significance of correlations between the study variables. We used the Pearson $\chi2$, Fisher, Mann-Whitney, and Kruskal-Wallis exact tests for qualitative variables and the Spearman correlation coefficient to measure association (dependence). Original data were tabulated and analyzed using the Statistical Package for the Social Sciences (SPSS) for Windows® version 17.0 (Chicago, USA).

The data collection team underwent training and performed calibration of the survey instruments, and the uniformity in the application of interviews was verified as having strong concordance (90%) by the kappa coefficient.

Ethical considerations

The study was conducted in accordance with Resolution 196/96 of the National Health Council (CNS/MS), which deals with research involving human subjects, and with the 1964 Helsinki Declaration and its revisions as of the year 2000. The study was approved by the Ethics in Research Committee (CEP) of the Universidade Federal do Piauí (UFPI) (No. 0212.0.045.000-09) on December 14, 2009.

RESULTS

The study consisted of 67 males and 40 females. The average age observed was 46 years (SD = 17.5 years); the minimum age recorded was 15 years, and the maximum was 86 years. The sociodemographic profile was as follows: aged 30 years or older (74.2%), males (62.6%), married/in a stable union (60.7%), with low education (62.6% only finished elementary school), living in urban areas (91.6%), from the lower socioeconomic classes (C1, C2, D, and E = 74.8%), and with a monthly income of up to R$ 1,391.00. Among the respondents, 33.6% reported interference in the work/study routine by leprosy: temporary removal (6.5%), retirement (1.9%), resignation (1.9%), difficulty in working (19.6 %), and permanent disability (3.7%).

The clinical characteristics of the study showed a slight prevalence of multibacillary cases (53.3%), a prevalence of late forms of leprosy (tuberculoid, borderline, and lepromatous = 69.2%), a high percentage of grade II disability at diagnosis (10.3%), recurrence in 9.3% of cases, adverse reactions in 33.6% of participants, and the presence of other pathologies (especially chronic diseases) in 34.6% of participants; only 25.2% were under some form of complementary therapy (physiotherapy, psychology, group therapy, etc.).

The epidemiological characteristics revealed that 44.8% of patients were from hyperendemic/very high/high-endemicity areas; 38.3% of respondents live/have lived with someone affected by leprosy, 68.2% of patients took 1 year or more to be diagnosed with leprosy since the initial symptoms, and leprosy detection in 85.9% of cases was by passive demand. As for the leprosy stigma: 70.1% of respondents indicated prejudice as the most negative aspect of the disease, while 74.8% of patients omitted who are affected by leprosy, 27.1% of respondents reported they had suffered discrimination.

Regarding HRQoL, the SF-36 mean scores showed high scores that are consistent with a low compromise of HRQoL by leprosy (**Table 1**). However, further statistical analysis revealed that there are some important determinants of the worsening of HRQoL in some patients.

The comparison of the various studied variables between groups resulted in five determinants of HRQoL in leprosy: late diagnosis, operational classification, reactional episodes, grade II disability at diagnosis, and discrimination.

Late diagnosis was significantly determinant of the emergence of disability (χ2 test, p = 0.001); it was observed that the degree of disability increased with the delay in detection. Late diagnosis showed a significant difference between sexes (Mann-Whitney test, p = 0.048); it took the women an average of 12.6 months to receive the diagnosis, while the average for men was 26.9 months.

In terms of HRQoL, late diagnosis (performed 2 years after the early symptoms of leprosy) resulted in a deterioration in SF-36 scores; thus, it was possible to estimate the odds ratio for cases diagnosed within 2 years as follows: functional status (Fisher's exact test, p = 0.003; odds ratio = 5.0 times; Spearman coefficient, p = 0.010), limitations due to physical aspects (χ2 test, p = 0.041; odds ratio = 2.4 times; Spearman coefficient, p = 0.042); general health status (χ2 test, p = 0.008; odds ratio = 3.5 times; Spearman coefficient, p = 0.008), social aspects (Fisher's exact test, p = 0.016; odds ratio = 5.0 times; Spearman coefficient, p = 0.010), and pain (Fisher's exact test, p = 0.007; odds ratio = 6.7 times; Spearman coefficient, p = 0.003).

Regarding operational classification, multibacillary forms of leprosy were determinants of the occurrence of grade II disability at diagnosis (χ2 test, p = 0.001), which prevailed in males (odds ratio = 4.8 times; χ2 test, p = 0.0001), and the occurrence of reactional episodes (χ2 test, p = 0.017), with odds ratios 2.8 times higher compared to the paucibacillary participants. Patients with paucibacillary forms of leprosy reported feeling discriminated against (χ2 test, p = 0.001; odds ratio = 05 times) and omit who are affected by leprosy the most (χ2 test, p = 0.003; odds ratio = 4.3 times).

With respect to HRQoL, it was observed that multibacillary forms were crucial to the worsening of the SF-36 scores in: functional status (Fisher's exact test, p = 0.008; odds ratio = 10.4 times; Spearman coefficient, p = 0.008), pain (Mann-Whitney test, p = 0.020), general health (Mann-Whitney test, p = 0.001), and social aspects (χ2 test, p = 0.045; odds ratio = 4.4 times; Spearman coefficient, p = 0.046).

The occurrence of reactional episodes proved to be decisive in making the patient feel discriminated against (χ2 test, p = 0.001); thus, it was possible to estimate odds ratios 4.4 times higher for the occurrence of discrimination among patients that had reactions.

The reactions were shown as a major determinant of the worsening of HRQoL as they resulted in a significant drop in scores for all the SF-36 domains (**Table 2**).

Grade II disability at diagnosis was a determinant of making the patient feel discriminated against (χ2 test, p = 0.001), with an estimated odds ratio 4.8 times higher compared to that of patients with no disabilities. Regarding HRQoL, the occurrence of grade II disability at diagnosis proved to be decisive for significant worsening in six SF-36 domains (**Table 3**).

TABLE 1 - Mean, median, standard deviation, and minimum and maximum scores on the quality of life questionnaire (SF-36) of patients in leprosy treatment in health units in the northern area of Teresina, State of Piauí, Brazil, in 2010.

Numerical variables	Mean	Median	Std dev	Min	Max
Functional capacity	85.0	95.0	21.5	5.0	100.0
Limitation caused by physical aspects	71.3	100.0	39.1	0.0	100.0
Pain	81.0	84.0	22.7	20.0	100.0
General health	62.9	67.0	17.8	15.0	95.0
Vitality	80.5	85.0	17.3	30.0	100.0
Social aspects	85.0	100.0	21.5	12.5	100.0
Limitation caused by emotional aspects	82.1	100.0	33.4	0.0	100.0
Mental health	82.1	88.0	17.7	28.0	100.0

Source: interview with patients (2010). **Std. dev:** standard deviation, **Min:** minimum, **Max:** maximum.

TABLE 2 - Mean, median, standard deviation, and statistical significance of scores on quality of life in the SF-36 domains compared by the occurrence of leprosy reactions.

Reactional episodes	Mean	Median	Std dev	p value
Yes				
functional capacity*	73.89	87.50	29.47	0.013*
limitation caused by physical aspects*	50.69	50.00	45.70	0.001*
pain*	69.00	70.00	24.89	0.001*
general health*	55.78	62.00	22.32	0.034*
vitality*	70.89	77.50	21.34	0.001*
social aspects*	76.04	81.25	26.62	0.005*
limitation caused by emotional aspects*	64.58	87.50	42.56	0.001*
mental health*	71.78	72.00	21.63	0.001*
No				
functional capacity*	90.70	100.00	13.07	
limitation caused by physical aspects*	81.69	100.00	30.75	
pain*	87.15	100.00	18.94	
general health*	66.51	67.00	13.89	
vitality*	85.41	90.00	12.48	
social aspects*	89.51	100.00	16.81	
limitation caused by emotional aspects*	90.96	100.00	23.48	
mental health*	87.38	92.00	12.53	

Source: Interview with patients (2010). *Mann-Whitney test. Std dev: standard deviation.

TABLE 3 - Mean, median, standard deviation, and statistical significance of scores on quality of life in the SF-36 domains compared by the degree of disability at diagnosis.

Degree of disability	Mean	Median	Std dev	p value
Zero				
functional capacity*	90.00	100.00	15.61	0.001*
limitation caused by physical aspects*	79.23	100.00	34.84	0.018*
pain*	84.63	100.00	19.92	0.002*
general health*	66.55	67.00	14.27	0.015*
vitality*	84.17	90.00	14.16	0.019*
social aspects	88.27	100.00	18.96	0.083
limitation caused by emotional aspects*	88.03	100.00	27.95	0.009*
mental health	84.28	88.00	15.44	0.666
Grade II				
functional capacity*	61.36	75.00	34.72	
limitation caused by physical aspects*	45.45	25.00	45.85	
pain*	57.64	70.00	31.25	
general health*	50.36	47.00	23.61	
vitality*	66.82	80.00	24.62	
social aspects	73.86	87.50	29.29	
limitation caused by emotional aspects*	57.58	66.67	44.95	
mental health	79.64	92.00	18.02	

Source: interview with patients (2010). *Mann-Whitney test; Std dev: standard deviation.

Suffering discrimination was significantly determinant of the worsening of scores for the following SF-63 domains: pain (Fisher's exact test, p = 0.001; odds ratio = 14.5 times; Spearman coefficient, p = 0.001), general health status ($\chi2$ test, p = 0.001; odds ratio = 5.5 times; Spearman coefficient, p = 0.001), vitality (Fisher's exact test, p = 0.001; odds ratio = 9.5 times; Spearman coefficient, p = 0.001), and limitations caused by emotional aspects ($\chi2$ test, p = 0.001; odds ratio = 10.3 times; Spearman coefficient, p = 0.001).

DISCUSSION

Sociodemographic, clinical, and epidemiological characteristics of study participants

The sociodemographic profile found in this study is consistent with those in other studies conducted in different regions of Brazil, which point out poor socioeconomic conditions as contributing factors to leprosy infection/spread, in addition to biological determinants[13-15]. These studies suggest that low educational level is directly related to low family income, resulting in poor housing conditions, hygiene, nutrition, and access to health, which in turn promote the appropriate environmental conditions for Hansen's bacillus infection or the spread of the disease in genetically vulnerable individuals. This cyclic process is reflected in the high levels of disability observed nowadays and the high prevalence in children younger than 15 years, which are indicators of delayed diagnosis and the strength of the disease, respectively.

Considering the potential risk of leprosy to lead to disabling deformities and that the disease mainly affects the economically active population, interference in the work and social life of the patient causes economic losses and psychological trauma, especially when it involves the family provider, who may end up unemployed and without social insurance[14-16].

Regarding the clinical characteristics, it is worth noting that the high prevalence of multibacillary cases and late forms of leprosy (tuberculoid, borderline, and lepromatous) associated with the high percentage of grade II disability at diagnosis are indicative elements of late diagnosis and lack of timely detection of the case[17]. The grade II disability at diagnosis is an indicator of the strength of the disease and is considered high in percentage when it is greater than 10%, so the study's findings suggest that there is a high risk of infection in the region studied[10]. The high percentage of participants with another pathology associated with high leprosy morbidity curiously reflects low use of complementary therapies (physiotherapy, psychology, group therapy). In this case, the literature suggests, there is low supply of specialized services; there is a cultural pattern of omission of the disease coupled with the involvement of economically active people, especially in informal settlements, resulting in little provision for this type of treatment[15-17].

The epidemiological profile found is associated with an increased risk of contracting leprosy, as the main risk group consists of poor young adults, who reported another leprosy patient in their home with whom they have had intimate and prolonged contact[18,19]. The risk of contracting the disease is sorted in decreasing order as follows: contact with family members with multibacillary infection, extradomiciliary contact with multibacillary patients, and contact with paucibacillary patients[4]. Thus, the delayed diagnosis of patients in endemic areas influences the maintenance of the transmission chain, resulting in higher disease-related morbidity and indicating the inefficiency of control strategies.

Regarding self-perception of prejudice and stigma, this effect is known to occur in each individual according to similar social behavior patterns. In Brazil, it is suggested that there is a strong tendency to *cover up* the disease with the support of the family and even of health services[12, 20, 21].

The health-related quality of life of survey participants

The mean SF-36 scores found in this study are consistent with the literature, which has shown high scores consistent with low commitment of HRQoL by leprosy[13, 22, 23]. It was found that in cases of early diagnosis, leprosy has a low impact on HRQoL, and as the disease progresses to severe and disabling forms, there is a very serious commitment that affects all dimensions of the quality of life of the person involved in treatment or even cured. The survey results in comparison with the literature resulted in the following discussion on the determinants of HRQoL worsening:

Delayed diagnosis

The worsening of HRQoL is associated with delayed diagnosis due to the chronic and progressive disease that evolves according to the patient's immune status, the degree of endemicity of the environment, and other genetic components that facilitate/complicate the relationship between the host and the bacillus[24]. For susceptible individuals, the delay in diagnosis allows the development of the initial, more benign form (unspecified) into the most disabling and polar forms (tuberculoid, borderline, lepromatous)[15].

Deformities are rare in patients diagnosed less than 1 year after the first symptoms; these increase to 3.9% when the diagnosis is reached between 1 and 3 years after the first symptoms, rising to 25% when the diagnosis is delayed (up to 8 years of evolution)[25]. Through the percentage of cases diagnosed with physical disability caused by leprosy, it is possible to evaluate both the operational and epidemiological components since the late diagnosis contributes to the maintenance of the sources of infection[26].

In terms of HRQoL, it was found that late diagnosis is an indirect determinant because it is related to the establishment of late forms of leprosy and disabling deformities. Thus, the relationship between delayed diagnosis and worse HRQoL is an indirect measure of injuries caused by a prolonged course of the bacillus in the susceptible host, leading to the emergence of reactions and impairments.

Operational classification

The multibacillary forms of leprosy are related to lower host resistance to the bacillus, and the impact of this type of infection is more severe when there is delayed diagnosis, whereas in paucibacillary cases, there is greater host resistance to the bacillus, resulting in fewer injuries and shorter treatment time[27]. The multibacillary forms are correlated with the degree of the observed disability when compared with paucibacillary cases, even for equivalent periods of illness[28].

The prevalence of multibacillary forms in males is associated with the delay in seeking medical treatment observed among men, which allows the evolution of paucibacillary forms of the disease[29] and explains the significantly higher risk of secondary injuries found in the male participants in the study.

The significant relationship between multibacillary forms and reactional episodes occurs because the reactions are manifestations of the immune system fighting against the bacillus antigen, resulting in secondary acute inflammatory processes; a high burden of bacilli results in a more intense immune reaction, which leads to a higher amount of reaction episodes[30]. It is noteworthy that type 2 reaction is a typical immune complication in multibacillary patients, the most frequent clinical manifestation of which is erythema nodosum leprosum, and that it may be associated with injuries of the nerves, eyes, joints, etc[23].

The association between multibacillary forms and discrimination occurs because prejudice is historically related to the more pronounced signs of the disease, such as spots on visible parts of the body or physical deformities[21]. The stigma and prejudice experienced by leprosy patients are attributed to the disabilities and deformities[1]. This same reason explains why those patients with paucibacillary disease omit who are affected by leprosy more often, revealing a cultural pattern of coping with the disease and at the same time exposing a defense mechanism in affected patients.

The multibacillary forms are also indirect determinants of HRQoL worsening because they are related to the occurrence of reactions and impairments. The research findings suggest that reactions and secondary lesions may be directly related to the worsening of the SF-36 physical component, while the prejudice and stigma associated with the lesions, which are more visible in multibacillary forms, may result in the worsening of the social aspects.

Reactional episodes and grade II disability at diagnosis

These two variables are addressed together because they are closely related, settling in each individual through a complex combination of environmental and biological factors, coupled with delays in diagnosis. The reactions are crucial for the emergence of disability, although they can occur in people who have not suffered from reactions.

These two conditions have been proven to be decisive in the worsening of HRQoL[31]. On the other hand, studies of patients with a lesser degree of disability and a low percentage of responses have shown a low impact on HRQoL of leprosy[22].

The following are considered to be two plausible causes of poor HRQoL of patients with disabilities and reactions: 1) lesions actually restrict the physical component of HRQoL and directly undermine this aspect, and 2) a historical-cultural association between the leprosy lesions and stigma directly impacts on the mental health component.

It should be noted that the research findings suggest that the reactive episodes are instrumental in the worsening of the SF-36 mental health component. Conversely, there are studies indicating that the reactions can be triggered by psychological disorders, suggesting that it is mental health that is decisive in the emergence of reactions[32]. Given this, it is believed that the process occurs in both directions.

The patient that reported suffering discrimination

This variable was not instrumental in the worsening of the SF-36 scores on the two aspects most strongly associated with motor skill components (functional capacity and limitations caused by physical aspects). Thus, this finding suggests that discrimination significantly compromises those aspects related to mental health, including changes in pain threshold.

Pain is a sensory and emotional experience that is completely subjective. Emotions delineate the relationships between pain, fear, and behavior so that both the perception and expression of pain can be mediated and modulated by the unique meanings assigned by each patient to their condition, and they are influenced by sex, gender, beliefs, religion, and culture[33].

The association between discrimination and leprosy patients' quality of life limitations is treated superficially in studies; most authors consider the impressions or reports of patients, especially regarding former hospital interns at colonies. It is believed that mechanisms similar to those applied to the subjectivity of pain can be associated with the deterioration that leads to discrimination in other SF-36 domains. Historical aspects, knowledge about the pathophysiology of leprosy, and stigma and prejudice are limiting aspects in the various life spheres of affected individuals[34].

At the end of the survey, it was found that leprosy still affects the lower social classes in historically endemic areas, causing high percentages of secondary injuries that negatively affect the work capacity and quality of life of affected people, thus perpetuating the stigma and the ancient prejudice associated with the disease.

The study of the impact of leprosy on quality of life reinforces the need to implement more effective strategies for early diagnosis and to break the chain of disease transmission since the earliest forms of leprosy showed reduced negative impact on HRQoL. Furthermore, late diagnosis implies the establishment of severe and disabling forms of leprosy, which are associated with a low HRQoL even in a cured patient.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

REFERENCES

1. Ministério da Saúde. Secretaria de Políticas de Saúde. Departamento de Atenção Básica. Guia para o controle da Hanseníase. Brasília: Ministério da Saúde; 2002.
2. Talhari S, Neves RG, Penna GO, Oliveira MLV. Dermatologia Tropical: Hanseníase. 4th ed. Manaus: Tropical; 2006.
3. Martelli CMT, Stefani MM, Penna GO, Andrade ALSS. Endemias e epidemias brasileiras, desafios e perspectivas de investigação científica: hanseníase. Rev Bras Epidem 2002; 5:273-285.
4. Andrade VLG. Evolução da hanseníase no Brasil e Perspectivas para sua eliminação como um Problema de saúde publica. [Doctoral thesis in public health]. [Rio de Janeiro-RJ]: Escola de Saúde Pública Sergio Arouca-ENSP; 1996. 198 p.
5. Barbosa JC, Ramos Jr NA, Castro CGJ. A aplicação da escala de SALSA em contextos de hanseníase: relatos de experiência no Brasil. Paper presented at: Congresso Brasileiro de Enfermagem; Nov 3-6; Belo Horizonte, MG, Brazil, 2008.
6. Fleck MPA, Leal OF, Louzada S, Xavier M, Chachamovich E, Vieira G, et al. Desenvolvimento da versão em português do instrumento de avaliação de qualidade de vida da OMS (WHOQOL-100). Rev Bras Psiquiatr 1999; 21:19-28.
7. Seidl EME, Zannon CMLC. Qualidade de vida e saúde: aspectos conceituais e metodológicos. Cad Saude Publica 2004; 20:580-588.
8. Fróes KSSO. Qualidade de vida relacionada à saúde de adultos com seqüelas de acidente vascular cerebral. [Master thesis in Public Health]. [Fortaleza-CE]: Universidade de Fortaleza; 2008. 103 p.
9. Fernández-Concepción O, Fiallo-Sánchez MC, Álvarez-González MA, Roca MA, Concepción-Rojas M, Chávez L. La calidad de vida Del paciente con accidente cerebrovascular: una visión desde sus posibles factores determinantes. Rev Neurol 2001; 32:725-731.
10. Ministério da Saúde. Secretaria de Vigilância em Saúde. Departamento de vigilância epidemiológica: situação epidemiológica da hanseníase no Brasil, 2008. Brasília: Ministério da Saúde; 2008.
11. World Health Organization. Weekely Epidemiological Record: Global leprosy situation [Internet]. World Health Organization. 2010 - [cited 18 Jan 2011]. Available from: http://www.who.int/lep/resources/wer/en/index.html.
12. Oliveira CAR. Perfil epidemiológico da hanseníase em menores de 15 anos no município de Teresina. [Master thesis in Public Health]. [Rio de Janeiro-RJ]: Escola de Saúde Pública Sergio Arouca-ENSP; 2008. 63 p.

13. Martins MA. Qualidade de vida em portadores de hanseníase. [Master thesis in Psychology]. [Campo Grande-MS]: Universidade Católica Dom Bosco; 2009. 98 p.
14. Duarte MTC, Ayres JA, Simonetti JP. Consulta de enfermagem ao portador de hanseníase: análise de um instrumento e caracterização da assistência prestada. Paper presented at: Simpósio Internacional de Políticas e Práticas em Saúde Coletiva na Perspectiva da Enfermagem; Sep 3-4. São Paulo-SP, Brazil, 2007.
15. Aquino DMC, Caldas AJM, Silva AAM, Costa JML. Perfil dos pacientes com hanseníase em área hiperendêmica da Amazônia, Maranhão - Brasil. Rev Soc Bras Med Trop 2003; 36:102-113.
16. Goulart IMB, Arbex GL, Carneiro MH, Rodrigues MS, Gadia R. Efeitos adversos da poliquimioterapia em pacientes com hanseníase: um levantamento de cinco anos em um Centro de Saúde da Universidade Federal de Uberlândia. Rev Soc Bras Med Trop 2002; 35:453-460.
17. Pereira EVE. Avaliação dos resultados das ações do programa de controle da hanseníase desenvolvidas no município de Teresina. [Master thesis in Science and Health]. [Teresina-PI]: Universidade Federal do Piauí; 2010. 72 p.
18. Van Beers SM, Hatta M, Klatser PR. Patient contact is the major determinant in incident leprosy: implications for future control. Int Jorn Lepr 1999; 67:119-128.
19. Lana FCF, Amaral EP, Lanza FM, Lima PL, Carvalho ACN, Diniz LG. Hanseníase em menores de 15 anos no Vale do Jequitinhonha, Minas Gerais, Brasil. Rev Bras Enferm 2007; 60:696-700.
20. Talhari S, Neves RG, Penna GO. Dermatologia Tropical: Hanseníase. 3rd ed. Manaus: Goffman E. Estigma: notas sobre a manipulação da identidade. 4th ed. Rio de Janeiro: Guanabara Koogan; 1988.
21. Queiroz MS, Carrasco MAP. O doente de hanseníase em Campinas: uma perspectiva antropológica. Cad Saude Publica 1995; 11:479-490.
22. Maitto FB, Souza CS. Hanseníase e a repercussão na qualidade de vida. [completion of course work in graduate medical]. [Ribeirão Preto-SP]. Universidade de São Paulo; 2006. 62 p.
23. Orsini MBP. Estudo da função dos nervos periféricos de pacientes com hanseníase, acompanhados por um período médio de 18 anos após o início da poliquimioterapia. [Master thesis in Science and Health]. [Belo Horizonte-MG] Universidade Federal de Minas Gerais; 2008. 124 p.
24. Osugue SM, Osugue JY. Hanseníase. *In*: TavaresW, Marinho LAC, editors. Rotinas de diagnóstico e tratamento das doenças infecciosas e parasitárias. 1st ed. São Paulo: Atheneu; 2005. p. 488-499.
25. Soares LS, Moreira RO, Vilela VV, Alves MJM, Pimentel AFM, Ferreira AP, et al. The impact of multidrug therapy on the epidemiological pattern of leprosy in Juiz de Fora, Brazil. Cad Saude Publica 2000; 16:343-350.
26. Kumar A, Girdhar A, Girdhar BK. Nerve thickening in leprosy patients and risk of paralytic deformities: a field based study in Agra, India. Lepr Rev 2004; 75:135-142.
27. Cotran RS, Kumar V, Robbins SL. Patologia Estrutural e Funcional, 6th ed. Rio de Janeiro: Guanabara Koogan; 2000.
28. Alves CJM, Barreto JA, Fogagnolo L, Contin LA, Nassif PW. Avaliação do grau de incapacidade dos pacientes com diagnóstico de hanseníase em serviço de dermatologia do estado de São Paulo. Rev Soc Bras Med Trop 2010; 43:460-461.
29. Ferreira J. Validade do grau de incapacidades como indicador de diagnóstico tardio da hanseníase. Hansen Int 1998; (Esp. number):79-84.
30. Mendonça VA, Costa RD, Melo GEBA, Antunes CT, Teixeira AL. Imunologia da hanseníase. An Bras Dermatol 2008; 83:343-350.
31. Martins BDL, Torres FN, Oliveira MLW. Impacto na qualidade de vida em pacientes com hanseníase: correlação do Dermatology Life Quality Index com diversas variáveis relacionadas à doença. An Bras Dermatol 2008; 83:39-43.
32. Opromolla DVA. Noções de Hansenologia. 2nd ed. Bauru: Centro de Estudos Dr. Reynaldo Quagliato; 2000.
33. Figueiró JAB, Angelotti G, Pimenta CAM. Dor e saúde mental. 1st ed. São Paulo: Atheneu; 2005.
34. Martins PV, Caponi S. Hanseníase, exclusão e preconceito: histórias de vida de mulheres em Santa Catarina. Cienc Saude Coletiva 2011;15: 1047-1054.