Journal of Nursing
Revista de Enfermagem
UFPE On Line
JNUOL
ISSN: 1981-8963

ORIGINAL ARTICLE

THE QUALITY OF LIFE OF PATIENTS WITH CHRONIC LEPROSY

A QUALIDADE DE VIDA DE PACIENTES COM HANSENÍASE CRÔNICA

LA CALIDAD DE VIDA DE LOS PACIENTES CON LEPRA CRÓNICA

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ABSTRACT

Objective: analyzing the quality of life of patients with chronic leprosy. ***Method:*** analytical observational cross-sectional study with quantiqualitative approach with people with leprosy, using as data collection instrument WHOQOL-BREF questionnaire, adapted to the Brazilian model. Values were assigned 0-5 every score, and these values were grouped and analyzed by statistical data. The project was approved by the Research Ethics Committee, Protocol EC/UCS-020/2012. ***Results:*** leprosy affects the quality of life of the participants. This includes a reduction in the score of physical and psychological fields due to disability and physical changes caused by the disease. The areas of social relations and the environment are less affected, but it is reported a decrease in leisure activities and social relations outside of institutional living. ***Conclusion:*** leprosy impairs the physical and psychological domains and requires an intensification of the bacillus disposal policies and socialization of these patients. ***Descriptors:*** Leprosy; Quality of Life; Commitment.

RESUMO

Objetivo: analisar a qualidade de vida de pacientes com hanseníase crônica. ***Método***: analítico do tipo transversal observacional, com abordagem quantiqualitativa, com pessoas com a hanseníase, utilizando-se como instrumento de coleta de dados o questionário *WHOQOL-BREF*, adaptado ao modelo brasileiro. Foram atribuídos valores de 0 a 5 a cada pontuação, e, estes valores foram agrupados e analisados por dados estatísticos. O projeto foi aprovado pelo Comitê de Ética em Pesquisa, Protocolo CE/UCS-020/2012. ***Resultados***: a hanseníase influencia na qualidade de vida dos participantes. Isto inclui uma diminuição do escore dos domínios físico e psicológico, devido a incapacidade e modificações físicas provocadas pela doença. Os domínios de relações sociais e com o meio ambiente são menos afetados, porém é relatada uma diminuição das atividades de lazer e de relações sociais fora do convívio institucional. ***Conclusão***: a hanseníase interfere negativamente nos domínios físico e psicológico e é necessária uma intensificação das políticas de eliminação do bacilo e socialização destes pacientes. ***Descritores***: Hanseníase; Qualidade de Vida; Comprometimento.

RESUMEN

Objetivo: analizar la calidad de vida de los pacientes con lepra crónica. ***Método:*** análisis observacional transversal con enfoque quantiqualitativo con personas con lepra, utilizando como instrumento de recolección de datos del cuestionario WHOQOL-BREF, adaptado al modelo brasileño. Se asignaron valores 0-5 cada partitura, y estos valores fueron agrupados y analizados por los datos estadísticos. El proyecto fue aprobado por el Comité de Ética en Investigación, Protocolo CE/UCS-020/2012. ***Resultados:*** la lepra afecta la calidad de vida de los participantes. Esto incluye una reducción en la puntuación de los campos físicos y psicológicos debido a la discapacidad y los cambios físicos causados por la enfermedad. Las áreas de las relaciones sociales y el medio ambiente son menos afectadas, pero se informó de una disminución de las actividades de ocio y las relaciones sociales fuera de la vida institucional. ***Conclusión:*** la lepra afecta los dominios físicos y psicológicos y requiere una intensificación de las políticas de eliminación de bacilos y socialización de estos pacientes. ***Descriptores:*** Lepra; Calidad de Vida; Compromiso.

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INTRODUCTION

The World Health Organization (WHO) defines quality of life as the perception of the individual in his cultural context, his position of life and his values. One can show its goals, expectations and standards, including various aspects of everyday life such as: (1) physical health, (2) psychological health, (3) level of independence, (4) social relations and (5) the environment.[1] According to WHO, physical health is related to pain and discomfort; energy and appetite; sleep and rest; mobility and ability to performing daily activities and addiction to treatment or medications. Psychological health is guided in positive and negative feelings, memory and concentration, self-esteem, body image and appearance, religion and spirituality. As regards social relationships are embedded personal relationships, personal support and sexual activities.[1]

The psychological well-being, the individual independence, the practice of physical activity and relationships, are factors that affect the quality of life.[2] The term quality of life (QOL), often mentioned in different situations, received the most diverse concepts throughout history. Although contradictory by many authors, it was cited by former US president Lyndon Johnson, who alluded to it as an important parameter to measuring the economy of a country. Years later this term was reused by Augus Campbell, who considered as something that people have a vague notion, but did not know exactly what was.[1-2]

Over time, the quality of life has become an important indicator to assess the health, social and economic status of the subject. With the emergence of the journal Quality of Life Research, the International Society for Quality of Life Research; the evolution of health actions, as well as the advent of the Unified Health System (SUS), quality of life was widely discussed in the context of health. This approach was also inserted by the WHO to be drawn up an instrument to assess the quality of life in its multidimensional aspect, a multidimensional and cross-cultural approach. Thus, the quality of life was defined by WHO as "the individual's perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."

This discussion about QOL is perpetuated and becomes part of one of the goals of health actions. With regard to assistance and daily practices also lead to concern about the quality of life factor, since this is part of a group of health actions judgments that can modify the prognosis. Also, when it comes to treatment can impact the patient's life in various aspects such as functional and psychosocial, allowing greater insight into the reality of the patient and therefore influence the decision of their own treatment. [3]

In the context of disease, diseases that affect the skin, appear to affect the quality of life of patients. Thus, leprosy, long remains a controversial topic in Public Health, as social isolation, prejudice and stigma, bring disastrous consequences to patients with this disease. Currently Brazil has the most unfavorable situation in America and the diagnosis of the second largest amount of world's leprosy cases after India.[4]

An epidemiological study showed that the incidence of leprosy patients in the state of Paraíba in 2010 was 20.1 people per 100.000 inhabitants. The mostly affected individuals were male, brown and with low schooling.[5] Because the quality of life an indicator that covers various aspects, we believe that patients suffering from chronic leprosy can and should be assisted. Thus, changes in several dimensions on the quality of life of these patients, after years of isolation for treatment can be expected. [5-7]

Given the exposed context, we can see what is essential to consider the quality of life of patients with diseases that affect the skin, including leprosy, as this can interfere with your quality of life. Within this context, this research aims to:

- Analyzing the quality of life of patients with chronic leprosy.

METHOD

This is an analytical study of observational cross-sectional with quantiqualitative approach.[8] The convenience sample consisted of 30 patients with chronic leprosy, 20 of Colony Getúlio Vargas in the town of Bayeux-PB and 10 of the Colony San Francisco in the city of Natal- RN. Both colonies have been disabled since the eighties, but still function as a treatment center for leprosy patients. The majority of participants are more than sixty years old. Among them, 19 patients were female and 11 male sex, totaling 30 patients.

The study consisted of 30 observations and 60 variables: sex-binary categorical variable (male and female); Marital status - categorical variable (Single, Married, Separated, Widowed and); Occupation - categorical variable (indicating the occupation of patients); Education - categorical variable indicating the level of education of the patients (illiterate, incomplete primary) and family income - categorical variable indicating the income in minimum wages (1-2 minimum wages).

On the variables corresponding to the questions in the questionnaire, 26 correspond to WHOQOL-BREF; 21 to Inventory Becker Depression and 8 to the financial score for economic classification.

The validation has undergone several adaptations of both the language and the applicability of the questionnaire. The responses were analyzed from a Likert scale, distributed an intensity scale (nothing extremely), capacity (nothing completely), frequency (never-always) and evaluation (very satisfied, very bad or very good). The WHOQOL-BREF questionnaire variables are also ordinal categorical (Likert Scale).

The results were evaluated from a score for each question was graded from zero to twenty (0-5) and subsequently transformed in scores. Score zero (0) corresponds to the worst health status and one hundred (100) to better health. The questionnaire was the multidimensional type and the results were to be grouped in areas and are represented by physical, psychological health, social relationships and environment.[9]

Data on quality of life were treated as the WHOQOL-BREF manual for calculation of scores in the areas of the instrument. The inclusion criteria for the study were: accept participate in the study through the Term of Consent; be Hansen's disease or have been affected by the disease and have been treated in the colonies. However the exclusion criteria were not agreeing to participate in research, have not undergone any treatment for leprosy and have not lived in the colonies belonging to the study.

Statistical analyzes were performed based on the type of study and according to the specific references on the subject.[10-1]

Regarding the course of the study, the project was approved by the Research Ethics Committee of the University Cruzeiro do Sul, Sao Paulo - EC/UCS Protocol No. 020/2012.[8]

RESULTS AND DISCUSSION

In this study there were analyzed 30 patients with chronic leprosy colonies and residents in the cities of Bayeux- PB and Natal- RN. Of this sample 63% female and 37% male. All patients in this sample were classified as retired occupation; therefore, the variable "occupation" was not used for any comparison of results of the measures of the instruments used in this study.

In the matters of civil status: 47% of subjects in the sample were married, while 53% fall into the category other (of which 30% were separated, 3% were single and 20% widowed). Regarding the education of the participants can be seen that 20% were illiterate and only 10% had primary education.

About WHOQOL-BREF questionnaire, this was produced by the sum of each facet four areas answers questions:

- Physical Domain
- Psychological Domain
- Personal relations Domain
- Environment Domain

Table 1 presents the results of the evaluation of quality of life WHOQOL soon, where the scores of the sums of the facets are re-scaled for the band 0-100.[12]

Table 1. Results of the evaluation of quality of life WHOQOL bref

Domain	Minimum	1st Quartile	Median	Average	3rd Quartile	Maximum	Standard deviation	IQR
Physical	28,57	32,14	33,93	34,64	35,71	42,86	4,10	3,57
Psychological	29,17	33,33	37,50	37,36	41,67	45,83	4,70	8,33
Social relationships	8,33	25,00	41,67	34,44	41,67	50,00	12,90	16,67
Environment	40,62	40,62	43,75	43,75	46,09	50,00	2,60	5,47
Total	**30,58**	**36,37**	**38,19**	**37,55**	**39,96**	**42,52**	**3,29**	**3,59**

It is evident that the male has better means of social relations and women in the psychological domain. It can be seen with the data obtained, a significant difference when comparing the WHOQOL-BREF scores in relation to marital status (p = 0,003). The worst scores of quality of life (QOL) were recorded for the separate individuals, and the social and psychological relations areas were the most affected.

Regarding income, a significant difference (p<0,001) between individuals with incomes of 1 and 2 minimum wages, relative to the total QOL, and social relationships domain that difference is more latent. Schooling also showed significant differences (p = 0,013) compared overall WHOQOL-BREF. The best means of total QOL were present in individuals who had not completed elementary study, and the most affected aspect was the domain of social relations comparing with the illiterate.

The results also revealed that thirty patients admitted living in colonies from infancy at the time; all had physical deformities when it was given a diagnosis of leprosy.

Considering a cohort study conducted in Rio de Janeiro, with a sample of 667 medical records of patients being treated for leprosy was identified that the majority of patients were women (52,3%) and only (43,5%) were men. Most were poor and gained between 1 and 2 minimum wages, were married and reported low educational level. The predominance of the female sample, this cohort study contradicts previous studies, which were evidenced predominance of the bacillus in male patients.[13-5]

The physical domain consisted of questions (Q3, Q4, Q10, Q15, Q16, Q17 and Q18), showed average ranged from 1.4 to 2.9 referring to low scores in the physical domain. This fact may be related to disease that develops in the peripheral innervation may lead to different degrees of disability if not treated early.

As most patients are elderly, and was not included with antibiotic therapy, all sample presented disability. This reality is different from the present day, as multidrug therapy provides the patient a treatment within the social and family context and prevents both the disability as the spread of the bacillus.

Regarding the complaints many referred pain, as the question Q3 (average of 2.9) even with the presence of health staff available to treat them on the spot. The question Q4 refers to the need of medical treatment, which showed a better score, average (3.6). For the patients of the Getúlio Vargas colony, although bothered with the pain, they do not complained about the need for treatment, because there is a team that meets every day.

With regard to patients of San Francisco colony, complained about access to health services, since the colony was in fact disabled. They state that despite the medical care, became chronic carriers of the bacillus and obtained some sequels after the disease, acquired some permanent disability, requiring wheelchair, others needed correction surgeries.

Ratifying the previous statement, a study in São Luiz do Maranhão, with 53 leprosy patients, which evaluated the correlation between physical disabilities caused by leprosy and the quality of life of their patients, we obtained the commitment of QOL, as the Most patients (31%) had high commitment in QoL; (28%) moderate impairment; (24%) little commitment; (13%) extreme commitment; only (4%) reported no impairment in quality of life. The same study associated with poor quality of life for patients to greater functional impairment. The importance of early detection and treatment is the reduction and prevention of disabilities[14], which in this study, has been identified as one of the factors worsening of QOL - Quality of Life.

The psychological domain comprises the issues (Q5, Q6, Q7, Q11, Q19, and Q26). In this respect it can be seen that the mean is comprised between 1.6 and 3.9. The question 11 resulted in lower scores, revealing that most subjects do not accept the physical appearance.

The presence of the bacillus may cause feline face, hands into claws, amputation of limbs, lagophthalmos (down the lower eyelid), which leads to impairment of physical appearance. On the other hand, the social stigma may lead to drop in self-esteem, self-image disturbance and psychiatric disorders related to dissatisfaction, such factors may interfere with the patient's perception regarding theirselves and their quality of life.[14]

Research conducted in São Paulo, on quality of life of 11 leprosy patients, reveals through testimonies that the subjects reported a radical change in your routine after diagnosis. During the living family members or close friends, they were concerned about the spread of the bacillus and in error, came to separate the belongings of patients as soap, towel, etc...[15]

The patients reported dissatisfaction with visible stains, which denounced an illness process framework, which sometimes prevented them from performing their work activities that made them feel useful and productive. They have also reported that upon receiving the diagnosis was the reaction of revolt, denial can come to acceptance over time.[16]

There was identified a good score in social relations, as shown in the table earlier in this study. Also, they were more likely to get along with colleagues from the colony, since they have no contact with the world outside the colony. They pointed out that prejudice is a concern, and that is present in their lives.

Discrimination Scale and anticipated stigma (Emic) in a sample of 1.358 respondents showed that failure caused by bacterium, has consequences, physical, economic and social. In the study, 77% of the sample surveyed presented in addition to mental illness, difficulty of socialization and relationship difficulties. In cases in which we observed mild depression, we identified a lower score among subjects with depression, difficulty in social relationships.

A study in 75 elderly and 63 females and 12 males in the Federal University of Rio de Janeiro, using the WHOQOL-BREF was identified a lower score in social relationships domain. The same study found that patients who had lower scores in the psychological domain and financial difficulties, also had difficulties in social relationships, proving the hypothesis that psychological morbidity may lead to impairment of social relations.[17]

The environmental domain presented the highest score. The subjects of the sample said they did not feel safe in the environment where they are, although observe positive points in the colony as afforestation and no car traffic, which removes pollution.

With the statements about the variable above, we notice that patients have associated environmental nature and the safety and neglecting other environmental contexts. This issue may be related to the isolation of the colony, all have TV, but do not have other means of communication, being prevented from leading a normal life. The lowest score was leisure, many do not have and ensure refer nostalgia also remember when the colony was active, for there was bonfire gang and leisure activities.

At the Institute Lauro Souza Lima (ILSL) in Bauru Sao Paulo, currently disabled leprosy, reside 36 patients with similar stories to the sample subjects. A study in the institution reveals that patients find it difficult to leave the night (38,8% of statements). In addition, the rest of the sample reported nostalgia the days when the colony was active, because in this period had leisure and entertainment opportunities.[17]

CONCLUSION

This study shows that leprosy is a disease that affects the quality of life of chronically infected patients, especially with regard to physical and psychological domain. Domains related to social relations and the environment showed less prejudiced.

In the physical domain the low score is especially assigned to physical disability caused by the disease itself. Pain is a frequent complaint and the difficulty of access to health services is often cited.

In the psychological domain to decreased quality of life refers mainly to physical changes caused by the disease. The appearance ends up promoting a change in the way to see the patient and how society sees him.

The social relationships domain, the score appears high, since institutionalized patients interact well with each other. But it is worth noting that there is a social stigma in patients with physical appearance of leprosy, and therefore these individuals have difficulty of living in ordinary society.

In relation to the environment, safety and patient attribute nature as main features. Thus, while not feel safe and feel lack of an appropriate leisure, think they are well inserted in the environment.

Institutionalized patients tend to adapt to reality due to resilience. However, through this study it can be seen that the difficulty of accepting the disease and removal of industrial activities, which directly undermines the financial situation as well as their social and family relationships, rather compromises the quality of life of these patients.

Based on these results, we see a need to intensify the bacillus disposal policies and (re) socialization of patients of the same, which were institutionalized. This is part of the comprehensive health concept which states both the WHO, as the SUS, welfare biopsychosocial, targeting both physical health and psychological patients.

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Submission: 2014/10/04
Accepted: 2015/02/17
Publishing: 2015/06/01

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