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ORIGINAL ARTICLE

QUALITY OF LIFE OF PEOPLE AFFECTED BY LEPROSY IN SELF-CARE SUPPORT GROUPS*

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ABSTRACT

Objective: To analyze the quality of life of people affected by leprosy in self-care support groups.
Method: A quantitative and descriptive study conducted with 43 participants in reference units with self-care support groups for people affected by leprosy in Recife and its Metropolitan Area. Data collection took place between January and July 2018 with the application of the WHOQOL-BREF instrument to assess quality of life. The distribution of the continuous numerical variables was analyzed by the Kolmogorov-Smirnov test; the categorical variables were presented by absolute and relative (%) frequency.
Results: The overall quality of life score was 56.4 and the domain scores were average, ranging between 50 and 60. The domains with the lowest scores were found to be the physical and environmental relationship domains
Conclusion: People affected by leprosy have a decreased quality of life. Although curable, it is a public health problem and requires attention for control and elimination.

DESCRIPTORS: Quality of Life; Leprosy; Self-care; Education; *Mycobacterium leprae*.

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QUALIDADE DE VIDA DE PESSOAS AFETADAS PELA HANSENÍASE INSERIDAS EM GRUPOS DE APOIO AO AUTOCUIDADO

RESUMO
Objetivo: analisar a qualidade de vida de pessoas afetadas pela hanseníase inseridas em grupos de apoio ao autocuidado.
Método: estudo quantitativo, descritivo, com 43 participantes em unidades de referência que possuíam grupos de apoio ao autocuidado em hanseníase, em Recife e Região Metropolitana. A coleta de dados ocorreu entre janeiro e julho de 2018 com a aplicação do instrumento de avaliação de qualidade de vida WHOQOL-bref. A distribuição das variáveis numéricas contínuas foi analisada pelo teste de Kolmogorov-Smirnov, as categóricas foram apresentadas por frequência absoluta e relativa (%).
Resultados: o escore global de qualidade de vida foi 56,4 e os escores dos domínios revelaram-se medianos, com faixas de 50-60. Verificou-se que os domínios com menores pontuações foram os domínios físicos e relações ambientais.
Conclusão: pessoas afetadas pela hanseníase apresentam diminuição da qualidade de vida. Apesar de ter cura, é problema de saúde pública, necessitando de atenção para controle e eliminação.

DESCRITORES: Qualidade de Vida; Hanseníase; Autocuidado; Educação; Mycobacterium leprae.

CALIDAD DE VIDA DE PERSONAS CON LEPRA QUE ACUDEN A GRUPOS DE APOYO PARA EL AUTOCUIDADO

RESUMEN:
Objetivo: analizar la calidad de vida de personas con lepra que acuden a grupos de apoyo para el autocuidado.
Método: estudio cuantitativo y descriptivo realizado con 43 participantes en unidades de referencia que poseían grupos de apoyo para el autocuidado de la lepra, en Recife y en su Región Metropolitana. Los datos se recolectaron entre enero y julio de 2018 con la aplicación del instrumento de evaluación de la calidad de vida llamado WHOQOL-bref. La distribución de las variables numéricas continuas se analizó con la prueba de Kolmogorov-Smirnov; las categóricas se presentaron por medio de frecuencias absolutas y relativas (%).
Resultados: el puntaje global de la calidad de vida fue 56,4 y los de los dominios resultaron medianos, con un margen de50 a 60. Se verificó que los dominios con los puntajes más bajos fueron los dominios físico y de relaciones ambientales.
Conclusión: las personas con lepra presentan una reducción en su calidad de vida. Pese a tener cura, es un problema de salud pública, que requiere atención para su control y eliminación.

DESCRIPTORES: Calidad de vida; Lepra; Autocuidado; Educación; Mycobacterium leprae.

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INTRODUCTION

Leprosy is an infectious, slowly progressive, curable and chronic disease, whose etiological agent is *Mycobacterium leprae*, a bacillus of high infectivity and low pathogenicity(1). The disease is transmitted through the respiratory route, with exposure to infected patients without proper treatment(1).

Considered a neglected and millenary disease, leprosy has a close relationship between the living conditions of the individuals affected and the health and disease process(2). According to the World Health Organization (WHO)(3), leprosy is still a public health problem. There are some difficulties in its diagnosis, as the clinical picture is often confused with other skin diseases, a situation that favors late diagnosis and, consequently, the occurrence of physical disabilities(3).

The disabilities and deformities caused by leprosy exceed the physical domain and affect the quality of life of the patients, with obvious obstacles to performing activities of daily living, lack of interaction between the person and the community and psychological impacts(4-5).

Over the last few years, international studies have highlighted the quality of life of people affected by leprosy, with emphasis on patient empowerment and focus on reducing stigma, rehabilitation programs, social integration and early diagnosis to minimize limitations and restrictions on social participation and improve quality of life(6-9).

The quality of life of people affected by leprosy can be impaired due to the physical alterations and deformities caused by the disease, causing changes in individuals' perception of their own body and how the community perceives them, generating great psychosocial impact(10-14).

Thus, all strategies aimed at preventing and treating disabilities and deformities are essential so that people affected by the disease improve their quality of life(15). One of the strategies is the promotion of self-care: actions taken and activities developed by the patients themselves, understanding the risks and taking actions to promote, prevent and recover their health. Self-care approaches include self-care support groups(16-17).

Given the importance of understanding the determinant factors of the disease and the existence of validated instruments measuring quality of life, this study aimed to analyze the quality of life of people affected by leprosy in self-care support groups.

METHOD

This was a quantitative and descriptive study. The survey was conducted from January to July 2018, with people affected by leprosy who are part of Leprosy Self-Care Support Groups (SCSGs) of local or state reference units located in the city of Recife (PE) and in the Metropolitan Area.

All six SCSGs holding periodic meetings were included. The study population involved the members of the group, which did not have a fixed number of participants, as they are open-access groups, thus allowing their members to enter or leave at any time.

The sampling process was performed non-probabilistically (convenience/accessibility). At the start of the survey there was a total of 70 participants registered in the groups. During the collection, 43 people participated in the survey, which corresponds to 61.4% of the total. For this study, the researchers attended a total of 30 meetings. Data was collected on average from seven participants per meeting. Data collection from all pf the participants was not possible since, during the collection period, some patients missed the meetings.

The sample size was calculated using the G*Power software, version 3.1.9.2. Considering the results obtained(14) for the question "How would you rate your quality of life?" (the frequencies being: "very poor"=0.0%, "poor"=0.0%, "neither poor nor good"=38.8%, "good"=52.7% and "very good"=8.3%), considering an alpha of 5% and a power of 80%, the minimum sample size required for this study would be 11 participants.

The inclusion criteria were the following: being a person affected by leprosy and participating in the SCSG. Participants with mental disabilities described in medical records that made it impossible to understand the questionnaire, instruments applied, the theme and/or objective of the survey were excluded from the study, as well as participants who were under treatment for less than three months and individuals under 18 years old.

Data collection was performed through the application of two instruments, with the presence of the researchers in a reserved and quiet setting, only one meeting being sufficient to fill in the information (for each participant, individually). The first instrument consisted of socio-demographic, economic and clinical data, which were collected through the participants' medical records.

Regarding the perception of quality of life, the World Health Organization Quality of Life (WHOQOL-BREF)(18) instrument was used in a short version, validated in Portuguese. It consists of 26 questions, the first two correspond to the general aspects of quality of life and the other 24 are divided into four domains (physical health, psychological, social relationships and environment), and the answers follow a Likert scale(18).

The analysis of the domains was performed individually and in a global quality of life score. Each domain has questions ranging from one to five points. The higher the score, the higher the quality of life, except for questions three, four and 26 that have an inverse score. The scores were transformed to a scale of 0-100 points(18).

The distribution of the continuous numerical variables was analyzed by the Kolmogorov-Smirnov test. The results were presented using descriptive statistics. The results of the continuous numerical variables were described by measures of central tendency (mean and median) and dispersion (standard deviation and interquartile range).

The binomial test was used to compare proportions in a random distribution for the gender, operational classification and leprosy reaction variables. The categorical variables were presented as absolute and relative (%) frequency. The Chi-square test for adherence was used to compare the observed frequencies against the expected ones. Data analysis was performed using the SPSS Statistics for Windows program, v 20.

The research was approved by the Ethics Committee for Research with Human Beings of the Hospital Complex of the University of Pernambuco, under opinion No. 2,309,191.

RESULTS

The study sample consisted of 43 individuals. The socio-demographic and economic data results are shown in Table 1.

Table 1 – Socio-demographic and economic characterization of people affected by leprosy (n=43) in self-care support groups in Recife (PE) and the Metropolitan Area. Recife, PE, Brazil, 2018 (continues)

Variable	**n**	**%**	**p**
Gender			

Male	23	53.5	0.761
Female	20	46.5	
Age			
20-39 years old	6	14	0.023
40-59 years old	20	46.5	
60 years old or more	17	39.5	
Ethnicity			
Brown	23	53.5	<0.001
Black	12	28	
Caucasian	7	16.3	
Others	1	2.2	
Origin			
Recife	15	35	0.003
Metropolitan Region	5	11.5	
Others	23	53.5	
Marital status			
Single	15	35	0.141
Married	14	32.6	
Stable union	6	14	
Others	8	18.4	
Work status			
Retired	15	35	0.062
Autonomous	4	9.3	
Housewife	10	23.3	
Unemployed	5	11.6	
Others	9	20.8	
Monthly income			
No income	4	9.2	<0.001
1 minimum wage	6	14	
2 to 3 minimum wages	27	62.8	
More than 3 minimum wages	6	14	
Schooling			
1-3 years of study	9	21	0.039
4-7 years of study	22	51	
8 or more years of study	12	28	
Home			
Own	37	86	<0.001
Leased	4	9.3	
Others	2	4.7	

Regarding the operational classification, the predominance was the multibacillary (MB), which corresponded to 37 (90.2%) participants, followed by the paucibacillary (PB), with four (9.8%) participants. Regarding the clinical forms, the following was observed: 19 (50%) individuals with Virchow cells, 18 (47.4%) with borderline leprosy and one (2.6%) with tuberculoid leprosy.

Regarding the degrees of disability, 18 (47.4%) individuals were diagnosed with grade II, 14 (36.8%) with grade I and six (15.8%) individuals had no disabilities (grade 0) at the time of diagnosis. Although 32 (84.2%) participants already had some degree of disability at the time of the initial assessment, the frequency of response was not significantly different among the classifications (p=0.052); this was also true for the leprosy reaction, being identified in 22 (57.2%) participants (p=0.418). The use of orthosis/prosthesis occurred in a smaller proportion, being reported by only five (17.2%) individuals (p=0.001).

When directly addressed with instrument questions related to the general aspects of quality of life, there are the following approaches: "How would you rate your quality of life?" and "How satisfied are you with your health?" Compared with the previous two weeks, only 14 (32.6%) individuals reported perceiving their quality of life as "good" and two (4.7%) reported it as "very good". More than half of the sample, 22 (51%) individuals, referred to it as "neither poor nor good" and five (11.7%) participants answered it was "poor" (p<0,001).

When analyzing satisfaction with their health, only one (2.3%) participant reported being "very satisfied", 11 (25.6%) said they were "satisfied", 19 (44.2%) were "neither satisfied nor dissatisfied", seven (16.3%) were "dissatisfied" and five (11.6%) were "very dissatisfied". In both questions, the distribution was different from that expected randomly (20% per alternative), but 11.6% and 27.9% indicated conditions that suggest the need for improvement in health and quality of life, respectively. The WHOQOL -BREF instrument has four domains: physical health, psychological, social relationships and environment. The domain scores are presented in Table 2.

Table 2 – Score of the quality of life domains of people affected by leprosy (n=43) in self-care support groups in Recife (PE) and the Metropolitan Area. Recife, PE, Brazil, 2018

WHOQOL-BREF Domains	**Mean**	**SD**	**Median**	**1st quartile**	**3rd quartile**
Physical	50.5	21.8	57.1	32.1	64.3
Psychological	62.1	16.1	66.6	54.2	70.8
Social relations	62.5	22.4	66.6	50	75
Environment	50.5	13.8	50	43.8	59.4

The participants' overall quality of life score was 56.4 (standard deviation=15; median=58.1; interquartile range=46.7-65.7) and the scores of the domains analyzed turned out to be average, ranging between 50 and 60, suggesting that no specific domain was more affected by the disease (Table 2). The results of the physical domain are presented in Table 3.

Table 3 – Physical health domain related to quality of life of people affected by leprosy (n=43) in self-care support groups in Recife (PE) and the Metropolitan Area. Recife, PE, Brazil, 2018

WHOQOL-BREF – Physical Health Domain						
Facets (%)	Nothing	Very little	More or less	Quite	Extremely	p
Pain and discomfort	14	32.5	20.9	18.6	14	0.285
Dependence on medication or treatment	16.3	46.5	25.6	9.3	2.3	<0.001
Facets (%)	Nothing	Very little	Medium	Very much	Completely	p
Energy and fatigue	7	16.3	20.9	44.2	11.6	0.001
Facets (%)	Very bad	Bad	Neither bad nor good	Good	Very good	p
Mobility	4.7	16.3	23.3	39.5	16.2	0.007
Sleep and rest	14	18.5	14	39.5	14	0.031
Daily life activities	14	11.6	27.9	37.2	9.3	0.014
Working capacity	20.9	25.6	18.6	27.9	7	0.221

The psychological domain had a higher score (62.1) than the physical health domain (50.5). A relevant data in the psychological domain shows how much the participants enjoy life, and more than 60.5% reported that they enjoy "nothing" and "very little". Most people (90.6%) realized that they experienced negative feelings, such as bad mood, despair, anxiety and depression, "often", "very often" or "always" during the past two weeks.

It was observed that the participants did not experience negative changes in their relationships with friends, relatives, and acquaintances and regarding sexual activity and support (social support). Table 4 below presents the results from the social relations domain.

Table 4 – Social relations domain related to quality of life of people affected by leprosy (n=43) in self-care support groups in Recife (PE) and the Metropolitan Area. Recife, PE, Brazil, 2018

WHOQOL-BREF– Social Relations Domain						
Facets (%)	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied	p
Personal relations	2.3	16.3	20.9	39.5	21	0.004
Sexual activity	9.3	11.6	16.3	48.8	14	<0.001
Social support	11.6	4.7	25.6	44.1	14	<0,001

It was observed that, when reporting on their physical safety and protection, 25.6% perceived "nothing" and "very little", respectively; the distribution was not different from the randomly expected (p=0.099). The participants were asked about their satisfaction with their means of transportation and 37% said they were "dissatisfied" or "very dissatisfied" (p=0.008). When asked about opportunities for leisure activities, 55.8% reported "nothing" or "very little"; the frequency was significantly (p<0.001) different than the randomly expected (Table 5).

Table 5 – Environmental relations domain related to quality of life of people affected by leprosy (n=43) inserted in self-care support groups in Recife (PE) and the Metropolitan Area. Recife, PE, Brazil, 2018

WHOQOL-BREF – Environment Domain						
Facets (%)	Nothing	Very little	More or less	Quite	Extremely	p
Physical security and protection	11.6	14	32.5	27.9	14	0.099
Home environment	0	14	32.6	39.4	14	0.032
Physical environment: pollution/ noise/traffic	7	7	23.3	53.5	9.2	<0.001
Facets (%)	Nothing	Very little	Medium	Very much	Completely	p
Financial resources	23.3	41.8	27.9	4.7	2.3	<0,001
Opportunities of acquiring new information and skills	9.3	27.9	32.6	25.5	4.7	0.012
Participation in and opportunities for recreation/leisure activities	9.3	46.5	23.3	16.3	4.6	<0,001
Health and social care: availability and quality	7	25.6	14	46.4	7	<0,001
Transportation	9	28	18.6	37.2	7.2	0.008

Regarding the financial situation, 65.1% reported having "no" or "very little" money to meet their needs, which corroborates the characterization of the income of these participants, who were in the range of two to three minimum wages (62.8%), predominantly. Regarding the availability of information for everyday life, 37.2% report "no" or "very little" restriction to access information, the distribution being different from the randomly expected (p=0.012), which may be related to the lack of information and/or to the level of education of the studied population which, for the most part, 51% have between four and seven years of study (Table 5).

DISCUSSION

In this study, it was possible to verify that people affected by leprosy have a decreased quality of life. It is noteworthy that the participants had an overall quality of life score of 56.4, and the scores of the domains analyzed were average, ranging between 50 and 60. It was identified that the presence of the disease may be related to the impairment in the general quality of life. By analyzing each domain, it was found that the domains with the lowest scores in comparison with the others were the physical (50.5) and environment (50.5) ones.

Regarding the characterization of the population, most of the participants were men (53.5%), which corroborates other studies(10-11), with 54.3% and 62.1%, respectively. Increased exposure to bacillus and lower health care among men were also mentioned, which leads to delayed diagnosis and increases the risk of developing physical disabilities(19).

Regarding the schooling level and income, the data from this study suggest greater fragility of the population affected by leprosy and support findings in some studies(10,12) on the characterization of people affected by the disease in Brazil. This information can be an obstacle and negatively contribute to the participants' understanding of the disease, diagnosis, treatment and self-care, and underscores the economic damage to them, their families and the society(10,12).

This study shows a predominance of the age group between 40 and 59 years old (46.5%), and of retired people (35%). Studies from two states of Brazil, Paraíba (100.0%)(12) and Minas Gerais (68%)(20), confirmed this socio-economic characterization(12,21). Due to the late diagnosis and to the presence of disabilities, people need to be away from their work activities due to the complications caused by the disease.

Regarding the operational classification, clinical form and degree of disability, the presence of the multibacillary form is the most prevalent in the studied populations, as in this study (90.2%, 47.4% with Virchow cells). For operational treatment purposes, the patients are classified as paucibacillary (PB – up to five skin lesions with negative smear test result) or multibacillary (MB – six or more skin lesions or positive smear test result)(1).

Studies on the profile of people affected by leprosy addressed the relationship between the high number of diagnosis of multibacillary cases and late diagnosis, since leprosy is a systemic disease that affects many organs and this is the most severe and potentially infectious clinical form(1,19,22).

Assessing the degree of disability is of utmost importance in developing strategies for disability prevention and self-care promotion(1). More than 84.2% of the participants in this study were assessed with disability grades I and II in the diagnosis. This differs from another study(14), which showed the presence of physical disabilities in 62% of the population. Therefore, it is noteworthy that the sample consisted of participants from self-care support groups and that this may have influenced the profile of the study participants, since in some units the groups are focused on individuals who already have some disability.

The physical health domain related to quality of life had a low score (50.1), and may be a consequence of the effects of the disease, evidenced in the physical disabilities. Brazilian studies also show lower scores in this domain(11-13).

The participants' perception in the social relations domain related to quality of life did not show any relation with decreased quality of life perceived by them, with a mean score of 62.5. The fact that the participants are part of a self-care support group, where they shared experiences and experienced difficulties together, can positively contribute to their perception of friendships and peer relationships.

In the psychological domain related to quality of life, even though the mean score was higher than in the other impaired domains (62.1), over 90% of the participants reported having negative feelings. In a study(12), the psychological domain contributed to decreased quality of life, and people affected by the disease reported that the physical changes caused by the disease reduced their self-esteem, self-perception and quality of life, contributing negatively to this domain.

The environmental domain can contribute to the impairment of quality of life, as it involves issues related to physical and social protection, home environment, financial resources and transportation and, in these issues, most felt impaired, which may be related to the socio-economic profile of the participants in this study, as found in other studies(23-24). This domain had the lowest mean score (50.5) in comparison with the other domains, which were also found in studies from Minas Gerais and Paraná(13-14). The participants perceived difficulties (62.8%) regarding their participation in community activities.

The results found in this study may provide guidance on the actions of the health professionals and on the reorganization of the work process within individualized care and/or in group sessions, in order to outline goals and strategies aimed at the impaired domains and at the determinants that lead to the reduced quality of life of these individuals.

The limitations of this study are related to the sampling method of the people affected by leprosy inserted in self-care support groups and the group itself, as they behave dynamically and people participate according to availability and interest, which hindered the data collection process. The cross-sectional design precludes possible views on the cause and effect of the problems identified in the quality of life domain scores, as well as the impact of the presence of self-care support groups on quality of life and prevention of disability in these individuals.

CONCLUSION

The results show that the participants' perception of their quality of life had a low score. Several problems were observed and related to the dissatisfaction of quality of life perceived by people affected by the disease. A broader view is needed, with a broad perspective on the care and understanding of the determinants that lead to impaired quality of life, always associating them with the clinic and psychosocial aspects.

There is a need for further studies on this subject, considering these people's perception of the illness, the concept of health-disease and the repercussions of self-care groups on the lives of the members.

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