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IMPAIRED QUALITY OF LIFE OF PEOPLE AFFECTED BY LEPROSY WITH PHYSICAL DISABILITIES

[1]Stephanie Steremberg Pires D'Azevedo, [1]Danielle Christine Moura dos Santos, [1]Gustavo Aires de Arruda, [1]Jaqueline Caracas Barbosa, [1]Niedja Madelon Nascimento Souza and [2]Marielle de Lima Belmonte

[1]Nossa Senhora das Graças Nursing School. University of Pernambuco, Recife, Pernambuco, Brazil
[2]Federal University of Ceará. Fortaleza, Ceará, Brazil

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***Corresponidng author:**
Stephanie Steremberg Pires D'Azevedo

ABSTRACT

Objective: to analyze the quality of life of people affected by leprosy with physical disabilities participating in self-care support groups. **Methods:** descriptive study, conducted with participants from self-care support groups in leprosy (n=27), in the state of Pernambuco, Brazil. Structured instruments were used, containing sociodemographic, economic and clinical information, as well as scales for the evaluation of quality of life. **Results:** when approached about the impact of the limitations in their life, 89.5% of the people realized that they have a negative effect on their quality of life. All areas seem to suffer impairment, with increasing magnitude considering autonomy (70.9), inclusion (63.8) and discrimination (60.1). **Conclusion:** High proportion of people affected by leprosy presented impaired quality of life.

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INTRODUCTION

Considered a neglected and millennial disease, leprosy is classified as a public health problem and constitutes the main cause of permanent physical disability among the contagious diseases (ALVES *et al*., 2014), due to the long incubation period, late diagnosis and neural involvement (BRAZIL, 2018). The course of the disease and the lack of early diagnosis favor the development of physical, functional, psychological and social disabilities, limiting people and affecting their quality of life. As well as the social isolation, the presence of the historical character of discrimination and fear, difficult acceptance and self-care, are still echoing in personal and professional lives (ARAÚJO *et al*., 2016). The concept of quality of life, according to the World Health Organization (WHO), involves the individual's perception of their state of health and those aspects of their life context, including physical, psychological, social relations and environmental dimensions (WHOQOL GROUP, 1998). Thus, two instruments were created to evaluate quality of life: the World Health Organization Quality of Life (WHOQOL-100) and abbreviated version of the WHOQOL-bref. The instruments are guided in three aspects: subjectivity, multidimensionality, and positive and negative dimensions (WHO, 1995). According to a study of Fleck (2008) about quality of life, the scales of the WHOQOL group were important tools for understanding health outcomes, due to their broad nature, in addition to being linked to the individual's perception. Enlarging the approaches in the care with these people aiming at improving the quality of life is essential, whether through the development of new researches, health interventions and/or public policies. The existence of instruments (WHO, 1995) providing this can lead to a reorganization the work and care processes of health professionals who work with primary prevention, health promotion, in addition to the perception of the implication of the disease, improving the health conditions and providing well-being for the person afflicted by it. Therefore, the objective of this study was to analyze the quality of life of people affected by leprosy with physical disabilities participating in self-care support groups in Pernambuco, Brazil.

MATERIALS AND METHODS

This was a cross-sectional descriptive study with a quantitative approach. The research was carried out in the period from January to July 2018, in the city of Recife and Metropolitan Region in Pernambuco, Brazil. It was performed at six health units of reference for the monitoring of people affected by the disease and who had self-care support groups. The sampling process was carried out in a non-probabilistic (accessibility) way. Thus, initially, the sample was composed of 27 participants with leprosy. The inclusion criteria were: being a participant in one of the groups, with diagnosis of leprosy under polychemotherapeutic treatment, treatment for leprosy reaction or post-discharge, aged over 18 years and being under treatment for at least three months. There was exclusion of participants with disabilities described in medical records that prevented the understanding of the instruments applied, theme, and/or the research objective. The quality of life of people affected by leprosy with physical disabilities was analyzed with the World Health Organization Quality of Life Disabilities Module (WHOQOL-dis), which represents a WHOQOL-brefadditional measure, oriented to the particularities of people with self-reported physical disabilities, according to the flowchart proposed by Bredemeier (2014) and colleagues (FLECK, 2010). The analysis was performed in overall score and domains of quality of life. Each domain has questions that vary from one to five points. The scores were transformed into a scale ranging 0-100. The syntaxes proposed by the WHO (POWER, 2010) were used to calculate the scores of the WHOQOL-dis instrument. The distribution of continuous numerical variables was analyzed using the *Kolmogorov-Smirnov* test. The results were presented using descriptive statistics. The Chi-square test of adherence was used for the comparison of the frequencies observed in relation to the expected ones. The binomial test was used for sex, operational classification and leprosy reactions variables. The significance level adopted was $p<0.05$.The analyses were performed using the software IBM SPSS Statistics for Windows, version 20 (IBM Corp., Armonk, N.Y., USA).

RESULTS

The study population was composed of 27 people affected by leprosy. In relation to their sociodemographic and economic characteristics, 51.9% (n=14) were female and 48.1%(n=13) were male, 48.1% (n=13) were 40-59 years, followed by 60 years or more with 37.1%(n=10) and 14.8% between 20-39rs (n=4); 59.3% (n=16) self-reported as pardos, followed by 29.6% (n=8) as black, 7.4% (n=2) as white and 3.7%(n=1) as Asians. In relation to marital status, 44.4% (n=12) of the participants were married, 22.2% (n=6), unmarried, 14.8% (n=4) were in a stable union and 18.6% (n=5) reported others. Regarding work status, the main results were 33.3% (n=9) were retired, 29.6% (n=8) were housewives; 11.1% (n=3) reported being unemployed. The income of 63.0% (n=17) of the sample were 1-2 minimum wages, followed by 1 minimum wage (18.5%, n=5), 3 or more minimum wages (11.1%, n=3) and without income, 7.4% (n=2). Concerning schooling, 48.1% (n=13) had between 4-7 years of study, 29.6% (n=8), eight or more years of study and 22.3% (n=6) with 1-3 years of study. In relation to the clinical data of the participants, regarding the operational classification, the predominance was the multibacillary (MB) form, which corresponded to 96.2% (n=25), followed by the paucibacillary (PB) with 3.8% (n=2). In relation to clinical forms, there was predominance of Virchowian and dimorphous forms, with 60.9% (n=18) and 39.1% (n=9), respectively.

In relation to the degrees of disability, 69.6%(n=16) were diagnosed with grade II and 26.1% (n=6) with the presence of grade I. only 4.3%(n=1) had no disability at the time of diagnosis and were evaluated with zero degree, thus showing that more than 95.6% (n=22) of participants already had some degree of physical incapacity at the time of initial evaluation; 14.8% (n=4) of the participants had no information on the disability grading on the medical records and were not taken into consideration in the statistical analysis. Of the analyzed sample, 70.8% (n=17) presented leprosy reaction during the treatment or post-discharge. Regarding quality of life based on the overall perception, the mean value was 64.7, standard deviation of 16.6 points (median = 66.6; interquartile range = 54.1- 75.0) for the international version of the instrument and for the Brazilian version, mean value of 47.9, standard deviation of 20.6 points (median = 50.0; interquartile range = 31.2- 62.5). When being approached about the impact of disabilities/limitations, through the question: "*Does your incapacity (disability/limitation) have a negative (bad) effect in your life?*", in relation to the previous two weeks, 89, 5% of people realized that the same has a negative effect on their quality of life and responded that affects "*very little*", "*more or*

Table 1. Discrimination Domain of the quality of life instrument of people affected by leprosy with physical disabilities participating in self-care support groups in Recife and metropolitan region, Pernambuco, Brazil, 2018 (n=27)

WHOQOL-*dis**	Mean	SD	Median	1stquartile	3rdquartile	
Discriminationdomain	60.1	21.7	58.3	50.0	75.0	
Facets (%)	Notatall	Verylittle	More orless	A lot	Totally	*p*
Discrimination	3.7	11.2	18.5	29.6	37.0	0.043
Protection	7.4	3.7	14.8	11.1	63.0	<0.001
Future perspectives	29.6	44.4	11.2	7.4	7.4	0.005

Source: Created by the authors

*WHOQOL-*dis:*Quality of life assessment instrument for people with disabilities - International and Brazilian versions.

Table 2. Autonomy Domain of the quality of life instrument of people affected by leprosy with physical disabilities participating in self-care support groups in Recife and the metropolitan region, Pernambuco, Brazil, 2018 (n=27)

WHOQOL-*dis**	Mean	SD	Median	1stquartile	3rdquartile	
Autonomydomain	70.9	22.3	75.0	58.3	83.3	
Facets (%)	Notatall	Verylittle	More orless	A lot	Totally	*p*
Controlofyourlife	11.1	7.4	26.0	33.3	22.2	0.188
Decision-making power	3.7	7.4	7.4	37.0	44.5	0.001
Autonomy	3.7	7.4	18.5	33.4	37.0	0.017

Source: Created by the authors

*WHOQOL-*dis:* Quality of life assessment instrument for people with disabilities - International and Brazilian versions.

Table 3. Inclusion Domain of the quality of life instrument of people affected by leprosy with physical disabilities participating in self-care support groups in Recife and the metropolitan region, Pernambuco, Brazil, 2018 (n=27)

WHOQOL-*dis**	Mean	SD	Median	1stquartile	3rdquartile	
Inclusiondomain	63.8	18.3	66.3	45.8	75.0	
Facets (%)	Notatall	Verylittle	More orless	A lot	Totally	*p*
Communication ability	0.0	3.7	18.5	33.3	44.5	0,017
Social acceptance	3.7	14.8	33.3	37.0	11.2	0,023
Respect	0.0	3.7	22.2	51.9	22.2	0,005
Social interaction	14.8	7.4	22.2	33.3	22.3	0,284
Social inclusion	14.8	18.6	37.0	14.8	14.8	0,284
Personalability	14.8	7.4	18.5	33.3	26.0	0,248

Source: Created by the authors
*WHOQOL-*dis:* Quality of life assessment instrument for people with disabilities - International and Brazilian versions.

Table 4. Local module: “environmental adaptations to limitations” of the Brazilian version of the quality of life instrument of people affected by leprosy with physical disabilities participating in self-care support groups in Recife and the Metropolitan Region, Pernambuco, Brazil, 2018 (n=27)

WHOQOL-*dis** Question (%)	Notatall	Verylittle	More orless	A lot	Totally	*p*
Are you satisfied with the opportunities you have to work?	33.3	18.5	33.4	7.4	7.4	0,058
Are you satisfied with your adaptations of your environment to your limitation?	14.8	18.5	37.0	26.0	3.7	0,079
Are you satisfied with the opportunities you have to study?	26.0	14.8	33.3	14.8	11.1	0,323
Are you satisfied with your diet?	7.4	3.7	22.2	40.7	26.0	0,017

Source: Created by the authors
*WHOQOL-*dis:* Quality of life assessment instrument for people with disabilities - and Brazilian versions.

less" and "*too much*" (48.1%, 33.3% and 7.4%, respectively), followed by the answer "*not at all*", with 11.2% and "*totally*", 0%. In both questions, $p<0.001$. Table 1 above shows that discrimination remains a relevant factor that can impair the quality of life of people affected by leprosy with physical disabilities, restricting them socially and isolating them from their activities. Of the participants, 66.6% reported being treated *"unfairly"* and 74.1% feel vulnerable and require *"someone to speak for them when they have a problem"*. Table 2 below addresses the Autonomy of the instrument of quality of life of people affected by leprosy with physical disabilities.

The findings in the autonomy domain do not bring difficulties perceived by participants related to the control of life (55.5% reported having "*a lot*" or "*total*" control of their life), decision-making power (81.5%) and autonomy (70.4%). Table 3 provides the results of the field Inclusion of instrument of quality of life of people affected by leprosy with physical disabilities. Table 4 below covers the local module that refers to the *"environmental adaptations to the limitations"* of the Brazilian version of the instrument of quality of life for people with physical disabilities. In the studied population, 51.8% of the participants reported not being "*satisfied*" with the work opportunities, but it is important to emphasize that the study sample consisted of retired participants (33.3%) and aged 40-59 years (48.1%), which can corroborate these difficulties in relation to labor market opportunities. Of the participants, 33.3% had some degree of *"dissatisfaction"* with their adaptations in the environment related to their limitation (*"not at all"* or *"very little"*), as answers. The low monthly income (1-2 minimum wages; 63.0%; n=17) and level of schooling, 48.1% (4-7 years), in this study, may be contributory factors to this *"dissatisfaction"*. Furthermore, 40.8% reported few opportunities to study. Nevertheless, it is important to highlight that most participants were not at school age and the implementation of the instrument has a temporal cutout.

DISCUSSION

Despite the advances related to information and treatment of the disease, the prejudice and stigma constitute barriers in coping with the disease and involves issues of body image, not only in physical, but also in psychological terms. Study on stigma and leprosy showed, through the narratives of people affected by the disease, that the process of stigmatization marked the history of life of these people significantly (LEITE *et al.,* 2015). The people affected by leprosy with presence of physical disabilities need to relearn how to live with their new body, adapting themselves to difficulties and obstacles. For this purpose, they need to have autonomy in relation to the self-care process, becoming an active agent in their treatment, taking decisions that affect their health, life and psychosocial integrity (MAIA *et al*., 2014). When raising data related to the control of life, decision-making power and autonomy, the participants of this study showed good scores, despite the need for someone to speak for them when they have problems and physical disabilities (95.6%). This finding may be related to the presence of participants into self-care support groups, which stimulate the autonomy of individuals and place them as protagonists in their treatment. The participants perceived their quality of life with physical disabilities as impaired. These issues provide an analysis of the feeling of participation of people with disabilities, important in the perception of their quality of life (CANTORANI *et al*., 2015). Concerning the context presented, the presence of physical disability affects the quality of life of people with leprosy. Physical disability during the course of the disease, if treated late or not treated, is well described, but understanding the implications on the quality of life makes all the difference in the care with these people and comes from an expanded perspective, dealing with issues related to this population in particular and their biopsychosocial context.

Conclusion

A high proportion of people affected by leprosy with physical disabilities presented impaired quality of life, with the autonomy, inclusion and discrimination domains as the most affected. This information can assist in the understanding of the impact of the disease and planning by health professionals involved and public policies, in addition to providing preventive measures and health promotion.

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