

Evaluation of the limitations in daily-life activities and quality of life in leprosy patients submitted to surgical neurolysis to treat neuritis

Avaliação da limitação das atividades diárias e qualidade de vida de pacientes com hanseníase submetidos à cirurgia de neurólise para tratamento das neurites

Evaluación de las limitaciones de las actividades diarias y calidad de vida de pacientes leprosos sometidos a cirugía de neurólisis para el tratamiento de las neuritis

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ABSTRACT | Neurolysis is indicated to reduce neural suffering and to prevent sequelae and disabilities in leprosy patients. The aim of this study was to determine the degree of limitation of daily activities and quality of life in leprosy patients submitted to neurolysis for neuritis treatment. The study included patients who underwent neurolysis from 1998 to 2011. We collected demographic and clinical information, data about activity limitations (Screening of Activity Limitation and Safety Awareness [SALSA]) and quality of life (WHO Quality of Life - Short Form-26 [WHOQOL-BREF]). Statistical analyses included frequency, central tendency and dispersion measures, Mann-Whitney and Kruskal-Wallis' tests, and Spearman's correlation coefficient adopting $p \leq 0.05$. The sample consisted of 36 patients with a mean age of 44.0 years and three years of postoperative period. Six patients had disability grade 0, 18 patients had grade 1, and 12 patients had grade 2. The main difference between the SALSA scale occurred between grades 0 (mean 31.8) and 1 (mean 42.56). The results obtained in the analysis of the WHOQOL-BREF included the following domains: physical facets (mean 11.10), psychological facets (mean 13.41), social relationships (mean 15.15), and environmental facets (mean 11.63). The most affected facets of the WHOQOL-BREF were as follows: work ability (physical), negative feelings (psychological), sexual activity (social relationships), and financial resources (environmental). Despite the

neurolysis, most subjects showed activity limitations, which were found to be higher in people with physical disabilities. The major dissatisfaction observed in the quality of life was in the physical domain, especially with regard to pain and the need for medical care.

Keywords | activities of daily living; leprosy; quality of life.

RESUMO | A neurólise é indicada para reduzir o sofrimento neural e impedir a instalação de sequelas e incapacidades em pacientes com hanseníase. O objetivo deste estudo foi verificar o grau de limitação das atividades e a qualidade de vida de pacientes com hanseníase submetidos a neurólise para tratamento das neurites. Participaram do estudo os pacientes submetidos à neurólise no período de 1998 a 2011. Foram coletadas informações sociodemográficas e clínicas, limitações das atividades (SALSA) e a qualidade de vida (WHOQOL-bref). As análises estatísticas incluíram a frequência, as medidas de tendência central e dispersão, os testes de *Mann-Whitney* e *Kruskal-Wallis* e o coeficiente de correlação de *Spearman* adotando-se $p \leq 0,05$. A amostra foi composta por 36 pacientes com média de idade de 44,0 anos e 3 anos de pós-operatório. Seis pacientes apresentaram grau 0 de incapacidade; 18, grau 1 e 12, grau 2. A principal diferença da escala SALSA ocorreu entre o grau 0 (média 31,8) e o grau 1 (média 42,56). Os valores obtidos na análise do WHOQOL-bref incluíram os domínios

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físico (média 11,10), psicológico (média 13,41), relações sociais (média 15,15), meio ambiente (média 11,63). As facetas do WHOQOL-bref mais comprometidas foram: capacidade para o trabalho; sentimentos negativos (psicológico); atividade sexual (relações sociais); recursos financeiros (meio ambiente). Apesar da realização da neurólise, a maior parte dos integrantes apresentou limitações nas atividades, sendo maior naqueles com incapacidades físicas. A maior insatisfação na qualidade de vida foi no domínio físico, principalmente no que se refere à dor e à necessidade de cuidados de saúde.

Descritores | hanseníase; qualidade de vida; atividades cotidianas.

RESUMEN | La neurólisis es indicada para reducir el sufrimiento neural e impedir la instalación de secuelas e incapacidades en pacientes con lepra. El objetivo de este estudio fue verificar el grado de limitación de las actividades de la vida diaria y la calidad de vida de pacientes con lepra sometidos a neurólisis para el tratamiento de las neuritis. Participaron del estudio los pacientes sometidos a neurólisis en el período de 1998 a 2011. Fueron recolectadas informaciones sociodemográficas y clínicas, limitaciones de las

actividades (SALSA) y la calidad de vida (WHOQOL-bref). Los análisis estadísticos incluirán la frecuencia, las medidas de tendencia central y dispersión, los tests de *Mann-Whitney*, *Kruskall-Wallis* y los coeficientes de correlación de *Spearman* adoptando $p \leq 0,05$. La muestra fue compuesta por 36 pacientes con edad media de 44,0 años y 3 años de post-operatorio. Seis pacientes presentan grado 0 de incapacidad, 18 grado 1 y 12 grado 2. La principal diferencia en la escala SALSA ocurrió entre el grado 0 (media=31,8) y el grado 1 (media=42,56). Los valores obtenidos en el análisis de WHOQOL-bref incluyen los dominios físico (media 11,10); psicológico (media 13,41); relaciones sociales (media 15,15); medio ambiente (media 11,63). Las facetas del WHOQOL-bref más comprometidas fueron la capacidad para el trabajo; sentimientos negativos (psicológico); actividad sexual (relaciones sociales); recursos financieros (medio ambiente). A pesar de la realización de la neurólisis, la mayor parte de los integrantes presentaron limitaciones en las actividades, siendo mayor en aquellos con incapacidades físicas. La mayor insatisfacción en la calidad de vida fue en el dominio físico, principalmente en los que se refiere al dolor y la necesidad de cuidados de salud.

Palabras clave | lepra; calidad de vida; actividades cotidianas.

INTRODUCTION

Leprosy is characterized by a chronic infection caused by *Mycobacterium leprae* that mainly affects the skin and peripheral nerves¹. In Brazil, the disease is a public health issue with 33,955 new cases found in 2011, which represents the second highest index worldwide².

Manifestations of such a disease depend on the patient's cellular immunity and can be divided into five groups: two polar and three inter-polar groups. One pole consists of patients with better resistance to the bacillus and fewer skin lesions (tuberculoid leprosy), while the other includes individuals with immunity impairment and high bacteriological load (lepromatous or Virchowian leprosy). Among the poles, there are the inter-polar kinds with instable immunological reactions (tuberculoid dimorph or tuberculoid-borderline, dimorph-dimorph or borderline-borderline, and lepromatous-dimorph or lepromatous-borderline). The World Health Organization (WHO) proposes a score that is based upon the number of skin lesions and is divided into paucibacillary (PB) with five lesions or multibacillary (MB) with more than six lesions³.

Neural damage in leprosy is responsible for the appearance of sequelae that may appear during the treatment with polychemotherapy (PCT) or after bacteriological healing³⁻⁶. Physical disability grades indicate neural damage of the eyes, nose, hands, and feet and are divid-

ed into the following grades: grade 0 (absence of sensorimotor damage), grade 1 (sensitive damage), and grade 2 (motor damage and/or sequelae presence)¹.

For prevention and treatment of the neural damage, the WHO recommends oral corticotherapy and/or a surgical approach for nerve decompression (neurolysis)⁶⁻¹⁰. Until now, the evaluation of postoperative results of the neurolysis was based on pain decrease and sensorimotor function, without considering the person's perception of his/her position in life with regard to the person's culture and his/her system of values and expectations, as proposed by the International Classification of Functioning, Disability and Health (ICF)⁹⁻¹².

This study aimed at identifying the grade of limitations in daily activities and quality of life in patients submitted to neurolysis for neuritis treatment in leprosy.

METHODOLOGY

This cross-sectional study was approved by the Research Ethics Committee of Hospital Universitário Clementino Fraga Filho at Universidade Federal do Rio de Janeiro (HUCFF/UFRJ) and registered under number 050/08.

The research included patients diagnosed with PB or MB leprosy who underwent neurolysis in any nervous trunk, aged between 18 years and 65 years, with more than six postoperative months. Patients

submitted to another surgery (correction of claws and tendinous transferences), in reactional state or with plantar ulcers and other diabetic diseases (diabetes, congestive heart or coronary, renal, and liver failure, HIV, psoriasis, atopic dermatitis, and vitiligo), were excluded from the study.

At first, sociodemographic (gender, age, education, and income) and clinical (PCT discharge time, postoperative time, operational classification, recent disability grade, and nerves and limbs submitted to surgery) information was collected.

Limitation of activities was assessed by the Screening of Activity Limitation and Safety Awareness (SALSA) instrument, which is composed of 20 items and is formulated based on the ICF and validated in Brazilian Portuguese¹². The results of the SALSA test vary from 1 to 80 points, and the scores can be explained as follows: from 10 to 24 (no significant limitation), 25 to 39 (mild limitation), 40 to 49 (moderate limitation), 50 to 59 (severe limitation), and 60 to 80 (extreme limitation)¹².

The quality of life evaluation was carried out with the WHO Quality of Life – Short Form-26 (WHO-QOL-bref)¹⁰. This is a self-administered questionnaire that comprises of 26 questions in which 24 of the questions have been divided into four domains (physical, psychological, social relationships, and environment) and two questions are general, concerning the person's quality of life and health condition. The WHOQOL-bref domains vary from 0 to 20 points and have facets valued from 1 to 5 in the Likert positive scale. The score of each domain was carried out according to the algorithm that was built and standardized by the WHOQOL group using the Statistical Package for the Social Sciences (SPSS) software, version 13.0 for Windows[®].

The SPSS 13.0 was used for data processing. Frequency analysis, central tendency, and dispersion measures; Kolmogorov-Smirnov, Mann-Whitney, Kruskal-Wallis, and Spearman's correlation coefficient tests with $p \leq 0.05$ were included in this investigation.

RESULTS

Sociodemographic and clinical profile

From the hospital records, it was found that 76 patients were submitted to neurolysis, of whom 31 patients did not match the eligibility criteria for this study as 16 patients were not localized, 2 patients were deceased, 8 patients had undergone other surgeries, and 5 patients presented with other illnesses. With regard to losses, three patients failed to attend, two patients

presented with complications, and four patients had incomplete records. Hence, a total of 36 subjects were finally included in the study sample.

The age group of the patients varied from 24 years to 65 years (mean=44.0, standard deviation [SD]=11.2), PCT discharge period ranged from 2 years to 24 years (mean=8.6, SD=5.9), and postoperative period ranged from one year to eight years (mean=3.0, SD=1.5). Sociodemographic and clinical data are presented in Table 1.

Limitations in activities and risk awareness

SALSA scale values varied from 24 to 70 points (mean=40.3, SD=10.6). From the group of assessed patients, 91.7% presented SALSA scores that were equal to or higher than 25, indicating that these patients showed mild to extreme degrees of limitation in their daily activities. Table 2 illustrates the distribution of classifications according to the SALSA score.

Table 1. Distribution of frequencies of the sociodemographic, clinical, and postoperative variables

	Variables	n	%
Sociodemographic	Gender		
	Male	25	69.4
	Female	11	30.6
	Education		
	Elementary school	20	55.6
	High school	16	44.4
	Reported income		
≤1 salary	23	63.9	
>1 salary	13	36.1	
Clinical and postoperative	Operational classification		
	Paucibacillary	4	11.1
	Multibacillary	32	88.9
	Grade inability		
	0	6	16.7
	1	18	50.0
	2	12	33.3
	Operated nerves		
	Ulnar	25	35.7
	Median	8	11.4
	Common fibular	13	18.5
	Tibial	24	34.2
	Number of operated nerves		
	1	17	47.2
	2	11	30.5
3	5	13.9	
4	4	11.1	
Operated limb			
Upper limbs	14	38.9	
Lower limbs	14	38.9	
Both	8	22.2	

Patients without physical disabilities (grade 0) obtained a mean score of 31.8 points (SD=5.3), while those with disabilities (grade 1 or 2) obtained a mean score of 42.1 points (SD=10.6) with $p=0.01$.

In the investigation of the association between PCT discharge time and the SALSA scale, a weak correlation ($r_s=0.22$) was seen, but the same was not verified when the postoperative time was considered in the investigation ($r_s=-0.06$).

Quality of life

About the perception of the quality of life (question 1), 15 (41.7%) patients were neither satisfied nor dissatisfied, 13 (36.1%) were satisfied, and 8 (22.2%) were dissatisfied. With regard to the perception of their health condition (question 2), 18 (50%) patients were dissatisfied.

The individuals were more satisfied with the social relationships (mean=15.1, SD=3.5) and psychological (mean=13.4, SD=2.7) domains. Physical (mean=11.1, SD=3.4) and environmental (mean=11.6, SD=2.1) domains were the most damaged domains. The individual perception of quality of life (general quality of life) varied from 4.0 to 18.0 points with a mean of 11.3 points (SD=3.5). The physical ($r_s=0.71$, $p<0.001$) and environmental ($r_s=0.56$, $p<0.001$) domains had a higher effect on the perception of individuals with regard to their general quality of life. Results from the various facets are illustrated in Table 3.

The comparison of the WHOQOL-bref domains according to the sociodemographic and clinical variables are presented in Tables 4 and 5, respectively.

DISCUSSION

Little information is available about the impact on the life of patients submitted to neurolysis⁷. Only one qualitative and quantitative study assessed the patients' satisfaction after neurolysis; however, the main limitations of the research were the type of questionnaire that was used, the absence of pain characterization, information on quality of life, and restrictions to participate¹³. The present study approached daily life activities and quality of life, using two instruments that were validated and previously applied in leprosy^{14,15}. The WHOQOL-bref choice was based on the quality of the psychometric characteristics and internal reliability^{10,16,17}.

Male gender predominance is in accordance with reference national data¹⁸, with 58.4% of these patients presenting sensorimotor sequelae. This fact may be associated with men's delay in seeking health services due to the fear of losing their roles as family providers¹⁹. Low

levels of education and income were also characteristics observed by Nascimento²⁰. These features may be associated with the fact that leprosy can restrict education and work opportunities due to prejudice and stigma²¹. Low income may also lead to difficult access to health services, favoring neural damage appearance^{15,19,22}.

In the outcomes of the SALSA scale, 91.7% of the patients presented some limitation degree, and 77.7% of patients had mild to moderate limitations. This datum can be associated with a bigger number of male participants, MB, and with disability grades 1 and 2¹⁹.

With regard to the quality of life, the most damaged domain was the physical, followed by the environmental,

Table 2. Distribution of the patients' frequencies according to the SALSA scale scoring

SALSA score	n	%
No limitation	3	8.3
Mild limitation	16	44.4
Moderate limitation	12	33.3
Severe limitation	3	8.3
Extreme limitation	2	5.6
Total	36	100

SALSA: Screening of Activity Limitation and Safety Awareness

Table 3. Mean and confidence intervals of the four WHOQOL-BREF facets

Domain	Facets	Mean	95%CI
Physical	Daily life activities	2.89	2.52-3.26
	Medication dependence	3.51	3.20-3.83
	Mobility	3.29	2.87-3.70
	Energy and fatigue	2.91	2.55-3.28
	Pain and discomfort	3.14	2.69-3.59
	Sleep and rest	2.80	2.38-3.22
	Work capacity	2.23	1.83-2.63
Psychological	Positive feelings	2.97	2.60-3.34
	Think, learn, memory	3.03	2.66-3.40
	Self-esteem	3.37	2.98-3.76
	Body image and appearance	3.37	2.97-3.77
	Negative feelings	2.57	2.18-2.96
	Spirituality/religion	4.09	3.79-4.38
	Social relationships	3.80	3.40-4.20
Social relationships	Personal relationships	3.80	3.40-4.20
	Social support	4.00	3.65-4.35
	Sexual activity	3.51	3.07-3.96
Environment	Physical security and protection	3.09	2.73-3.44
	Home environment	3.40	2.93-3.87
	Financial resources	2.20	1.91-2.49
	Health and social care	3.00	2.66-3.34
	Acquisition of new information	3.26	2.85-3.66
	Recreation and leisure	2.57	2.19-2.96
	Physical environment	3.23	2.89-3.56
	Transportation	2.57	2.19-2.96

CI: confidence interval

Table 4. Mean scores (standard deviation) of the WHOQOL-bref facets according to the participants' demographic characteristics

Variables	n	Physical	Psychological	Social relationship	Environment	General quality of life
Gender						
Male	25	10.7 (3.7)	13.4 (2.8)	14.6 (3.6)	11.1 (2.2)	10.9 (3.7)
Female	11	11.8 (2.9)	13.3 (2.5)	16.2 (3.1)	12.8 (1.6)	12.3 (3.0)
p-value*		0.18	0.94	0.20	0.02	0.37
Education						
Elementary school	20	11.6 (3.7)	13.7 (2.5)	14.6 (3.9)	12.0 (2.1)	12.0 (3.3)
High school	16	10.4 (3.1)	13.0 (2.8)	15.7 (2.9)	11.0 (2.1)	10.6 (3.8)
p-value*		0.36	0.64	0.52	0.12	0.33
Reported income						
≤1 salary	23	10.6 (3.3)	13.1 (2.7)	14.8 (3.8)	11.3 (1.7)	11.1 (3.6)
>1 salary	13	11.9 (3.7)	13.9 (2.7)	15.5 (2.9)	12.1 (2.8)	11.8 (3.5)
p-value*		0.11	0.33	0.50	0.007	0.33

General quality of life: individual perception on quality of life; *Mann-Whitney's test

Table 5. Mean scores (standard deviation) of the WHOQOL-bref facets according to clinical and postoperative variables

Variables	n	Physical	Psychological	Social relationships	Environment	General quality of life
Classification						
Paucibacillary	4	8.0 (2.3)	11.0 (1.5)	11.0 (3.5)	9.6 (1.4)	8.0 (3.2)
Multibacillary	32	11.4 (3.4)	13.7 (2.6)	15.6 (3.2)	11.8 (2.1)	11.8 (3.4)
p-value*		0.07	0.07	0.03	0.04	0.05
GIF						
0	6	12.8 (2.9)	14.8 (1.5)	17.3 (1.6)	11.9 (2.4)	12.8 (2.9)
1	18	10.4 (3.2)	12.8 (2.7)	14.6 (4.1)	11.9 (1.9)	10.4 (3.2)
2	12	11.1 (3.9)	13.5 (2.9)	14.7 (3.0)	11.0 (2.4)	11.1 (3.9)
p-value**		0.25	0.22	0.17	0.44	0.56
Operated nerves						
1 nerve	17	11.4 (4.1)	13.4 (3.0)	14.5 (3.5)	11.8 (2.3)	11.5 (3.5)
2 nerves	10	10.1 (2.5)	12.6 (2.4)	11.1 (4.0)	11.1 (1.9)	10.6 (3.6)
3 nerves	5	12.8 (3.0)	15.6 (1.2)	17.6 (2.1)	12.1 (3.0)	13.2 (3.6)
4 nerves	4	9.7 (2.3)	12.3 (2.0)	14.6 (3.9)	11.5 (1.7)	10.5 (3.7)
p-value**		0.39	0.14	0.31	0.80	0.62
Operated limbs						
Upper limb	14	9.9 (2.5)	12.4 (2.5)	14.8 (3.2)	10.9 (2.0)	10.7 (3.4)
Lower limb	14	11.8 (4.3)	14.0 (2.8)	15.3 (3.8)	12.0 (2.1)	11.5 (3.9)
Both	8	11.7 (3.0)	14.0 (2.4)	16.3 (3.4)	12.1 (2.4)	12.2 (3.9)
p-value**		0.37	0.27	0.31	0.30	0.26

General quality of life: individual perception of then quality of life; GIF: physical disability grades; *Mann-Whitney's test; **Kruskal-Wallis's test

psychological, and lastly, social relationships. This finding was also observed by Costa et al.¹⁶. Taking into consideration the physical domain facets, "pain and discomfort" and "medication dependence" were the most damaged. Pain has been a complaint seen in other studies after PCT discharge²³⁻²⁵.

In the environmental domain, the most mentioned dissatisfactions were in the following facets: "financial resources" and "transportation." Satisfaction with

financial resources can be associated with work capacity and education. The "transportation" facet depends on the local socioeconomic condition and quality of services^{26,27}.

In the psychological domain, presence of negative feelings may reflect nonconformity, sadness, shame, insecurity, and an empty feeling. The highest satisfaction observed with the "spirituality and beliefs" facet, is associated with the search for a way of confronting and relieving the health condition²⁸.

In social relationships, dissatisfaction with sexual activities may reflect the impact that the disease has on the family environment, causing an effect not only on the individual's public life but also on his/her emotional life¹⁶.

The number of operated nerves does not seem to have an effect on activity limitation and quality of life. These findings are also in accordance with those observed by Alencar et al.¹⁴.

The main limitations in this study are associated with the absence of preoperative measures, the absence of a control group, as well as the absence of information about the sensorimotor function. It can also be mentioned the limitation of the WHOQOL-bref instrument, which was not designed to find a brief measure of quality of life, besides it does not have a cut point, people cannot say or write what they feel (limitation of the research instrument)¹⁰.

CONCLUSION

Although neurolysis is a part of the leprosy treatment, in this study, we observed that most of the participants presented limitations in daily activities, especially those with physical disabilities. This finding may be associated with the delay in diagnosing the disease or the absence of agreement at the adequate time to perform the surgery. With regard to the quality of life, the highest level of dissatisfaction was observed in the physical domain, especially concerning pain and the need for health care. It must be emphasized that neurolysis follow-up should not be limited to sensorimotor findings. Information collected with SALSA and WHOQOL-bref instruments may contribute to the postoperative follow-up, rehabilitation, and public policies, which may value a person's perceptions.

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