EVALUATION OF THE QUALITY OF LIFE OF LEPROSY PATIENTS: A QUNTITATIVE APROACH

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ABSTRACT

Introduction: Leprosy, due to its high prevalence and disabling potential is very important in the area of public health, especially when considering the economically active group of society. Even though leprosy is a well studied disease, there aren't many studies evaluating how the disease affects the patient's quality of life. Objective: Evaluate the quality of life of leprosy patients with the appropriate instruments. Methods: The study was conducted in the Ambulatório de Especialidades Antônio João Miranda do Hospital Dom Rodrigo de Menezes in Salvador – BA, where twenty – five patients agreed to answer two questionnaires validated for the evaluation of quality of life. The two questionnaires were the following: a Socio-Demographic-Occupational questionnaire and the SF-36 questionnaire. For the analysis of the categorical variables and of the domains of the SF-36 questionnaire, it was used the Mann-Whitney test, while it was used the Spearman correlation test to analyze the continuous demographic variables. Results: Out of pool of patients, there was a higher prevalence of male patients (56%), of Catholics (64%), employed (76%) and that do not perform any physical activity (88%). The majority of the subjects live with someone (84%) and possess a job (88%) with a monthly income varying from 300 to 600 DOLARS (84%). It was shown that 44% are married and that women have better quality of life. Analysis indicated that family monthly income influences on "Physical Appearance,". The presence of children at home positively influences the "Mental Health" of patients. Conclusion: Analyzing such data is very important to conduct appropriate public policies in order to improve the quality of life of patients with leprosy.

Keywords: Leprosy; Quality of Life; Public Health.

AVALIAÇÃO DA QUALIDADE DE VIDA DE PACIENTES HANSÊNICOS: UMA ABORDAGEM QUANTITATIVA

RESUMO

Introdução: A hanseníase, devido a sua prevalência e alto poder incapacitante, possui significativa importância no âmbito da saúde pública, especialmente quando se considera a porção economicamente ativa da população. Apesar de a Hanseníase ser uma doença bem estudada, não existem muitos estudos que foquem na avaliação da qualidade de vida dos pacientes portadores da hanseníase. Objeticvos: Avaliar a qualidade de vida de pacientes portadores da hanseníase através do uso de instrumentos adequados. Metodos: O estudo foi conduzido no Ambulatório de Especialidades Antônio João Miranda do Hospital Dom Rodrigo de Menezes em Salvador – BA, onde 25 pacientes concordaram em responder a 2 questionários validados para a avaliação da qualidade de vida. Os dois questionários eram os seguintes: o questionário sociodemográfico ocupacional e o questionário SF– 36. Para a análise das variáveis categóricas e dos domínios do questionário SF – 36, foi utilizado o teste de Mann – Ehitney, enquanto que, para análise das variáveis demográficas continuas, foi utilizado o teste de spearman. Resultados: Do total de pacientes, houve uma maior prevalência de homens (56%), Católicos (64%), empregados (76%) e sedentários (88%). A maior parte dos pacientes convivem com alguém (84%) e possuem um trabalho (88%) com rendimento mensal variando de 300 a 6000 dólares (84%). Foi indicado que 44% são casados e que as mulheres possuem melhor qualidade de vida. A análise dos dados indicou que a renda mensal familiar influencia a "aparência física". A presença de crianças em casa influencia de forma positive a "saúde mental" dos pacientes. CONCLUSÃO: Avaliar a qualidade de vida de pacientes com hanseníase é importante para guiar políticas públicas que possam aumentar a qualidade de vida destes pacientes.

Palavras-chave: Hanseníase; Qualidade de Vida; Saúde Pública.

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INTRODUÇÃO

Leprosy is among the oldest diseases of the world, with its name originating from Egypt, china and India, countries from where came its first description. Today, Brazil stands among the countries with the highest prevalence of leprosy, most of its cases are present in the northeast region.

Initially, the measures to control the disease included the construction of specialized houses for confinement of the patients. Today, although, the treatment is focused on chemotherapy adequate for each of leprosy's clinical forms allied with the early diagnosis; detection and treatment of contacts; prevention and treatment of deficits and deformities and health education.

When diagnosed late, leprosy can lead to physical deformities; chronic pain and psychological limitations which can deeply compromise the patients quality of life, increasing his dependency on others and the public health care, for the most afflicted populations are those of the poorest origins, most vulnerable.

Inadequate health care policies and self limited actions imposed by leprosy, became a challenge to Brazilian public health system.

Even though we could find a significant amount of studies on leprosy, few of those papers emphasized quality of life in leprosy, so this study aims is to evaluate the impact of leprosy in the quality of life of the afflicted population by the means of the adequate instruments.

METHODS

The study was conducted in the Ambulatório de Especialidades Antônio João Miranda of the Hospital Dom Rodrigo de Menezes in Salvador – BA, where twenty – five patients, admitted for the treatment of leprosy's neurological complications, agreed to answer two questionnaires validated for the evaluation of quality of life. Out of the 25 patients, 14 were males and 11 were females.

The two questionnaires were the SF – 36, composed of 36 items organized into domains which includes functional capacity; physical and emotional aspects; pain; general health status; social vitality and mental health, and the sociodemographic occupational questionnaire, composed of 24 items evaluating variables like age; occupation; religion; monthly income; life habits and habitation. The SF – 36 is graded from 0 to 100 and the lower the score, the worse is the patients quality of life.

In order to be included in the study, the patients from both sexes had to be above 18 years old of age and had to sign a term of informed consent authorized by the comitte of ethical considerations from the Escola Bahiana de Medicina e Saúde Pública.

For the analysis of the categorical variables and of the domains of the SF-36 questionnaire, it was used the Mann-Whitney test, while it was used the Spearman correlation test to analyze the continuous demographic variables.

RESULTS

After analysis of the data collected, it was noticed that out of the 25 patients, there was a higher prevalence of males (56%) over females (44%); as there was of declared Catholics (64%) over other religions (36%). Most of the patients had a job with a rate of unemployment of 24% of the total. We have noticed that the patients had a predominately sedentary life style, with only 12% of them admitting to exercise regularly. Most of the patients (84%) live with someone else while only 44% of the total are married. The income of the patients is predominantly US$400,00 (84%), considering that 88% were not retired. When evaluating family total income, 16% of the families had a monthly income US$2000,00 dollars, while the others 84% had a monthly income of US$500,00.

At table 1, it can be seen the distribution of the accordingly to the sociodemographic occupational questionnaire variables.

Table 1 – Frequency and variables of the QSDO

Variable		Frequence	Percentage
Sex	Female	11	44%
	Male	14	56%
Religion	Catholic	16	64%
	Other	9	36%
Works?	Yes	19	76%
	No	6	24%
Physical activity	Yes	3	12%
	No	22	88%
Lives with	Someone	21	84%
	Alone	4	16%
Salary	US$ 400,00	21	84%
	< US$ 100	4	16%
Civic status	Single	9	36%
	Married	11	44%
	Divorced/separate	4	16%
	Widow	1	4%
Retired	Yes	3	12%
	No	22	88%
Monthly Family income	< US$ 100,00	1	4%
	US$ 400,00 MS	21	84%
	US$ 2000,00 MS	3	12%

Source: Data obtained from SF – 36 (2012) questionnaire

At table 2, there can be seen the average score for each of the SF – 36 questionnaire's domains.

Table 2 – Comparison between SF – 36 questionnaire's domains

Domains	N	Average	Medium	Percentile 25	Percentile 75
Functional capacity	25	49			
Physical aspects limitations	25	16			
Pain	25	36,24			
General state of health	25	43,16	46,08	31,06	55,66
Vitality	25	53,2			
Social aspects	25	59			
Emotional aspects limitations	25	29,33			
Mental Health	25	56,48			

Source: Data obtained from SF – 36 (2012) questionnaire

Table 3 offers a comparison between genders, considering the domains of the SF – 36 questionnaire. There was no statistically significant differences between the male and female groups.

Table 3 – Comparison between the genders of the participants, considering the SF - 36 questionnaire's domains

Domains	Variables	N	Average	SD*	U	P - value
Functional capacity	F	11	40,45454545	16,65150826		
	M	14	55,71428571	27,23523897	48,50	0,1232
Pain	F	11	32,454545	15,37766976		
	M	14	39,21428571	22,05300807	59,00	0,3352
General state of health	F	11	36,90909091	17,51259287		
	M	14	48,0714286	11,055554	52,50	0,1879
Vitality	F	11	53,63636	10,26911		
	M	14	54,642857	13,931741	69,50	0,6994
Social aspects	F	11	40,90909	14,88593		
	M	14	43,75	17,5068668	64,50	0,4828
Emotional aspects linitaions	F	11	18,18181818	34,52740414		
	M	14	38,1	43,0857999	57,50	0,2379
Mental Health	F	11	52,36364	15,94536		
	M	14	56,571429	19,39019	67,00	0,5998

Source: Data obtained from the 2012 research

Table 4 shows that a comparison, considering the domains of the SF – 36 questionnaire, between adepts of the Catholicism and adepts of other religions showed no statistically significant differences, despite the fact that the Catholics had predominantly better results in the questionnaires.

Table 4 – Comparison between the religion of the participants, considering the SF - 36 questionnaire's domains

Domains	Variables	N	Average	SD*	U	P - value
Functional capacity	CO	169	50,625	24,28133714	69,50	0,7231
			46,11111111	24,72066162		
Physical aspects	CO	169	23,4375	37,04586122	51,00	0,1422
			2,777777778	8,333333333		
Pain	CO	169	39,3125	21,11644884	56,00	0,3352
			30,77777778	14,85578825		
General state of health	CO	169	43,5	14,32014898	71,00	0,9774
			42,55555556	17,11075036		
Vitality	CO	169	57,1875	10,64091945	47,50	0,1702
			48,88888889	13,64225462		
Social aspects	CO	169	42,96875	15,79078713	69,00	0,8797
			41,66666667	17,67766953		
Emotional aspects linitaions	CO	169	35,41666667	43,40043644	59,50	0,4409
			18,51851852	33,79312517		
Mental Health	CO	169	51,5	12,63856532	41,50	0,0866
			60,44444444	12,23837317		

Source: Data obtained from the 2012 research

Table 5 shows that there was no significant differences between the groups of patients who live alone and whom live with someone else, although, patients who have a roommate showed better results in most of the domains.

Table 5 – Comparison between sharing or not a habitation with someone else, considering the SF - 36 questionnaire's domains

Domains	**Variables**	**N**	**Average**	**SD***	**U**	**P - value**
Functional capacity	Y N	16 9	47,5 49,28571429	34,03429643 22,76432045	39,50	0,8818
Physical aspects	Y N	16 9	6,25 17,85714286	12,5 33,6738559	38,50	0,7786
Pain	Y N	16 9	46,75 34,23809524	28,04014979 17,4410572	29,50	0,3731
General state of health	Y N	16 9	49,75 41,9047619	11,44188213 15,53030831	31,00	0,4359
Vitality	Y N	16 9	63,75 52,38095238	6,291528696 12,31046786	16,00	0,0577
Social aspects	Y N	16 9	43,75 42,26190476	16,13743061 16,52469292	41,50	1,0000
Emotional aspects linitaions	Y N	16 9	25 30,15873016	31,91423693 42,03802763	42,00	0,9665
Mental Health	Y N	16 9	57 54,28571429	6 14,00408104	36,50	0,7088

Source: Data obtained from the 2012 research

Table 6 showed that having children can considered a protective factor when considering the mental health domain of the SF – 36 questionnaire (P value < 0,05). Leprosy patients who have children are less likely to develop anxiety disorders; depression and posses better control over emotional and psychological states.

Table 6 – Comparison between having children or not having children, considering the SF - 36 questionnaire's domains

Domains	Variables	N	Average	SD*	U	P - value
Functional capacity	Y	18	48,33333333	22,8807651	53,00	0,5634
	N	7	50,71428571	28,63979915		
Physical aspects	Y	18	11,11111111	26,04044115	48,50	0,2840
	N	7	28,57142857	41,90408549		
Pain	Y	18	35,5	20,64617897	57,00	0,7388
	N	7	38,14285714	16,76731514		
General state of health	Y	18	41,3	16,02775371	37,50	0,1295
	N	7	50,71428571	9,141741003		
Vitality	Y	18	54,16666667	8,703703704	59,00	0,8311
	N	7	54,28571429	13,87121892		
Social aspects	Y	18	40,27777778	17,96419824	49,00	0,3824
	N	7	48,21428571	8,625819492		
Emotional aspects linitaions	Y	18	20,37037037	34,56336208	34,50	0,0551
	N	7	52,38095238	46,5758754		
Mental Health	Y	18	51,55555556	13,36466906	26,50	0,0281
	N	7	62,85714286	7,90418816		

Source: Data obtained from the 2012 research

There was no statistically significant difference between patients who exercised on a regular basis and patients who had a sedentary lifestyle, as can be seen in table 7.

Table 7 – Comparison between having physical activity or having a sedentary lifestyle, considering the SF - 36 questionnaire's domains

Domains	Variables	N	Average	SD*	U	P - value
Functional capacity	Y	3	48,33333333	45,36885863	26,50	0,6137
	N	22	49,09090909	21,5271901		
Physical aspects	Y	3	8,333333333	14,43375673	18,00	0,1252
	N	22	17,04545455	33,08211612		
Pain	Y	3	31	21	26,00	0,5844
	N	22	36,95454545	19,50940499		
General state of health	Y	3	56,33333333	9,018499506	11,50	0,0781
	N	22	41,36363636	14,91099133		
Vitality	Y	3	55	10	28,50	0,7355
	N	22	54,09090909	12,69011273		
Social aspects	Y	3	45,83333333	14,43375673	33,00	0,9643
	N	22	42,04545455	16,61246598		
Emotional aspects linitaions	Y	3	11,11111111	19,24500897	24,00	0,4210
	N	22	31,81818182	41,75675686		
Mental Health	Y	3	69,33333333	10,06644591	10,50	0,0634
	N	22	52,72727273	12,19750879		

Source: Data obtained from the 2012 research

There was no statistically significant differences between the groups of patients whose families had a monthly income of US$ 400,00 and of patients whose families had a monthly income of US$ 2000,00, even though the patients with the greater family monthly income had better results in the domain of physical aspects, with a score of 0 in the SF – 36 questionnaire. Table 8 shows the comparison between patients considering their family monthly income.

Table 8 – Comparison between participants' family monthly income, considering the SF - 36 questionnaire's domains

Domains	Variables	N	Average	SD*	U	P - value
Functional capacity	US$ 400,00	22	50	46,19047619		
	US$2000,00	3	41,66666667	12,58305739	25,00	0,5294
Physical aspects	US$ 400,00	22	18,18181818	32,89758475		
	US$2000,00	3	0	0	-	-
Pain	US$ 400,00	22	34,54545455	18,80913474		
	US$2000,00	3	48,66666667	22,50185178	21,00	0,3357
General state of health	US$ 400,00	22	42,36363636	15,67693317		
	US$2000,00	3	49	8,544003745	24,50	0,5028
Vitality	US$ 400,00	22	52,27272727	11,09775532		
	US$2000,00	3	68,33333333	12,58305739	10,00	0,0594
Social aspects	US$ 400,00	22	42,61363636	17,10397602		
	US$2000,00	3	41,66666667	7,216878365	25,50	0,5318
Emotional aspects	US$ 400,00	22	28,78787879	38,89404212		
linitaions	US$2000,00	3	33,33333333	57,73502692	32,50	1,0000
Mental Health	US$ 400,00	22	53,27272727	12,61209479		
	US$2000,00	3	65,33333333	12,85820101	18,00	0,2221

Source: Data obtained from the 2012 research

Table 9 showed no statistically significant differences between the groups of patients who had a job and of those whom were unemployed, even though patients who were employed had better results in the SF – 36 questionnaire in most domains.

Table 9 – Comparison between having a job or not having a job, considering the SF - 36 questionnaire's domains

Domains	Variables	N	Average	SD*	U	P - value
Functional capacity	S	19	50	25,92724864		
	N	6	45,83333333	18,280226111	56,50	1,0000
Physical aspects	S	19	13,15789474	28,09757435		
	N	6	30	44,72135955	50,50	0,6293
Pain	S	19	39,05263158	18,283185		
	N	6	36	21,56540439	38,50	0,2491
General state of health	S	19	45,78947368	13,5670309		
	N	6	34,83333333	17,67955505	35,50	0,1801
Vitality	S	19	55	13,33333333		
	N	6	51,66666667	8,164965809	45,50	0,4797
Social aspects	S	19	44,73684211	14,01622911		
	N	6	35,41666667	21,5300178	39,50	0,2473
Emotional aspects linitaions	S	19	33,33333333	40,06168084		
	N	6	16,66666667	40,82482905	42,50	0,3121
Mental Health	S	19	55,57894737	10,90522703		
	N	6	52	19,26655133	52,00	0,7727

Source: Data obtained from the 2012 research

Table 10 shows the average of the age of the patients participating in this study.

Table 10 – Descriptive statistics of the variable age

Variable	N	Average	Standard deviation	Minimum	Maximum
Age	25	40,84	12,44213	25	67

Source: Data obtained from the 2012 research

Table 11 shows that the age of leprosy patients has a negative correlation with the domain physical aspects, as can be demonstrated by a negative spearman correlation coefficient. The greater the age of a patient, the worse will be his performance under the domain of physical aspects of the SF – 36 questionnaire.

Table 11 – Correlation between age and the SF - 36 questionnaire's domains

Domains	Spearman correlation (r)	P - value
Functional capacity	-0.2488	0.2303
Physical aspects	-0.4693	0.0179
Pain	-0.1965	0.3463
General state of health	0.1836	0.3797
Vitality	0.0292	0.8898
Social aspects	0.1946	0.3511
Emotional aspects linitaions	-0.1612	0.4413
Mental Health	-0.2307	0.2671

Source: Data obtained from the 2012 research

DISCUSSION

The sample showed a male predominance of leprosy patients with a prevalence of 56%. The literature shows that it is more common for leprosy to affect male patients over female ones, with a reason of 1:2 in favor of male subjects (2). Martins MA showed in another study about the quality of life of leprosy patients showed a prevalence of 63,3% male patients, while Lustosa AA showed a prevalence of males ranging the 62,6% (4,6).

Martins et al, although, in a study composed of 40 patients showed a prevalence of 60% female patients and, its been noted that the differences between the prevalence of leprosy between male and female populations has been decreasing (7,8).

In this study, the ages of the patients varied between 25 and 67 years old, while in the literature it is said that leprosy is most prevalent between the ages of 13 and 50 years old (1).

In this study, it was observed a higher prevalence of Catholics among the patients, even though there was no statistically significant differences between religious groups. Nevertheless, the Cristian belief has always influenced the way society views leprosy, relating the disease as a divine punishment for physical; spiritual ou moral impurity (9).

There was no statistically significant differences between exercising regularly or not, even though it is expected for those who exercise to increase endorphins in the central nervous system, which is related with pain and humor modulation (10). This result could be justified by our small number of participants. Exercising is also important increase the patients social interactions and to prevent motor disabilities (2).

The physical limitations and the chronic pain that are frequently associated with leprosy are a major cause of disability among patients, so, the employment rate of 76% showed by this study, is not usual (11). A study conducted in Minas Gerais – BRA, showed that the fear of contagion within the work environment is a cause for leprosy patients to be fired (12).

This study could not show the impact that the patients' monthly income has in his quality of life, although those whose family had the greater monthly income had better results when considering the physical aspects of the SF – 36 domain.

Leprosy has higher prevalence amongst poorer populations, 84% of the participants of this has a family monthly income of US$400.00, associated with worse sanitary and habitation conditions and low schooling, which increases its risk of transmission (14).

This study could indicate that having children is a protective factor for leprosy patients when considering the mental health domain of the SF – 36 questionnaires. Those who have kids were less likely to develop humor or anxiety disorders as they were less likely to show depression.

This study could not show a significant impact of living with someone else for the quality of life of leprosy patients. Nevertheless, in 1970 was instituted the BSB Nº 165 ordinance, which objectives were to preserve the family integrity and social integration of the leprosy patient, an important mark in leprosy, once it is very difficult for the patients to be reintegrated into society and for the prevention of transmission (15,16).

At last, this study showed a negative correlation between the age of the patients and their performance under the physical aspects of the SF – 36 questionnaires, which can be justified by the physiological deterioration of the body's functions over the time and the longer duration of disease the greater the age.

CONCLUSION

It is very important to describe aspects concerning the quality of life of leprosy patients for the improvement of future policies and to facilitate the approach and treatment of these

patients by health care professionals, even though more studies with a greater number of participants is required.

LIMITATIONS OF THE STUDY

Due to our small number of participants, this study could be the subject of chance and of confounding factors not conceived during its planning and execution.

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