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Influence of medical care in the quality of life (WHOQOL-100) of women living with systemic lupus erythematosus



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ABSTRACT

Lupus requires careful treatment by medical specialists. This study aimed to evaluate the quality of life of patients living with Systemic Lupus Erythematosus (SLE). The method approached women with a confirmed diagnosis of SLE under medical supervision in a University hospital outpatient clinic or in a private clinic. We used an instrument containing relevant information of the patient and also the Portuguese version of the World Health Organization Quality of Life Group (WHOQOL-100) questionnaire. The study population consisted of 39 women, married in their majority (56.4%); prevalently aged 37–60 years old; prevalence of diagnosis time over five years (66.7%); and in use of less than 5 medications (69.2%). 92.3% had the disease inactive with higher means in mobility ($p=0.0463$) and quality of life ($p=0.0199$) facets; on the other hand, the physical safety and security facet ($p=0.0093$) showed higher mean for people with active disease. Health and social care analysis showed availability and quality ($p=0.0434$), even when with other associated diseases (33.3%); and the highest means were Dependence on medicinal substances and medical aids ($p=0.0143$). The negative results for associated diseases were higher in sexual activity ($p=0.0431$) and transportation ($p=0.0319$) facets. In conclusion: if women living with SLE receive continuous medical attention, they will enjoy good quality of life, while minimizing the complications inherent in this condition.

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Influência da atenção médica na qualidade de vida (WHOQOL-100) de mulheres com lúpus eritematoso sistêmico

RESUMO

O lúpus exige tratamento cuidadoso por médicos especialistas. Este estudo teve como objetivo avaliar a qualidade de vida de pacientes com lúpus eritematoso sistêmico (LES). O método abordou mulheres com diagnóstico confirmado de LES sob acompanhamento médico em ambulatório de hospital escola ou particular. Usou-se instrumento que continha informações relevantes do paciente e a versão em português do instrumento de pesquisa

Palavras-chave:

Lúpus eritematoso sistêmico

Qualidade de vida

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World Health Organization Quality of Life Group (WHOQOL-100). A população estudada percebeu 39 mulheres, na sua maioria casadas (56,4%); com idade prevalente de 37 a 60 anos; tempo de diagnóstico prevalente maior de cinco anos (66,7%); uso de menos de cinco medicamentos (69,2%). Obteve-se que 92,3% estavam com a doença controlada com médias maiores nas facetas mobilidade ($p=0,0463$) e qualidade de vida ($p=0,0199$). Já a faceta segurança física e proteção ($p=0,0093$) apresentou média maior para pessoas com a doença em estado ativado. As análises de cuidados de saúde e sociais apresentaram disponibilidade e qualidade ($p=0,0434$) mesmo com outras patologias associadas (33,3%) e as maiores médias foram dependência de medicação ou de tratamentos ($p=0,0143$). Os resultados negativos para doença associada foram maiores nas facetas atividade sexual ($p=0,0431$) e transporte ($p=0,0319$). Conclui-se que se a mulher com LES receber atenção médica de forma contínua apresentará qualidade de vida que minimizará as complicações inerentes a essa patologia.

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Introduction

Systemic lupus erythematosus (SLE) is an autoimmune chronic disease with highest incidence in the age group from 15 to 40 years old.¹ SLE affects 10 times more women than men, its treatment varies according to the type and severity of symptoms and, due to its complex nature, this disease requires active participation of the patient to maintain a satisfactory level of health. SLE has a poor prognosis, but the advancement of therapeutic possibilities has provided better quality of life (QoL) for people living with this disease.²

Being a chronic disease, SLE has a prevalent psychosomatic dimension, and it is important to consider the stress and the psychosocial suffering on its onset, evolution, aggravation and potential control. This disease requires an interdisciplinary intervention for its care, in addition to considering the peculiar way with which the disease is expressed in the life of every individual, as the psychosocial aspects contribute to the complexity of the development and exacerbation of symptoms.³

The effect of the changes caused by the disease process and its treatment in the clinical course of the disease demand measures that favor QoL as a critical instrument of satisfaction for patients and health professionals. In people with SLE, a decrease of QoL occurs compared with the general population. This QoL loss is due to physical and emotional changes caused by the disease process, especially in periods of exacerbation of SLE.¹

QoL can be understood as consisting of three factors: subjective well-being, which refers to the perception of the individual, his/her values and beliefs; health, understood as a state of physical, mental and social well-being and not merely as the absence of disease; and thirdly, social well-being, which refers to the situation of the person in relation to his/her environment and society.⁴

The assessment of QoL for women with SLE can be as important as the measurement of their morbidity and mortality,⁵ focusing on the ability to live without disease or overcoming difficulties stemmed from morbid states or conditions.⁶

In many cases, the difficulty in understanding the etiology and the pathophysiological process related to this difficult to diagnose disease prevents its specific treatment.⁷

The assessment of QoL in these patients is an essential element so that one can get an idea of the impact of the disease and its treatment in a distinct and complementary way, which contributes to a better care of patients and their families in the emotional distress management, and also facilitates the experience with a disease that is painful, chronic and often disabling.

This study was conducted with the aim to evaluate QoL of patients living with SLE medically treated in the City of Maringa, State of Parana, aiming to qualify the associated factors and their interference in QoL, with specific contributions to this area of knowledge.

Patients and methods

This is a cross-sectional study involving women with established SLE, aged over 18 years, seen at a Rheumatology private clinic and at a university hospital outpatient clinic located in Maringa, Parana. For inclusion in the study, the women must have had an appointment frequency of at least once a year, with medical follow-up, regardless of the nature of the point of care.

The number of participants was delimited based on the access to patients and on their agreement to participate in the study, and also by their regularity in attendance to medical care for at least once a year.

After signing the Informed Consent Form in agreement with the study, the patient had scheduled the place and date for completion of the study questionnaires; or the completion of the questionnaires was carried out when the woman was approached, after obtaining her written consent.

In the study, the patients completed a self-reported instrument, without interference from the researcher. The evaluation was structured in two parts: Part 1. A questionnaire for assessment of clinical and socio-demographic data, including age, education, marital status, occupation, number of working hours per day, family income, housing, disease onset, physical activity, tobacco and alcohol use, drugs used and associated diseases; Part 2. Application of the World Health Organization Quality of Life (WHOQOL-100) questionnaire – Portuguese version.

The World Health Organization Quality of Life Group (WHOQOL-100) questionnaire is a generic QoL instrument drawn up in 1998 by the World Health Organization (WHO) based on a multicenter study. WHOQOL-100 contains questions that address the following areas: physical health (pain, discomfort, energy and fatigue, sleep and rest); psychological (positive feelings, thinking, learning, memory, concentration, self-esteem, body image and physical appearance, and negative feelings); independence level (mobility, daily activities, dependence on medicinal substances and medical aids and working capacity); social relationships (personal relationships, social support and sexual activity); environmental (physical safety and security, home environment, financial resources, health care, social care, recreation/leisure, physical environment and transportation) and spiritual aspects/religion/personal beliefs (spirituality, religion, personal beliefs).

The results of WHOQOL-100 are expressed through scores assigned for each facet and domain. For obtaining these scores, descriptive statistics of each item were held for the following elements: mean, standard deviation, and minimum and maximum values.⁸ To assess QoL, it was decided that the closer from 100 was the sum of the scores of the domains, the better the quality of life; the reverse is true.

Data were computed in Microsoft Excel spreadsheet software (2010). For statistical analysis, the tool provided by Pedroso et al. (2011),⁸ based on Microsoft Excel software, was used. This instrument performs calculations resulting from the WHOQOL-100 application, according to the syntax proposed by the WHO WHOQOL Group. Non-paired t-tests for domains and facets were performed, always considering as reference the statistical programs Statistica 8.0 and SAS System 9.1.

The project was evaluated and approved by CESUMAR Ethics Committee (CEP-CESUMAR), according to certificate No. 106/2011 and protocol No 122/2011.

Results

The study population consisted of 39 female patients; most were married (56.4%) and the prevalent age group was that of 37–60 years old (35.9%), followed by 18–24 years old (30.8%). This group had a good educational level: 84.6% reported 11 years or more of study. With respect to social support, 30.8% work 8–9 h/day, and 20.5% work 10–12 h/day; an income of three or more minimum wages were prevalent (84.6%) in the group. As for housing, 79.5% were homeowners and 89.7% were living with family members. About reported habits, 97.4% did not use tobacco and 89.7% did not use alcohol (Table 1).

At the time of the interview, 92.3% had their disease in a controlled state and 7.7% exhibited an active disease. For most women (66.7%), the diagnosis had been established over 5 years ago, and most (69.2%) used less than 5 medications. 33.3% of participants reported other associated diseases. Comparing the domains of QoL (WHOQOL-100) with the time elapsed since the diagnosis of SLE, the highest mean (17.5 ± 2.6) score was obtained for Spiritual aspects domain, and the lowest mean (12.9 ± 2.9) was found for Independence level. With regard to total scores (QoL), patients with less than

Table 1 – Characterization of socio-demographic data of women with SLE, City of Maringá.

Sample characterization	n	%
Marital status		
Married	22	56.4
Divorced	4	10.3
Single	12	30.8
Widow	1	2.6
Age group		
18–24	12	30.8
25–36	11	28.2
37–60	14	35.9
More than 60 years	2	5.1
Education		
Primary complete	6	15.4
High School complete	21	53.8
University degree incomplete	6	15.4
University degree complete	1	2.6
Post-graduate complete	5	12.8
Daily workload		
Up to 6 h	4	10.3
8–9 h	12	30.8
10–12 h	8	20.5
Does not work/not reported	15	38.5
Income		
2 Salaries	5	12.8
3 Salaries	14	35.9
More than 3 salaries	19	48.7
Not reported	1	2.6
Housing		
Rented	7	17.9
Home ownership	31	79.5
Lives with		
Family	35	89.7
Other people	1	2.6
Alone	2	5.1
Not reported	1	2.6
Smoking		
Not	38	97.4
Yes	1	2.6
Alcoholism		
Not	35	89.7
Yes	4	10.3

5 years elapsed since the diagnosis of SLE had better quality of life (87.3) versus those with more than 5 years (82.2). In the setting of a statistical significance of 5%, no difference was found between the means for patients, regarding the time elapsed since the diagnosis of SLE (Table 2).

Table 3 depicts the correlation between the mean of QoL domains (WHOQOL-100) with the total number of medications used daily by the patient, irrespective whether for SLE or not. The greatest scoring mean was obtained for spiritual aspects domain (16.9 ± 2.4) and the lowest mean for physical domain (12.8 ± 2.8). It is noteworthy that the number of medications used influences the quality of life: the use of less than five medications had a total of 86.0, and more than five medications, 84.9. The mean for domains of patients taking more than five medications did not differ from the mean for domains

Table 2 – Comparison of quality of life domains and facets (WHOQOL-100) related to the time of diagnosis, City of Maringá.

Domains/facets	Diagnosis time				p ^a
	>5 years (n = 27)		<5 years (n = 13)		
	Mean	SD	Mean	SD	
Physical health	13.2	2.9	12.0	2.5	0.2081
Pain and discomfort	12.6	3.8	13.9	3.0	0.2766
Energy and fatigue	12.5	4.2	11.5	3.9	0.5144
Sleep and rest	15.6	3.9	14.2	3.9	0.3042
Psychological	13.8	2.3	12.9	2.3	0.3066
Positive feelings	15.2	2.7	14.6	2.8	0.5473
Thinking, learning, memory and concentration	14.0	3.2	13.2	2.4	0.4489
Self-esteem	14.8	2.8	13.3	2.6	0.1137
Body image and appearance	12.9	3.2	11.6	4.2	0.3141
Negative feelings	12.1	2.9	12.1	2.9	0.9999
Independence level	12.9	2.9	12.6	3.1	0.7766
Mobility	14.6	4.3	14.2	3.8	0.8033
Activities of daily living	14.2	3.9	12.8	3.9	0.3059
Dependence on medicinal substances and medical aids	16.2	3.5	14.2	4.2	0.1103
Work capacity	15.0	4.2	13.7	3.3	0.3320
Social relations	15.6	2.4	14.4	2.8	0.1791
Personal relationships	15.8	2.6	14.9	3.0	0.3688
Social support	16.5	2.8	15.5	3.3	0.3302
Sexual activity	14.5	4.2	12.8	3.4	0.2184
Environment	14.5	2.1	14.1	1.8	0.5838
Physical safety and security	12.6	2.1	12.9	1.5	0.6807
Home environment	15.7	2.4	14.9	2.8	0.3159
Financial resources	13.0	3.5	13.5	3.0	0.6603
Health and social care: availability and quality	14.5	2.6	13.9	1.9	0.4275
Opportunities to acquire new information and skills	15.3	3.2	15.4	3.0	0.9190
Participation in. and opportunities for recreation/leisure	13.9	3.9	13.5	2.6	0.7983
Physical environment: (pollution/noise/traffic/climate)	14.1	2.4	12.4	2.9	0.0527
Transportation	16.7	3.1	16.4	3.2	0.8011
Spiritual aspects/spirituality/religion/personal beliefs	17.5	2.6	16.2	1.6	0.1169
Quality of life from the point of view of the evaluated subject	14.7	2.7	13.9	2.7	0.4088

SD, standard deviation.

^a Non-paired t test.

of patients taking less than five medications (5% significance level).

Table 4 shows the comparison between groups for active or inactive disease, where the highest mean score belongs to Spiritual/Religion/Personal Beliefs aspects (16.7 ± 1.2) and the lowest for independence level (10.3 ± 3.8), and the means of domains both for patients with active versus inactive disease did not differ, at a 5% significance level.

With respect to the individual analysis of facets, it was found that in people with inactive disease their means were higher for mobility ($p=0.0463$) and quality of life facets reported by the interviewee ($p=0.0199$), while for physical safety and security facet ($p=0.0093$) the group with active disease (Table 4) had a higher mean.

It was observed that QoL is better for those patients with disease remission (86.1) versus those with active disease (80.5). A significant difference ($p < 0.05$) for the means of the analyzed domains was not evidenced (Table 4).

As to diseases associated with SLE, six patients reported having another disease(s): one of the interviewees reported

more than one condition, quoting osteoarthritis, osteoporosis, and fibromyalgia; and the others, only one condition for each: bronchitis, anemia, hypertriglyceridemia, antiphospholipid syndrome, and drug-induced hepatitis.

Table 5 shows the means for the comparison of groups with respect to diseases associated, with higher scores for the environment (13.8 ± 1.9). The mean for independence level domain differs when patients with versus without associated diseases were compared, with means of 11.1 ± 2.4 vs. 13.6 ± 2.9 ($p=0.0102$), respectively, considering the significance level of 5%.

In the analysis of facets, with respect to the reference of associated diseases, it was found that the mean of affirmative references was higher for medication or treatment dependency facet ($p=0.0143$). The negative references were higher in Sexual activity ($p=0.0431$) and transportation ($p=0.0319$) facets.

When comparing the total of mean values (QoL) for associated diseases, it becomes clear that those patients who reported not being carriers had higher QoL (87.7) versus those

Table 3 – Comparison of quality of life domains and facets (WHOQOL-100) related to the amount of medications taken, City of Maringá.

Domains/facets	Number of medications				p ^a
	Less than 5 (n = 27)		More than 5 (n = 12)		
	Mean	SD	Mean	SD	
Physical health	12.8	2.8	12.7	3.0	0.8966
Pain and discomfort	13.3	3.7	12.4	3.4	0.4760
Energy and fatigue	12.4	4.2	11.7	3.9	0.6196
Sleep and rest	15.3	4.0	14.8	3.9	0.6432
Psychological	13.5	2.6	13.4	1.7	0.8540
Positive feelings	15.2	3.0	14.7	2.2	0.6091
Thinking, learning, memory and concentration	13.6	3.4	14.2	1.7	0.5434
Self-esteem	14.3	3.1	14.3	2.1	0.9331
Body image and appearance	12.6	3.6	12.2	3.6	0.7498
Negative feelings	12.0	2.6	12.3	3.5	0.7074
Independence level	13.0	3.3	12.3	2.0	0.5173
Mobility	14.1	4.6	15.3	2.6	0.4090
Activities of daily living	13.9	4.0	13.3	3.9	0.6995
Dependence on medicinal substances and medical aids	14.8	4.3	17.3	1.5	0.0523
Work capacity	14.8	3.9	14.0	4.0	0.5474
Social relations	15.3	2.8	14.9	2.1	0.6508
Personal relationships	15.5	2.9	15.5	2.4	0.9831
Social support	16.2	3.3	15.9	2.2	0.7688
Sexual activity	14.2	4.0	13.3	4.2	0.4946
Environment	14.5	2.2	14.0	1.3	0.4677
Physical safety and security	13.0	1.8	11.9	2.0	0.0933
Home environment	15.7	2.8	14.8	1.9	0.3165
Financial resources	13.3	3.5	13.1	2.8	0.8730
Health and social care: availability and quality	14.8	2.2	13.2	2.4	0.0434 ^b
Opportunities to acquire new information and skills	15.3	3.7	15.3	1.4	0.9401
Participation in. and opportunities for recreation/leisure	13.5	3.8	14.3	2.9	0.4776
Physical environment: (pollution/noise/traffic/climate)	13.7	2.4	13.3	3.3	0.6473
Transportation	16.7	3.4	16.2	2.3	0.5892
Spiritual aspects/spirituality/religion/personal beliefs	16.9	2.4	17.6	2.4	0.3834
Quality of life from the point of view of the evaluated subject	14.3	3.1	14.7	1.5	0.7119

SD, standard deviation.

^a Non-paired t test.

^b Significant considering a significance level of 5%.

who reported comorbidity (81.6). The analyzed patients had total mean values above 80 in all aspects analyzed, meaning a good quality of life.

Discussion

The quality of life questionnaires provide a more complete assessment of the impact of disease and of treatment in the patients' daily life.⁹

With regard to diagnosis, a higher mean for independence level was found. A diagnosis with definition of pathology represent a time when life can undergo significant changes, depending of the specifics of the disease and the symptoms experienced, besides the need to control and/or minimize the recurrence of these symptoms.

Araújo and Traverso-Yépez (2007)³ suggested that most women find it difficult to face such a diagnosis, and most of them express a sense of shock, centered on the finding of a disease that has no cure. When evaluating patients followed in

a rheumatology outpatient clinic, Santiago Dantas, Carvalho, Viana, and Fontenele¹⁰ found that 86.7% of patients who were hospitalized had up to 5 years of diagnosis. Assisi and Baaklini (2009)¹¹ stressed that the survival of patients with SLE has increased in recent decades, thanks to earlier diagnoses and the use of medications.

The use of less than five medications may be critical for QoL. The same number was obtained by Santos (2009)¹²; these authors showed that the number of medications ranged from one to 15, with a mean of 5.09 ± 2.48 . This amount of medications is justified by Borba et al. (2008)¹³; in their view, the maintenance of drug therapy in inactive patients reduces the possibility of a new outburst of activity, improves their lipid profile and reduces the risk of thrombosis.

Patients who had their disease controlled showed a higher Independence level, with significance for mobility and quality of life facets. Patients with active disease had higher scores in environmental domain, for physical safety and security facet.

Human problems can contextualize the mismatch between the needs of the individual and the physical and social

Table 4 – Comparison of quality of life domains and facets (WHOQOL-100) related to disease state – active or inactive, City of Maringá.

Domains/facets	Disease state				p ^a
	Active (n = 23)		Inactive (n = 36)		
	Mean	SD	Mean	SD	
Physical health	11.7	1.2	12.9	2.9	0.4940
Pain and discomfort	14.3	0.6	12.9	3.7	0.5198
Energy and fatigue	8.7	5.7	12.4	3.9	0.1290
Sleep and rest	16.7	3.1	15.0	4.0	0.4945
Psychological	12.4	1.0	13.6	2.4	0.4041
Positive feelings	14.0	2.7	15.1	2.8	0.5195
Thinking, learning, memory and concentration	14.0	1.0	13.7	3.1	0.8768
Self-esteem	13.0	1.0	14.4	2.9	0.4027
Body image and appearance	9.0	1.7	12.7	3.5	0.0815
Negative feelings	12.0	2.7	12.1	2.9	0.9635
Independence level	10.3	3.8	13.0	2.8	0.1311
Mobility	10.0	5.6	14.8	3.8	0.0463 ^b
Activities of daily living	10.0	6.2	14.0	3.6	0.0895
Dependence on medicinal substances and medical aids	15.0	1.0	15.6	4.0	0.8043
Work capacity	12.3	5.1	14.8	3.8	0.3099
Social relations	15.4	1.3	15.2	2.7	0.8534
Personal relationships	15.7	1.5	15.5	2.8	0.2569
Social support	17.0	2.7	16.1	3.0	0.6065
Sexual activity	13.7	4.9	13.9	4.0	0.9189
Environment	14.0	0.6	14.4	2.0	0.7575
Physical safety and security	15.3	1.2	12.4	1.8	0.0093 ^b
Home environment	15.0	1.7	15.5	2.6	0.7635
Financial resources	12.7	1.2	13.3	3.4	0.7734
Health and social care: availability and quality	13.0	1.7	14.4	2.4	0.3371
Opportunities to acquire new information and skills	16.0	1.0	15.3	3.2	0.6951
Participation in. and opportunities for recreation/leisure	11.7	4.2	13.9	3.5	0.2906
Physical environment: (pollution/noise/traffic/climate)	12.0	2.7	13.7	2.7	0.3011
Transportation	16.3	2.5	16.6	3.2	0.8953
Spiritual aspects/spirituality/religion/personal beliefs	16.7	1.2	17.1	2.5	0.7627
Quality of life from the point of view of the evaluated subject	11.0	3.6	14.7	2.5	0.0199 ^b
SD, standard deviation.					
^a Non-paired t test.					
^b Significant considering a significance level of 5%.					

environment. The perception of the environmental dimension depends on a hierarchy of values and this is an individual process, but it reflects the current conditions of collective life and its impact on the lives of women analyzed in this study. Women with active SLE had worse QoL in physical, psychological and environmental domains. In SLE patients with an intensely active disease, it was observed a worse condition of QoL versus women with inactive SLE.¹

Thumboo and Strand (2007)¹⁴ found that patients with SLE show major deficiencies in functional status compared to the general population, and that the specific manifestations of lupus (disease activity, prior renal involvement and fibromyalgia) can influence the QoL reported.

Freire et al. (2011)¹⁵ suggested that, in many cases, the organic and psychological damage to which patients with SLE are subject result in physical or mental disability, besides other drawbacks, worsening QoL, which has been recognized as an important indicator of health for patients with chronic diseases.

When referring associated diseases, the patients in this study indicated that the dependence on medicinal substances and medical aids facet interferes with QoL. Araújo and Traverso-Yépez (2007)³ reported that some patients reported that they no longer had a “normal” life, also admitting with regret the need “to have to depend on medication for life.” Medication is the key factor for helping in disease control. The lack of medication would also be the main detrimental factor for these patients. However, it is clear that not all participants make this relationship, when indicating emotional factors as major contributors to their uncontrolled disease.

Among the negative responses, significance was observed for sexual activity and transportation facets. Silva (2009)¹⁶ showed that 4% of women and adult men with SLE presented sexual dysfunctions, according to their medical history. Folomeev and Alekberova (1990)¹⁷ identified a high frequency of sexual/erectile dysfunction in 35% of men with SLE. From a structured interview with adult women, Curry et al. (1994)¹⁸ observed reduced frequency of sexual activity, vaginal

Table 5 – Comparison of quality of life domains and facets (WHOQOL-100) related to reports of other diseases associated with SLE, City of Maringa.

Domains/facets	Associated diseases				p ^a
	Yes (n = 13)		No (n = 26)		
	Mean	SD	Mean	SD	
Physical health	11.9	2.7	13.2	2.8	0.1656
Pain and discomfort	14.4	3.0	12.4	3.7	0.5788
Energy and fatigue	10.9	3.3	12.8	4.3	0.1604
Sleep and rest	15.2	4.3	15.2	3.8	0.9999
Psychological	13.1	2.2	13.7	2.4	0.4130
Positive feelings	14.7	2.8	15.2	2.7	0.6282
Thinking, learning, memory and concentration	13.0	3.1	14.1	2.9	0.2688
Self-esteem	14.5	2.1	14.2	3.1	0.7164
Body image and appearance	11.2	2.7	13.0	3.8	0.1355
Negative feelings	12.2	3.0	12.0	2.9	0.8160
Independence level	11.1	2.4	13.6	2.9	0.0102 ^a
Mobility	12.9	3.8	15.3	4.0	0.0790
Activities of daily living	12.2	3.8	14.4	3.9	0.1003
Dependence on medicinal substances and medical aids	17.6	1.7	14.5	4.2	0.0143 ^b
Work capacity	13.1	4.2	15.3	3.6	0.0941
Social relations	14.2	3.0	15.7	2.2	0.0788
Personal relationships	14.9	2.9	15.8	2.7	0.3085
Social support	15.5	3.9	16.4	2.5	0.3922
Sexual activity	12.1	4.5	14.8	3.5	0.0431 ^b
Environment	13.8	1.9	14.6	2.0	0.2570
Physical safety and security	12.3	2.1	12.9	1.8	0.4092
Home environment	14.9	2.1	15.7	2.8	0.3811
Financial resources	12.5	2.9	13.6	3.5	0.3228
Health and social care: availability and quality	13.9	2.2	14.5	2.5	0.5104
Opportunities to acquire new information and skills	14.3	3.4	15.8	2.9	0.1605
Participation in. and opportunities for recreation/leisure	13.9	3.7	13.7	3.5	0.8951
Physical environment: (pollution/noise/traffic/climate)	13.9	2.3	13.4	2.8	0.6088
Transportation	15.1	4.0	17.3	2.3	0.0319 ^b
Spiritual aspects/spirituality/religion/personal beliefs	17.5	2.5	16.9	2.3	0.3995
Quality of life from the point of view of the evaluated subject	13.6	3.0	14.9	2.5	0.1841
SD, standard deviation.					
^a Non-paired t test.					
^b Significant considering a significance level of 5%.					

lubrication, and sexual satisfaction in the group with lupus versus a matched control group.

Silva (2009)¹⁶ showed that sexual dysfunction in female adolescents with lupus is a multifactorial condition and can occur related to disease activity itself, or by medications such as corticosteroids and immunosuppressants. The study has not shown an association between sexual dysfunction and lupus activity, the cumulative damage caused by disease, or medication use.

In contrast, Reis (2009)¹⁹ assessed satisfaction in the relationship and affection in the period of exacerbation of the disease among 74 women with SLE who kept heterosexual relationship, and noted that those women who had greater physical intimacy with their partners reported great satisfaction with their relationship; those who avoided or had less physical intimacy pointed to an intensely negative effect. This study also revealed the dilemmas faced by women to maintain intimacy with their partners during disease activity.

Vido and Scanavini (2007)²⁰ emphasized that economic dependence, discrimination, difficulties affecting sexual and

reproductive lives and inadequate housing and environmental conditions are factors that contribute to progressive deterioration of health, relationships and QoL to those who experience SLE.

The transportation referenced by interviewees was characterized by Reis (2009),¹⁹ when this author identified difficulties experienced by women in order to maintain their treatment and access to care. Transportation was not always guaranteed, the distances were large, the travel time lengthy, the access to specific medications was poor and the women had difficulty in meeting their requirements for food while traveling.

Final considerations

Taking into account the pathology, use of medications and of other intervening factors on quality of life, in this study we obtained a good index of quality of life among the interviewees. Most women were satisfied with their lives and showing

optimism, with acceptance of their limitations and enjoying what is best for them in their life, seeking in their family and personal beliefs forces for the challenges that the disease imposes.

It was demonstrated that women with SLE may have a good QoL, should they take advantage of specialized medical care. With an effective treatment, the disease remains inactive, providing security to patients and resulting in emotional control, decreased pain and improvement in other symptoms and in improved expectations, meaning that it is possible to get on well with the disease, culminating with a good quality of life.

As to limitations of this study, we can mention the fact that SLE patients completed the instruments used in this study in the waiting room of the medical office; this fact could imply in concentration difficulties to answer the questionnaires. Another limitation relates to the instrument used which, by being lengthy and repetitive, could be tiring for the women. The origin of patient care can be a weak point of this study. Due to the number of respondents, it was not possible to stratify the subjects in a group with public unit care and in another group with private health care. Further studies with specific groups, according to unit type, are suggested.

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Conflicts of interest

The authors declare no conflicts of interest.

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