

Health-related quality of life in patients with systemic lupus erythematosus in Midwest Brazil

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ABSTRACT

Introduction/Objective: Evaluate the quality of life (QOL) of women with systemic lupus erythematosus (SLE) and the association between QOL domains, measured by the World Health Organization Quality of Life Group (WHOQOL-100) assessment instrument, and disease activity. **Patients and Methods:** A cross-sectional analytic study involving 95 patients with SLE, according to the American College of Rheumatology (ACR) criteria, aged 20-49 years, attended at the University Center of Universidade Federal de Mato Grosso do Sul, Campo Grande, MS. We used the following instruments: demographic and clinical data collection form and WHOQOL-100 instrument. Evaluation of disease activity was performed by SLEDAI. On statistical analysis, we applied Student's t-test, ANOVA, and Pearson's correlation. **Results:** Group-case: 79 female with mild to moderate SLE activity (SLEDAI = 1-10) and severe activity (SLEDAI \geq 11). Control group: 16 female with inactive SLE (SLEDAI = 0). All domains of WHOQOL-100 proved to be affected, with significant difference ($P < 0.005$) between the case and control groups in which there was a better perception of QOL in the domain Spirituality and worst perception of QOL in the domain Environment. When confronting QOL domains with education, we detected a significant difference ($P < 0.05$) in the Physical, Psychological, Level of independence, and Environment domains. The comparison between QOL and disease activity was significant ($P < 0.005$) in three domains: Physical, Psychological, and Environment. **Conclusion:** SLE with intense activity determines a worse QOL condition than inactive SLE. The assessment of QOL enables the knowledge of disease and treatment impact in a contextualized way, which can render more appropriate and more comprehensive interventions.

Keywords: quality of life, women's health, systemic lupus erythematosus.

INTRODUCTION

Assessment of quality of life (QOL) of women with systemic lupus erythematosus (SLE) can be as important as measurements of morbidity and mortality.¹ The effect of changes caused by the disease process and therapy in the clinical course of disease demands actions that improve the QOL as an essential tool of satisfaction for patients and health professionals.²

In periods of intense inflammatory activity, the widespread deposition of immune complexes in sites like blood vessel walls produces inflammation and functional changes in various

organs, which gives the disease its systemic character.^{1,3,4} These periods are marked by severe signs and symptoms and clinical and laboratory changes, requiring the use of high dose steroids and, quite often, immunosuppressants.¹

Several signs and symptoms may interfere with QOL during periods of SLE activity, such as vasculitis causing skin rash; painful lesions and hyperemia in palms and soles, palate or limb regions; fever without infection; weight loss; headache; alopecia; asthenia; myalgia; eye problems; hepatomegaly; splenomegaly; and adenopathy.³

Although the etiology remains unclear, the disease is strongly influenced by genetic, hormonal (estrogen),

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environmental (ultraviolet radiation, drugs), infectious (viral), and psychological stress factors, which participate in its pathogenesis.^{5,6}

SLE is one of the most common autoimmune diseases in young women, with the highest incidence in the age group of 15-40 years, at a ratio of six women for each man. Therefore, the odds of developing this predominantly female disease differ between genders.⁷

The QOL issue incorporated into the health practice of professionals has been designated as *health-related quality of life* and used in clinical setting to express the physical and psychosocial impact caused by physical and biological changes produced by disease and therapies that interfere with daily life conditions.⁸⁰⁻¹⁰

The attempt to achieve QOL, as well as seeking to define it, has followed the historical and cultural development of mankind.¹¹ The QOL construct is very comprehensive, reflecting the historical moment, social class, and culture of the individual, since it comes from experience, knowledge, and values both individual and collective.

One definition of QOL has been proposed by a study group on QOL of the World Health Organization (WHO), World Health Organization Quality of Life Group (WHOQOL): "An individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns."¹²

The WHOQOL-100 is a generic QOL instrument developed by the WHO in 1998 from a multicenter study. It contains 100 questions divided into 24 groups of four questions whose answers are punctuated by scores that range from 0 to 1.0 for each domain. Each group of four questions refers to a facet. A given number of facets constitute a domain. The domains with their respective facets are: Physical (pain, discomfort, energy and fatigue, sleep and rest); Psychological (positive feelings, thinking, learning, memory, concentration, self-esteem, body image and appearance, and negative feelings); Level of Independence (mobility, daily activities, dependence on accompaniment or treatment and work capacity); Social (personal relationships, social support, and sexual activity); Environment (physical safety and security: the home environment, financial, health care, social care, recreation/rest, physical environment, and transport); and Spirituality (spirituality, religion, personal beliefs).¹²

Among the various instruments for measuring QOL in literature, the WHOQOL-100 was chosen for this study because of the breadth of its domains and facets, structure of

the instrument, the complexity of SLE due to impairments that patients may develop, and the possibility of self-administration by the selected population. The aim of this study was to evaluate the perceived health-related QOL of adult women with SLE, considering the association between QOL and disease activity.

PATIENTS AND METHODS

This was a cross-sectional analytical study developed in the Department of Rheumatology of the Núcleo do Hospital Universitário da Universidade Federal de Mato Grosso do Sul (NHU-UFMS) and included 95 women, with data collected from March 2, 2007, through September 2, 2008.

Inclusion criteria were presence of records in the NHU-UFMS, female, age 20-49 years, meeting at least four criteria for SLE diagnosis (according to the American College of Rheumatology-ACR-1982), ability to communicate verbally or in writing on interview and data collection instrument, agree to participate in the study, and sign informed consent. Exclusion criteria were presence of other chronic infectious diseases non-associated with SLE activity and chronicity, and suspected or confirmed pregnancy.

The instruments used for data collection were: form for collecting demographic and clinical data and WHOQOL-100. The Systemic Lupus Erythematosus Disease Activity Index (SLEDAI)¹⁴ was used to classify groups of participants based on disease activity index. The case group consisted of 79 women with mild to moderate SLE activity (SLEDAI = 1-10) and severe activity (SLEDAI \geq 11). The control group consisted of women with inactive SLE (SLEDAI = 0).

Completion of WHOQOL-100 was performed preferentially by the participant herself, respecting the privacy requirements of the clinical setting. When indicated, due to clinical status or education level, the filling was carried out with assistance and support directly from the researcher.¹³ In these situations, the questions were read by the researcher and the participant indicated her response options. The question was repeated as often as was needed, without adding explanations that would direct the response.

Study complied with the Guidelines and Standards for Human Research, according to Resolution 196/96 of the National Research Council, and obtained approval of the Research Ethics Committee (CEP CEP/UFMS), under the Protocol No 363/06 of August 7, 2006.

For statistical analysis were applied the Student's t-test and analysis of variance (ANOVA) for the domains addressed in WHOQOL-100, and Pearson's correlation for continuous

demographic variables. Through statistical analysis, we attempted to detect significant differences ($P < 0.05$) when there was an association between the QOL domains and case and control groups, and also between these domains and demographic and clinical variables.

RESULTS

Of the 95 women who participated in this study, 45 (47.4%) had primary education and 50 (52.6%) had mid-level education or higher. As for marital status, 67.4% lived with a partner and 32.6% lived alone or with children and families. Regarding the origin, 49.5% were from Campo Grande. Among the 48 who came from other cities, 44 (91.7%) came from the interior of Mato Grosso do Sul, three (6.2%) from other states, and one (2.1%) from Paraguay. All study participants were treated at NHU-UFMS with funds from the SUS (a Brazilian unified healthcare system). Only 16.8% sporadically used private healthcare systems to perform some tests (Table 1).

The average age of participants in the research period was 34.22 years (± 8.29), the mean age at diagnosis was 27.57 years (± 8.95), and the time of SLE during the study period was 6.69 years (Table 2).

In the present study sample, the disease was very active (SLEDAI ≥ 11) in 21 (22.1%) of participants, mild to moderate activity (SLEDAI = 1-10) in 58 (61.1%), and inactivity (SLEDAI = 0) in 16 (16.8%). Therefore, the first 79 (83.2%) patients mentioned comprised the case group and only the last 16 (16.8%) formed the control group (Table 3).

In all study participants, the WHOQOL-100 questionnaire was applied and we identified mean scores of QOL according to each QOL domain (Table 4.) As a basis for calculating these scores, we used the reference values (0 to 1.0) indicated by the WHOQOL group. Thus, the Spirituality domain, which presented the highest score (0.79), was assessed as the domain with the best perception of QOL and, the Environment domain, which was associated with the lowest score (0.53), was considered the worst perception of QOL. Analysis of variance (ANOVA) was used in all patients to assess possible differences between mean scores of the six QOL domains of WHOQOL-100. Statistical analysis identified significant differences between all QOL domains (physical, psychological, level of independence, social relationships, environment, and spirituality) in all participants, with 95% confidence interval ($P < 0.05$, Table 4).

In this research, the most prevalent results were those associated with QOL and education of participants with SLE. When confronting the domains of QOL with the results

Table 1

Sociodemographic characteristics of adult women with systemic lupus erythematosus treated at NHU-UFMS: marital status, education, origin, and use of healthcare system. Campo Grande, MS, 2007-2008 (N: 95)

Sociodemographic Variables		n	%
Education	Primary School	45	47.4
	High School	39	41.0
	Superior Education	11	11.6
Origin	Campo Grande	47	49.5
	Other cities*	48	50.5
Marital status	With a partner	64	67.4
	Without a partner	31	32.6
Healthcare system	SUS	79	83.2
	Private	16	16.8

Includes 44 women (91.7%) from the interior of Mato Grosso do Sul, three (6.2%) from other states, and one (2.1%) from another country.

Table 2

Mean age, age at diagnosis, and time of diagnosis in adult women with systemic lupus erythematosus (SLE) treated at NHU-UFMS. Campo Grande, MS, 2007-2008

Variable	n	Mean	SD*
Age (years)	95	34.22	± 8.29
Age at SLE diagnosis (years)	95	27.57	± 8.95
Age at diagnosis (anos)	95	6.69	± 6.04

*SD = standard deviation.

Table 3

Disease activity in adult women with systemic lupus erythematosus (SLE) treated at NHU-UFMS, second score of the Systemic Lupus Erythematosus Disease Activity Index (SLEDAI), by study group. Campo Grande, MS, 2007-2008

		SLEDAI score	n	%
Case	Intense	≥ 11	21	22.1
	Mild to moderate	1-10	58	61.1
Control	Inactive	0	16	16.8
Total			95	100

for education of women with SLE, a significant difference ($P < 0.05$) was identified in the Physical, Psychological, Level of Independence, and Environment domains, which leads us to conclude that there is a better QOL perception in these domains (Table 5).

To compare the QOL of women with SLE in all domains of WHOQOL-100 with the levels of disease activity, we applied the ANOVA test, with 95% reliability. Significant difference ($P < 0.05$) was found in three areas: Physical, Psychological, and Environment. It was found that adult women with intense SLE activity showed worse QOL perception than adult women with SLE without activity (Table 6).

DISCUSSION

The level of education appears to be associated with QOL.¹⁵ In all participants, the relevant results were those in which higher levels of education showed better perception of QOL in Physical, Psychological, Level of Independence, and Environment domains. For Martinez,¹⁶ higher levels of education among women with SLE determine the adoption of cognitive and behavioral strategies to better cope with situations, representing higher level of mental preparation and shifting the focus of emotional problems. Therefore, the higher the education, the better the perceived QOL of women with SLE, in the domains indicated.

According to reports from participants themselves, the most significant limitations affecting the relationship with their partners and family members included pain, fatigue, stress, decreased self-esteem, altered self-image, decreased libido, physical disability, medication use, need for support from other

Table 4
Quality of life (QOL) domains of the World Health Organization Quality of Life Group (WHOQOL-100), averaged scores of adult women with systemic lupus erythematosus (SLE) treated at NHU-UFMS. Campo Grande, MS, 2007-2008

QOV Domains	n	QOL Mean Scores*	SD	P
Physical	95	0.60	0.13	< 0.001
Psychological	95	0.60	0.11	
Level of Independence	95	0.61	0.17	
Social	95	0.65	0.17	
Environment	95	0.53	0.13	
Spirituality	95	0.79	0.16	

*Reference value for QOL mean scores: 0.0 to 1.0.
SD = standard deviation; P (value) = level of statistical significance (value < 0.005).

people, and financial difficulties. Because they are young and at reproductive age, these women reported that their marital and family QOL are affected. Therefore, the affective relations of women with SLE and their partners also go through processes of adaptation at different stages of disease.

These reports are consistent with the literature, which shows that children who live with people with SLE (partner, children, and other relatives) are faced with emotional reactions, clinical fluctuations, and interference in social role, work, and performance of daily activities.¹⁷

Other studies show similarity to the results of this research with respect to mean age at the time of diagnosis.^{2,16,18-20,24} The diagnosis of SLE is always a nuisance,²¹ leaving young women anxious because it occurs in a productive and crucial phase of their life, a time to stabilize their relationships, constitute a family, or choose a career. The author's argument quoted previously is consistent with the results of this study, as the

Table 5
QOL domains of the World Health Organization Quality of Life Group (WHOQOL-100) in terms of education of adult women with systemic lupus erythematosus (SLE) treated at NHU-UFMS. Campo Grande, MS, 2007-2008 (N: 95)

QOL Domains	Education	n	QOL Mean Scores*	SD	P
Physical	Primary	45	0.56	0.12	0.001
	High	39	0.65	0.12	
	Superior	11	0.54	0.16	
Psychological	Primary	45	0.56	0.11	0.002
	High	39	0.64	0.10	
	Superior	11	0.56	0.11	
Level of Independence	Primary	45	0.55	0.16	0.001
	High	39	0.68	0.14	
	Superior	11	0.62	0.20	
Social Relationships	Primary	45	0.60	0.16	0.06
	High	39	0.71	0.16	
	Superior	11	0.66	0.20	
Environment	Primary	45	0.47	0.11	< 0.001
	High	39	0.60	0.11	
	Superior	11	0.53	0.16	
Spirituality	Primary	45	0.76	0.13	0.459
	High	39	0.81	0.17	
	Superior	11	0.80	0.20	

*Reference value for QOL mean scores: 0.0 to 1.0.
SD = standard deviation; P (value) = level of statistical significance (value < 0.005).

Table 6

QOL domains of the World Health Organization Quality of Life Group (WHOQOL-100) in relation to disease activity in adult women with systemic lupus erythematosus (SLE) treated at NHU-UFMS. Campo Grande, MS, 2007-2008. (N: 95)

Domínio de QV	LES Activity	n	QOL Mean Scores*	SD	P
Physical	Intense	21	0.54	0.16	0.049
	Moderate	58	0.60	0.12	
	Inactive	16	0.65	0.12	
Psychological	Intense	21	0.55	0.11	0.028
	Moderate	58	0.60	0.12	
	Inactive	16	0.65	0.08	
Level of Independence	Intense	21	0.54	0.17	0.095
	Moderate	58	0.62	0.16	
	Inactive	16	0.65	0.16	
Social Relationships	Intense	21	0.61	0.15	0.058
	Moderate	58	0.64	0.18	
	Inactive	16	0.74	0.16	
Environment	Intense	21	0.47	0.13	0.034
	Moderate	58	0.54	0.13	
	Inactive	16	0.58	0.11	
Spirituality	Intense	21	0.76	0.14	0.658
	Moderate	58	0.79	0.16	
	Inactive	16	0.81	0.17	

*Reference value for QOL mean scores: 0.0 to 1.0.

SD = standard deviation; P (value) = level of statistical significance (value < 0.005).

SLE patients were on average 34 years old, but at the time of SLE diagnosis they were on average six years younger.

The total number of women with active disease (83.2%) was close to results reported by Khanna *et al.*²⁰ who found disease activity in 70% of the sample surveyed. The presence of activity, albeit mild, is manifested by new symptoms, clinical and laboratory signs, another organ involvement, or worsening of an organ already affected.^{1,22,23}

Several studies have shown that in individuals with SLE, QOL is impaired in different domains, compared with general population.²⁴⁻²⁶ QOL impairment is due to physical and emotional changes caused by the disease process, especially during periods of SLE exacerbation. In this study, although all QOL domains were affected in both groups (case group and control group), in general, SLE patients had a better perception of QOL in the Spirituality domain and worse perception in the Environment domain. One must take into account that the QOL

domains are interrelated, since human beings are a holistic and indivisible whole.²⁷

In Psychological domain, for example, there is involvement of disease physical effect repercussion and its potential severity, impact on performance of daily activities by functional limitations and pain, effect of altered self-image and self-esteem on physical appearance, fatigue, memory changes, negative feelings, difficulties in personal relationships, lack of social support, dissatisfaction in the sexual sphere and other areas. The same interrelation of reasoning applies to other domains.

Participants showed better QOL perception in the Spirituality domain (Table 4), with higher scores on the answers to the WHOQOL-100 questions correlated with personal beliefs, sense of meaning in life, strength to face difficulties, and understanding life difficulties. These results led us to conclude that the patients surveyed probably use their beliefs to cope with the disease, especially when this belief is more intense and promotes emotional, social and spiritual security, giving meaning to the suffering caused by chronic disease and being a source of hope in the face of changes in health status when the disease becomes active.²⁸

Consistent with this idea, Pinto and Ribeiro²⁹ report that "Spiritual beliefs are part of a cognitive-active type of framework that enables people to cope with existential threatening crises, encouraging social and emotional support".

The experience of strong intrinsic religiosity correlates with more rapid remission of depression,³⁰ an association particularly important when physical function is compromised or is not improving in these patients. Religiosity can be a support in health situations,²⁹ and the invocation of beliefs is not only emotionally and spiritually comforting, but also has an influence on health.³¹

However, there are few studies that focus on spirituality in terms of strategies for coping with stress, and there are also few studies that compare how religiosity can help address difficult situations in lives of sick individuals.³²

The result on Environment domain (Table 4) that showed the lowest score of perceived QOL is consistent with literature, which suggests that human problems can be contextualized by the mismatch between the needs of people and the physical and social environment.⁹ The perception of this dimension is an individual process and depends on the hierarchy of values, but reflects the current conditions of collective life and its impact on the lives of women surveyed.

The results of this investigation show that perception of QOL in adult SLE women with intense disease activity is worse than the QOL of those who have inactive disease, and

also show that there were statistical significance in Physical, Psychological, and Environment domain ($P < 0.05$) (Table 6). Similarly, Rinaldi *et al.*,¹⁹ when examining the QOL of Italian women in a cohort of 126 patients with the disease and 96 healthy controls, found that mental and physical components were reduced only in patients with active disease.

In the study of Benitha and Tikly,³³ all domains of QOL were significantly worse in the group with SLE and when the disease was active. However, the results of this investigation differ from those of McElhone *et al.*,²⁵ which showed worse QOL in patients with SLE, although with no association with disease activity or damage.

An Australian research that established a correlation of QOL with physical, psychological, and spiritual needs; health services; health information; social support; and lifestyle of 363 women revealed many aspects in which Psychological domain and lifestyle were affected, interfering with daily life of people with SLE. The study stresses the importance of understanding these needs and limitations, so that valid strategies for conducting treatments, interventions, and guidelines can be developed.³⁴

Patients with active SLE in this research had worse perceived QOL in the Physical domain (Table 6), resulting from the diversity and simultaneity of manifested symptoms, which included swelling, pain, fatigue, skin changes, limited mobility, depression, fever, visual disturbances, alopecia, wounds, arthritis, weight loss or gain, renal and cardiac changes, hypertension, ascites, bleeding gums, oral/vaginal mucosa lesions, and anemia.

Skin changes and photosensitivity cause embarrassment affecting psychosocial level and self-image; and arthralgia³⁵ is translated as a limiting factor of functional status in joint involvement.^{36,37}

The study undertaken by Thumboo and Strand²⁶ showed that SLE patients have lower functional status than the general population and that disease specific manifestations (activity, renal involvement, fibromyalgia) may influence the QOL reported. The authors call attention to skin lesions and alopecia, which worsen QOL in patients with SLE.

Therefore, all that is limiting in any sphere affects behavior, attitudes, and perceptions. For example, the fatigue, which is a common and limiting factor in SLE, and therefore is the subject of several studies, is not always associated with the immune status or inflammation, but with psychosocial factors, anxiety, depression, non-restorative sleep, and muscle and joint pain.³⁸⁻⁴⁰

The adaptation process to which women are forced during the stages of disease is a major cause of negative emotional changes, such as fear and anxiety.⁹ The most common reactions

in the most critical phases of disease are directed to maintain emotional balance, preserving the satisfying self-image, family and social relations, and remove uncertainty about the future.

When the woman becomes ill and lives with a chronic disease, she is faced with limitations, treatment implications, wear, and suffering.¹⁷ The Psychological domain, when affected (Table 6), shows that the physical, emotional, social, environmental, and spiritual needs are interrelated, requiring interdisciplinary and multidisciplinary care.⁴¹

In the study by Cruz,⁴² the women with SLE recognized that the disease has a chronic course and stressed the routine difficult of examinations, visits, medication and hospitalization, but described feeling more anxiety at times of further adjustments resulting from the disease and when they became aware of the vulnerability during the active phases of disease. The passive strategies for facing difficult situations, often driven by emotion, are associated with increased psychological distress and, consequently, worst QOL.¹⁶

Emotional factors, psychological stress, and disease activity itself are marked by unpredictability,³⁵ revealing the need for innovative forms of health care, individual or group, in order to alleviate the suffering.

The interventions that address complaints and grievances promptly are quite often unsatisfactory; therefore, interventions that promote changes for a better QOL are needed.

CONCLUSIONS

The perception of QOL by adult women with SLE evaluated in this study, in all WHOQOL-100 domains, was affected. Better perception of QOL occurred in the Spirituality domain, and worse QOL in the Environment domain. In the perspective of SLE patients with higher education, perception of QOL was better evaluated in Physical, Psychological, Level of Independency, and Environment domains.

The more intense the activity of the disease, the worse the perceived QOL of women with active disease, while women with inactive disease have better QOL perception. The Physical, Psychological, and Environment domains were the most affected in women with active SLE. Physical, Psychological, and Environment domains were the most affected in women with active SLE.

The assessment of QOL based on the individual permits the knowledge of disease and treatment impact in a different but complementary way to the biological, preserving the human character, identifying relevant issues, and enabling interventions to become more effective and comprehensive.

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