Original Article

Factors influencing quality of life in people with systemic lupus erythematosus

Fatores influentes da qualidade de vida em pessoas com lúpus eritematoso sistêmico

Factores influyentes en la calidad de vida de personas con lupus eritematoso sistémico

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Abstract

Objective: To identify an association between quality of life and clinical manifestations and symptoms of depression in individuals with systemic lupus erythematosus.

Methods: This is a quantitative study conducted with 141 individuals with lupus under follow-up at the rheumatology outpatient clinic of a university hospital. Data were collected through interviews using the WHOQOL-bref, the Cognitive Depression Scale and a sociodemographic characterization questionnaire. For analysis, data were entered in a spreadsheet in Microsoft Excel® and analyzed in Statistical Analysis Software, using Odds Ratio to measure risk estimation and adjustments of binary logistic regression models for each of the covariates of interest. Statistical significance was set at $p < 0.05$. Positive and negative predictive values were calculated for the diagnostic variables that presented statistical significance.

Results: Of the 141 participants, 135 (95.7%) were female, 81 (57.9%) were over 40 years old and in 89 (63.1%) lupus had been diagnosed for more than five years. The presence of some clinical manifestations related to exacerbation of the disease increases the chances of an unsatisfactory perceived quality of life in all WHOQOL-bref domains, and the highest number of manifestations associated with unsatisfactory perceived quality of life was observed in the physical health domain, followed by the psychological health domain. The presence of symptoms of depression was also associated with unsatisfactory perception in all WHOQOL-bref domains.

Conclusion: The clinical manifestations that characterize the activity of the disease, as well as the presence of complications, increase the chances of an unsatisfactory perceived quality of life and this, in turn, increases the chances of individuals presenting depressive symptoms.

Resumo

Objetivo: Identificar associação entre qualidade de vida e manifestações clínicas e sintomas de depressão em indivíduos com Lúpus Eritematoso Sistêmico.

Métodos: Estudo quantitativo, realizado com 141 indivíduos com lúpus em acompanhamento no ambulatório de reumatologia de um hospital universitário. Os dados foram coletados mediante entrevistas, utilizando o WHOQOL-*bref*, a Escala Cognitiva de Depressão e o questionário de caracterização sociodemográfica. Para análise, os dados foram digitados em planilha no Microsoft Excel® e analisados no *Statistical Analysis Software,* utilizando o Odds Ratio para medida de estimativa do risco e ajustes de modelos de regressão logística binária para cada uma das covariáveis de interesse. A significância estatística foi estabelecida quando $p<0,05$.

Resultados: Dos 141 participantes, 135 (95,7%) era do sexo feminino, 81 (57,9%) tinha mais de 40 anos e

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89 (63,1%) tinha diagnóstico de lúpus há mais de cinco anos. A presença de algumas manifestações clínicas relacionadas à exacerbação da doença aumenta as chances de uma percepção insatisfatória da qualidade de vida em todos os domínios do WHOQOL-*bref*, sendo que o maior número de manifestações associadas à percepção insatisfatória da qualidade de vida foi observado no domínio saúde física, seguida pelo domínio saúde psicológica. A presença de sintomas de depressão também apresentou associação com percepção insatisfatória em todos os domínios do WHOQOL-*bref*

Conclusão: As manifestações clínicas que caracterizam a atividade da doença, bem como a presença de complicações aumentam as chances de uma percepção insatisfatória da qualidade de vida e esta, por sua vez, aumenta as chances de o indivíduo apresentar sintomas depressivos.

Resumen

Objetivo: Identificar la relación entre calidad de vida y manifestaciones clínicas y síntomas de depresión en individuos con lupus eritematoso sistémico.

Métodos: Estudio cuantitativo, llevado a cabo con 141 individuos con lupus que realizan seguimiento en consultorios externos de reumatología de un hospital universitario. Los datos fueron recopilados mediante entrevistas, utilizando el WHOQOL-*bref*, la Escala Cognitiva de Depresión y el cuestionario de caracterización sociodemográfica. Para el análisis, los datos fueron digitalizados en planilla de Microsoft Excel® y analizados en *Statistical Analysis Software*, utilizando el Odds Ratio para la medida estimativa del riesgo y ajustes de modelos de regresión logística binaria para cada una de las covariables de interés. La significación estadística fue establecida cuando p<0,05.

Resultados: De los 141 estudiantes, 135 (95,7 %) eran de sexo femenino, 81 (57,9 %) tenían más de 40 años y 89 (63,1 %) tenían diagnóstico de lupus hace más de cinco años La presencia de algunas manifestaciones clínicas relacionadas con la exacerbación de la enfermedad aumenta las chances de una percepción insatisfactoria de la calidad de vida en todos los dominios del WHOQOL-*bref*, donde el mayor número de manifestaciones relacionadas con la percepción insatisfactoria de la calidad de vida fue observado en el dominio salud física, seguido del dominio salud psicológica. La presencia de síntomas de depresión también presentó relación con la percepción insatisfactoria en todos los dominios del WHOQOL-*bref.*

Conclusión: Las manifestaciones clínicas que caracterizan la actividad de la enfermedad, así como la presencia de complicaciones, aumentan las chances de una percepción insatisfactoria de la calidad de vida, que por su parte aumenta las chances de que el individuo presente síntomas depresivos.

Introduction

Systemic lupus erythematosus (SLE) is an autoimmune, incurable to date, chronic inflammatory and multi-systemic disease with various clinical and laboratory manifestations, (1) whose incidence has been increasing in recent decades. It should be noted that about five million people in the world live with lupus, of which 90% are women of childbearing age.(2)

Despite advances in the process of diagnosis and treatment of the disease, which positively affect its prognosis, the morbidity and mortality of people with SLE is significantly higher when compared to that of the general population.(3) Diagnosis usually occurs late, because the initial symptoms and manifestations are heterogeneous and of varying evolution,(4) which can trigger severe and sometimes irreversible complications. (5)

Among the characteristics of the disease, we highlight the oscillation between the periods of exacerbation and remission,(6) in cutaneous, articular and immunological involvement, which is related to the quality of treatment adhesion. These disorders trigger a wide variety of symptoms, the most common being arthralgia, tiredness and fatigue, followed by skin lesions, hematological, pediatric, cardiovascular, neuropsychiatric and pulmonary symptoms, Sjögren's syndrome (excessive dry eyes and mouth), pain, edema in the upper and lower limbs, among other manifestations.(7.8) In addition to specific symptoms, the frequent presence of pain has been related to levels of fatigue, anxiety and depression,(8) that associated with other symptoms end up compromising daily life and health-related quality of life (HRQoL).(9)

In addition, due to SLE, patients can develop complications such as chronic kidney disease, vascular damage, atherosclerosis, among others,(10) marked by significant physical and psychological limitations, which also impact on the physical, psychic and social condition of individuals and consequently on their HRQoL.

Thus, the involvement of chronic diseases, such as SLE, is one of the main reasons for low HRQoL, since it permanently interferes in people's lifestyle.(11,12) It is emphasized that quality of life refers to the "perception that an individual has of his living condition",(13) and this is influenced by culture, value systems, life goals, experiences, expectations and concerns.

Despite all these aspects, studies in this area are still incipient, especially in Brazil, since culture interferes with QoL. From this perspective, understanding the aspects related to HRQoL in individuals with SLE can support the care planning of interdisciplinary teams, especially nurses, who take on the role of care mediators and represent the professional class that is directly connected to the patient, favoring the development of care that includes physical, psychological and social health. In this sense, this study aimed to identify an association between quality of life and clinical manifestations and symptoms of depression in individuals with SLE.

Methods

This is a cross-sectional study with individuals diagnosed with SLE, under follow-up at the rheumatology outpatient clinic of a University Hospital (HU) in southern Brazil. It is a teaching hospital, a reference in treatment of rheumatic diseases in the Unified Health System (SUS – *Sistema Único de Saúde*) for the 30 municipalities of the 15th Health Regional Of Paraná State. Outpatient care is performed daily (every morning) by two rheumatology residents (in individualized offices) and their preceptor. On average, 12 patients are treated daily with various rheumatic diseases, and in general, lupus patients return to the service every three months.

To define the sample size, we considered the total number of individuals under follow-up (190), with maximum variability of the sample of 50%, estimation error of 5% and confidence level of 95%, plus 10% for possible losses or exclusions, resulting in a minimum sample of 140 individuals. The previously defined inclusion criteria were: being 18 years of age or older and being diagnosed with lupus under follow-up at the rheumatology outpatient clinic for at least six months. Individuals with lupus affected by other diseases that hindered communication between researcher and interviewee (01 case) were excluded. Of the 149 individuals that were approached, four refused to participate, one was excluded due to stroke and three had other rheumatic problems, thus the study sample consisted of 141 individuals.

The participants were approached individually and invited to participate in the study until the previously established minimum number was reached, which occurred from February to July 2019, on the days and times that the individuals attended the outpatient clinic for medical consultation. The approach and interviews were conducted by two nurses, master's students of a Graduate Program in Nursing, and occurred while the patients were waiting for care. This was possible because the patients remained in the outpatient clinic practically all morning due to the dynamics of care, which involves three stages: 1) individual consultation of all scheduled patients with residents; 2) discussion circle among the medical team about cases and conducts to be taken; 3) consultation wrap-up - patients are called individually in the office to pass on guidance, prescriptions and scheduling of the next return.

Data were collected through structured interviews, while individuals were waiting to return to the office. They lasted an average of 20 minutes and were performed in the outpatient clinic by two duly trained researchers (nurses – students of a master's course). Three instruments were applied in data collection: a form developed by the authors addressing sociodemographic and clinical characteristics of participants, the WHOQOL-bref (14) and the Depression Cognition Scale (DCS).(15)

The investigated sociodemographic characteristics were: age, sex, education, marital status, race/color, occupation, family income, religion, labor situation and presence of deleterious habits such as smoking and alcohol consumption. The clinical characteristics were: type of lupus, time of diagnosis, general manifestations, dermatological and articular manifestations, presence of comorbidities, family history, use of continuous medications and perception of health.

The questions about manifestations of the disease and comorbidities were elaborated from a literature review and presented in a list of the most common items for the participant to indicate those he/she experienced, as well as a space to write down any unmentioned manifestation. It is emphasized that no definition was presented for the main clinical manifestations of the disease and that the participants did not show doubts about their identification. For example, in skin rashes they clearly said 'no, it was only in the beginning'. Furthermore, all obtained information was self-reported, as there was no consultation of medical records.

The WHOQOL-bref is composed of 26 questions, the first two referring to self-perceive QoL and satisfaction with health, and the others distributed in four domains: "physical", "psychological", "social relations", and "environment".(14) WHOQOL-bref questions present a five-point Likert response scale, including intensity, capacity, frequency, and evaluation. (14)

Each domain consists of a different number of questions. For analysis, we observed the total number of points obtained in each of the four domains and in the instrument as a whole. The cutoff point for positive evaluation of each domain was to reach 60% of the possible points in each of them: physical health (maximum score: 35, cutoff point 21), psychological health (maximum score: 30, cutoff point: 18), social relations (maximum score: 15, cutoff point: 9), environment (maximum score: 40, cutoff point: 24). Therefore, individuals with scores below the cutoff point have an unsatisfactory perception of the domain, and above this value, it is considered satisfactory.

DCS assesses cognitive symptoms of depression. The conceptual basis of DCS is Beck's Cognitive Theory of Depression and Erikson's Theory of Psychosocial Development. DCS evaluates feelings of uselessness, helplessness, loneliness, worthlessness, impotence, lack of purpose and hopelessness. (15) It consists of eight items with a six-point Likert-scale response (between 0 and 5 - I totally agree, in general I agree, I agree a little, I disagree a little, I generally disagree, and I totally disagree). The final score ranges from 0 to 40 points, thus a score lower than 20 means negative DCS and equal to or above 20 DCS, positive. Therefore, the higher the score, the greater the cognition of depression.

Data were organized in Microsoft Excel® software and later analyzed in SAS (Statistical Analysis Software), version 9.4. For the measurement of risk estimation, Odds Ratio (OR) was used. Binary logistic regression models were adjusted for each of the covariates and events of interest. Statistical significance was set at $p < 0.05$. Positive and negative predictive values were calculated for the diagnostic variables that presented statistical significance.

The study development met the ethical precepts disciplined by resolution 466/2012 of the Brazilian National Health Council (CNS – *Conselho Nacional de Saúde*) and its project was approved by the Permanent Research Ethics Committee Involving Human Beings of *Universidade Estadual de Maringá*, CAAE (*Certificado de Apresentação para Apreciação Ética* - Certificate of Presentation for Ethical Consideration) 00498518.8.0000.0104. All participants signed the Informed Consent Form.

Results

Of the 141 individuals with lupus in the study, 135 (95.7%) were female, 30 (21.4%) were less than 30 years old, 29 (20.7%) were between 30 and 39 years old, and 81 (57.9%) were 40 years old or older. It was observed that more than half of participants (51.1%) was white and 62 (44.0%) had between 9 and 11 years of education. Regarding occupation, 55 (39.3%) had an employment relationship, 19 (13.5%) had a family income of up to one minimum wage, and 80 (56.7%) were married. Regarding life habits, 13 (9.2%) were smokers and 17 (12.1%) alcoholics.

Regarding clinical characteristics, there was a predominance of participants with SLE - 125 (88.7%), of which 10 (7.1%) had discoid lesions and the other six (4.2%) had discoid lupus. Regarding the time of living with the disease, 89 (63.1%) were diagnosed more than five years ago, 32 (22.7%) had a family history, 136 (96.5%) used continuous medications, 86 (61.0%) have been affected by opportunistic infections, and 78 (55.7%) were overweight or obese.

The most frequently reported chronic diseases were: anxiety (53.2%), hypertension (HP) (40.4%), depression (34.0%), Diabetes Mellitus (DM) (12.1%), fibromyalgia (FM) (12.1%), hypothyroidism (9.9%), visual loss (6.4%), anemia (4.3%), antiphospholipid antibody syndrome (APS) (1.4%), and autoimmune hepatitis (0.7%).

The mean score of perceived QoL was 3.48, considered regular. In relation to health satisfaction, the score was 2.72, considered low. Regarding the "physical health" domain, it is observed in (Table 1), that the chances of an unsatisfactory perception are higher when in the presence of lupus manifestations.

Similarly, the presence of arthritis, FM, skin manifestations, numbness or tingling of limbs and neuropsychological changes increase the chances of an unsatisfactory perception of "psychological health" (Table 2).

In the "social relations" domain, it was found that individuals with scars, skin depigmentation and fatigue are more likely to have an unsatisfactory perception of "social relationships". Moreover, it is observed that the absence of muscle strength is the main risk factor for an unsatisfactory perception in relation to the "environment" domain (OR=4.541, p value=0.0182) (Table 3).

Finally, Table 4 shows that individuals with depressive symptoms are more likely to present an unsatisfactory perception in relation to the WHOQOL-bref four domains.

Table 1. Comorbidities and clinical manifestations associated with perceived physical health, the WHOQOL-bref domain, in individuals with systemic lupus erythematosus

Comorbidities and clinical manifestations	Perceived physical health		OR*	†95%CI	‡p value
	Satisfactory n(%)	Unsatisfactory n(%)			
HP					
No	38(69.1)	46(53.5)	1	-	0.0006
Yes	17(30.9)	40(46.50)	3.643	[1.736 - 7.644]	
Fatigue					
No	27(49.1)	18(20.9)	1	-	0.0261
Yes	28(50.9)	68(79.1)	3.34	[1.638 - 6.796]	
Fibromyalgia					
No	53(96.4)	71(82.6)	1	-	0.0449
Yes	2(3.6)	15(17.4)	5.599	[1.227 - 25.539]	
Transient rashes on the skin					
No	37(67.3)	43(50.0)	1	-	0.0449
Yes	18(32.7)	43(50.0)	2.055	[1.016 - 4.157]	
Permanent rashes on the skin					
No	44(80.0)	45(52.3)	1	-	0.0012
Yes	11(20.0)	41(47.7)	3.644	[1.663 - 7.987]	
Alopecia					
No	17(30.9)	11(12.8)	1	-	0.0104
Yes	38(69.1)	75(87.2)	3.050	[1.300 - 7.157]	
Articular manifestations					
No	8(14.5)	2(2.3)	1	-	0.0153
Yes	47(85.5)	84(97.7)	7.149	[1.458 - 35.059]	
Loss of bone mass					
No	50(90.9)	62(72.1)	1	-	0.0102
Yes	5(9.1)	24(27.9)	3.870	[1.458 - 35.059]	
Numbness					
No	26(47.3)	22(25.6)	1	-	0.0088
Yes	29(52.7)	64(74.4)	2.608	[1.272 - 5.344]	
Lack of strength					
No	28(50.9)	11(12.8)	1	-	0.0088
Yes	27(49.1)	75(87.2)	7.070	[3.100 - 16.126]	
Swelling					
No	25(45.5)	18(20.9)	1	-	0.0025
Yes	30(54.5)	68(79.1)	3.148	[1.498 - 6.616]	

*OR=Odds Ratio; †95% CI = 95% confidence interval; ‡p value

Table 2. Clinical manifestations associated with perceived psychological health, the WHOQOL-bref domain, in individuals with systemic lupus erythematosus

Clinical manifestations	Perceived psychological health Satisfactory n(%)	 Unsatisfactory n(%)	OR*	†$_{95\%}$CI	‡p value
Arthritis					
No	94(94.0)	31(75.6)	1	-	0.0036
Yes	6(6.0)	10(24.4)	5.054	[1.699 - 15.040]	
Fibromyalgia					
No	92(92.0)	32(78.1)	1	-	0.0261
Yes	8(8.0)	9(21.9)	3.233	[1.150 – 9.095]	
Permanent eruptions					
No	69(69.0)	20(48.8)	1	-	0.0255
Yes	31(31.0)	21(51.2)	2.337	[1.110 - 4.921]	
Numbness					
No	40(40.0)	8(19.5)	1	-	0.0226
Yes	60(60.0)	33(80.5)	2.750	[1.152 - 6.563]	
Neurological manifestations					
No	19(19.0)	2(4.9)	1	-	0.0479
Yes	81(81.0)	39(91.1)	4.574	[1.014 – 20.628]	
Memory loss					
No	55(55.0)	13(31.7)	1	-	0.0134
Yes	45(45.0)	28(68.3)	2.632	[1.223 - 5.666]	
Stomachache					
No	51(51.0)	10(24.4)	1	-	0.0048
Yes	49(49.0)	31(75.6)	3.227	[1.430 - 7.278]	

*OR=Odds Ratio; †95% CI=95% confidence interval; ‡p value

Table 3. Clinical manifestations associated with perceived social relations and environment, WHOQOL-bref domains, in individuals with systemic lupus erythematosus

Clinical manifestations	Perceived social relations Satisfactory n(%)	 Unsatisfactory n(%)	OR*	†$_{95\%}$CI	‡p value
Scars					
No	81(76.4)	20(57.1)	1	-	0.0308
Yes	25(23.6)	15(42.9)	2.430	[1.086 - 5.439]	
Skin depigmentation					
No	82(77.4)	20(57.1)	1	-	0.0227
Yes	24(22.6)	15(42.9)	2.563	[1.141 – 5.757]	
Fatigue					
No	40(37.7)	5(14.3)	1	-	0.0136
Yes	66(62.3)	30(85.7)	3.636	[1.305 - 10.133]	
Complications related to the Circulatory System					
No	63(59.4)	14(40.0)	1	-	0.0477
Yes	43(40.6)	21(60.0)	2.198	[1.008 - 4.792]	

	Perceived environment Satisfactory n(%)	 Unsatisfactory n(%)	OR*	†$_{95\%}$CI	‡p value
Fibromyalgia					
No	100(90.9)	24(77.4)	1	-	0.0485
Yes	10(9.1)	7(22.6)	2.917	[1.007 - 8.450]	
Lack of strength					
No	36(32.7)	3(9.7)	1	-	0.0182
Yes	74(67.3)	28(90.3)	4.541	[1.294 - 15.936]	
Visual loss					
No	106(96.4)	26(83.9)	1	-	0.0210
Yes	4(3.6)	5(16.1)	5.096	[1.278 - 20.317]	

*OR=Odds Ratio; †95% CI=95% confidence interval; ‡p value=Probability of significance

Table 4. Relationship between presence of depressive symptoms and WHOQOL-bref domains in individuals with systemic lupus erythematosus

Perceived quality of life	Presence of depressive symptoms No n(%)	Presence of depressive symptoms Yes n(%)	OR*	†95%CI	‡p value
Physical health					
Satisfactory	52(45.6)	3(11.1)	1	[1.912 - 23.54]	0.0004
Unsatisfactory	62(54.4)	24(88.9)	6.71	-	
Psychological health					
Satisfactory	90(78.9)	10(37.0)	1	[2.588 - 15.705]	0.0001
Unsatisfactory	24(21.1)	17(63.0)	6.37	-	
Social relationships					
Satisfactory	98(85.9)	8(29.6)	1	[5.456 - 38.784]	0.0001
Unsatisfactory	16(14.1)	19(70.4)	14.54	-	
Environment					
Satisfactory	99(86.8)	11(40.7)	1	[3.748 – 24.578]	0.0001
Unsatisfactory	11(13.2)	16(59.3)	9.59	-	

*OR=Odds Ratio; †95% CI=95% confidence interval; ‡p value=Probability of significance

Discussion

The limitations of this study are related to the cross-sectional design, which does not allow the generalization of its findings and the fact that clinical information was obtained by self-report. In any case, its results are valid because they refer to the characteristics of more than 70% of people with SLE under follow-up in a reference health service for 30 municipalities.

The achieved results may contribute to the improvement of health care provided to individuals with SLE, emphasizing that nurses play a relevant role in this scenario, because they constitute an important link between patients and health services. In this sense, identifying the characteristics that can compromise the HRQoL of these individuals is important, because SLE is a disease with great physical, psychological and social impact and that requires constant health care with the purpose of meeting, in an integral and holistic way, the needs arising from the disease process.

Participants' sex and age characteristics support what is identified in the scientific literature,(13,16,17) which indicates that SLE affects approximately five million people worldwide, of whom 90% are women and of reproductive age.(2)

In this study, it is evidenced that individuals with SLE have an increased chance of having an unsatisfactory perception of their HRQoL when lupus symptoms are exacerbated. Even though survival rates of individuals with SLE have significantly increased in recent years,(18) this has not necessarily impacted HRQoL, (13,16,19,20) because it is influenced by manifestations of the disease resulting from the disease process. After all, SLE is an incurable disease of non-uniform evolution, and it is common for patients to experience periods of exacerbation and remission, (6-21) leading to impairment of daily life, recurrent hospital admissions and, consequently, a low HRQoL.

With regard to the physical domain, the involvement of other pathologies, such as SAH and FM, increases the chances of an unsatisfactory perception of physical health. This is because people with chronic diseases are more likely to limit daily life activities due to pain, discomfort, and physical limitations imposed by the disease, which reflects negatively on QoL, especially in the physical domain. (14)

A study conducted in Sorocaba - SP with women aged 40 to 44 years, divided into three groups (individuals with FM, SLE and FM+ SLE), identified that the presence of FM negatively affected the QoL of individuals with SLE. (22) This was also identified in an experience report on the action of physiotherapy in individuals with SLE, rheumatoid arthritis and FM (23) and in the present study, since it was identified that individuals with FM had higher chances of dissatisfaction in the physical, psychological and environmental health domains. It is also notable that the prevalence of FM was 12.06%, slightly lower than that found in the literature, which indicates a variation of 17% to 22%. (24,25)

In this study, the presence of fatigue increased the chance of unsatisfactory physical health three times, an aspect that is also identified in other studies. (21,26) This manifestation causes significant physical limitations, as identified in a study conducted in China with 119 people with SLE, which aimed to assess the effects of fatigue on QoL, which showed that individuals with fatigue had significantly lower QoL compared to individuals without fatigue.(21) In this sense, it is extremely important to intervene in fatigue, because its remission can contribute to the improvement of physical health and, consequently, to HRQoL.

In addition to the presence of opportunistic diseases and fatigue, skin manifestations such as transient and permanent rashes and alopecia can also negatively impact physical health and, consequently, daily life. Such manifestations increased three times the chance of an unsatisfactory perception of physical health, and articular manifestations increase this chance by up to seven times. These manifestations have an impact on everyday life, since they are linked to the perception of self-image and self-esteem, negatively impacting HRQoL. (6,27)

In relation to the psychological health domain, it was observed that, in addition to FM and articular manifestations, the presence of neurological manifestations increases by up to four times the chances of an unsatisfactory perception. Neuropsychological manifestations in SLE are common and responsible for many of the limitations imposed by the disease.(21,28)

Thus, depression is one of the main psychological complications of SLE and contributes substantially to suffering and low HRQoL.(29) This is because, although the relationship between depressive symptoms and immunological processes of SLE is not yet well known, a study pointed out a strong correlation between the pain manifested by patients with this disease and depression. (29) Moreover, meta-analysis involving 59 studies found a higher prevalence of depression and anxiety among patients with SLE (24% and 37%, respectively) than that found in the general population and in people with other rheumatic and connective tissue diseases. Furthermore, it was found that the development of depression and anxiety in these individuals may contribute to increased morbidity and mortality and low quality of life.(30)

Further in this direction, a study conducted in Denmark showed that individuals with systemic and discoid lupus had a twice-higher risk of developing depression when compared to the general population. It also found that the risk of depression was similar in individuals with SLE and discoid lupus, which allowed us to infer that cutaneous involvement has the same impact as the systemic disease on the mental health of individuals. (31)

Thus, the vast limitations caused by SLE result in a reduction in social, work and leisure activities, which is related to depression and anxiety, which have a considerable impact on quality of life.(16) The high prevalence of depression in patients with SLE, besides resulting from the psychosocial impact of this chronic disease, also results from biochemical and neurophysiological changes that result in the development of neuropsychiatric symptoms.(32) Brain lesions in areas of the limbic system of patients with lupus, despite their unclear etiology, suggest impaired brain performance in emotional and behavioral functions, which highlights the importance of disease control.(32)

The results showed that individuals with a positive score on the DCS scale presented higher chances of unsatisfactory perception in all HRQoL domains. It can be inferred that depression has a negative impact and influences on everyday life, since it compromises the work process and social relations, and it is necessary that care also contemplates this manifestation associated with illness by SLE, in order to reduce the damage generated by it and, consequently, to increase perception of HRQoL.

Regarding social relations, it was observed that, in addition to fatigue, the presence of lupus scars and depigmentation on the skin increases by up to twice the chances of an unsatisfactory perception of this domain. Moreover, complications of the circulatory system also negatively impact social relations. Thus, it is common for individuals with SLE to present social distancing, evidenced by isolation, communication deficit and depression,(18) which may be associated with several factors, including skin complications, causing low self-esteem and consequent social absence. (28,33)

Finally, it was found that FM, lack of muscle strength and visual loss have a negative impact on the environment domain. HRQoL can be influenced by the environment, as it encompasses social, cultural and ecological aspects, allowing its modification or transformation. (14) Thus, care for individuals with SLE should understand the context where they are inserted, as well as the variables that permeate and influence not only the process of illness, but also in the way individuals experience it. It must, therefore, have an interdisciplinary, educational character and to understand all aspects that permeate the process of illness.

Thus, knowing the HRQoL of individuals with SLE and the characteristics that influence it enables the development of more personalized care plans, favoring the control of symptoms and complications of the disease, which in turn increases the chances of a more satisfactory perception of HRQoL.

Conclusion

The clinical manifestations that characterize the activity of the disease, as well as the presence of complications, increase the chances of an unsatisfactory perceived quality of life and this, in turn, increases the chances of individuals presenting depressive symptoms.

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Collaborations

Souza RR and Marcon SS contributed to project design, data collection and analysis, writing, relevant content review, article formatting and approval of the version to be published. Seguraço, RSC and Silva ES contributed to data collection and analysis. Teston, EF, Reis P, Achilles, GJ and Giacon-Arruda BCG contributed to writing, content review and approval of the version to be published.

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