Depressive symptomatology and quality of life in patients with Systemic Lupus Erythematosus

Sintomatología depresiva y calidad de vida en pacientes con lupus eritematoso sistémico

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Resumen

Las enfermedades crónicas implican un cambio radical en la vida de quien las padece y la de su familia o cuidadores primarios. Los padecimientos crónicos requieren cuidados especiales porque alteran notoriamente el funcionamiento cotidiano y la percepción de vida. Objetivo. El presente estudio buscó identificar la relación entre la calidad de vida (CV) y la depresión de pacientes con *lupus eritematoso sistémico (LES).* Método. Participaron doscientos pacientes de una institución pública de salud en la ciudad de México, 172 (84.7%) eran mujeres, con edades de 16 a 68 años (media = 33.52, desviación estándar = 10.37). Los participantes tenían diagnóstico confirmado de LES

Abstract

Chronic diseases imply a radical change in the sufferer's life and that of his or her family or primary caregivers. Chronic conditions require special care because they markedly alter daily functioning and perception of life. Objective. *The present study sought to identify the relationship between quality of life (QOL) and depression in patients with systemic lupus erythematosus (SLE).* Method. *Two hundred patients from a high-specialty public health institution in México City participated; 172 (84.7%) were women aged 16 to 68 (mean = 33.52, standard deviation = 10.37). Participants had a confirmed diagnosis of SLE, assigned from 1 to 42 years back (mean = 7.71, standard devia-*

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asignado desde 1 a 42 años (media = 7.71, desviación estándar = 6.88). Los participantes respondieron los inventarios de depresión de Beck (BDI) y el Inventario de Calidad de vida y salud (InCaViSa). El estudio usó un diseño correlacional-descriptivo con análisis de regresión para explorar la relación. Resultados. Los resultados mostraron una correlación alta y significative entre síntomas depresivos, preocupaciones, aislamiento y percepción corporal deteriorada. Otros resultados reflejaron asociación con deterioro cognitivo, actitud al tratamiento, uso escaso del tiempo libre, redes sociales pequeñas y deterioro general de la vida cotidiana. Los resultados no documentaron asociación entre síntomas depresivos y relación con el médico o dependencia médica. Discusión. En general los principales hallazgos muestran correlación clínica y estadísticamente sinificativa entre síntomas depresivos y calidad de vida. Es muy probable que una calidad de vida deteriorada agregue riesgo al paciente en su vida cotidiana y sus allegados inmediatos. El tratamiento médico y la atención psicológica pueden ayudar en gran medida a evaluar e intervenir a los pacientes, en el contexto de que, un diagnóstico crónico autoinmune modifica radicalmente componentes conductuales, cognitivos y emociones que requieren atención especializada.

Palabras clave
Calidad de vida, lupus eritematoso sistémico, deterioro, atención especializada

tion = 6.88). Participants responded to the Beck Depression Inventory (BDI) and the Inventory of Quality of Life and Health (InCaViSa). The study used a correlational-descriptive design with regression analysis to explore the relationships. Results**.** *The main findings showed a high and significant association between depressive symptoms, worries, isolation, and impaired body perception. Other results reflected associations with cognitive impairment, attitude to treatment, poor use of leisure time, small social networks, and general impairment in daily life. The results did not document an association between depressive symptoms in patient-doctor relations or medical dependence.* Discussion**.** *Overall, the main findings show a clinically and statistically significant correlation between depressive symptoms and quality of life in LES patients. A deteriorated quality of life likely adds risk to the patient's daily life and immediate family and friends. Medical treatment and psychological care can significantly help to assess and intervene in patients in the context that a chronic autoimmune diagnosis radically modifies behavioral, cognitive, and emotional functioning that requires specialized attention.*

Keywords
Quality of life, Systemic Lupus Erythematosus, deterioration, specialized attention

Introduction

Chronic diseases imply a radical change in the sufferer's life; any person with health difficulties requires punctual care of their condition. Careful administration of medications, and changes in their lifestyle, all of which usually drastically alter the quality of their usual way of living and perceiving their life (Grau, 2016).

Systemic Lupus Erythematosus (SLE) is a chronic degenerative, systemic disease of autoimmune nature of relatively unknown origin (Klippel, 2010; Saavedra-Salinas, Carrillo-Vázquez, Jara-Quezada, & Miranda--Limón, 2005). The diagnosis involves clusters of signs, symptoms, and alterations in laboratory data (Castellano, Monsalve & Soriano, 2015; Cervera & Jiménez-Alonso, 2011; Martínez-Elizondo, 2003; Vilardell & Ordi, 2004). Typically, there is no cure for this type of condition, but an appropriate intervention or treatment facilitates the patient to learn to live with the disease and prolong their lifespan (Castellano *et al*., 2015; Sánchez- Sosa, 1998).

Although SLE varies in various populations, figures indicate approximately 300-400 patients per 100,000 inhabitants. Although its epidemiological incidence is relatively low, its interest as an object of the study lies mainly in the severity of the physical and psychological detriment it causes. Some ethnic groups tend to be more prone, for example, African--Americans. In general, 70% of diagnosed patients present the systemic form (Ariza, Isaza, Milena, Margarita, Vinaccia, & Alvarán, 2010). SLE usually affects predominantly women of childbearing age, with a female--to-male ratio of 9:1 (Martínez-Elizondo, 2003).

Several factors are involved in the development and progression of SLE, mainly environmental, hormonal, immunological, and genetic (Harris, Budd, Firestein, Genovese, Sergent, Ruddy & Slenge, 2006; Martínez-Elizondo, 2003). Care and treatments usually include non-steroidal anti-inflammatory drugs (NSAIDs), antimalarials, glucocorticoids, and immunosuppressants (Cervera & Jiménez-Alonso, 2011; Klippel, 2010).

Although the drugs used in Lupus' medical treatment often cause discomfort due to their adverse side effects, the prognosis of the disease is usually reasonably good or acceptable as long as it remains treated (Ramos, 2001).

The World Health Organization (WHO, 2005) has recommended strategies to enhance the effectiveness of treatments and promote the well-being of patients with chronic conditions as part of their quality of life (QoL). QoL includes individuals' perception of their position in life in the context of their culture and "value" systems concerning their goals, expectations, standards, and interests (Harper & Power, 1998). In this context, the study of QoL is also relevant in its psychosocial and psychological aspects.

Depressive symptoms when the individual is sick are so common that they have been called the *common cold* among mental health problems (Nezu, Nezu & Lombardo, 2006; Nezu, Nezu & Perri, 1989). Indeed, people with depressive symptoms feel incapacitated, and symptoms may evolve into a profound depression, including suicidal ideation or attempts (Morrison, 2016).

As in other clinical contexts, depressive symptoms in SLE contain sadness, loss of interest or pleasure, guilt, lack of self-esteem, sleep or appetite disturbances, tiredness, and difficulty concentrating (WHO, 2017). In general, the incidence of depressive symptoms in medical pathologies is high and implies a bidirectional relationship impacting prognosis (Arias, Fosalía, Asteggiante & Bartesaghi, 2011). Additionally, SLE symptoms include persistent fatigue, chronic pain, and changes in physical appearance. These symptoms impact emotional, behavioral, and cognitive functioning, which could trigger major depressive disorder (Barile & Olguín, 2003).

A study (Vinaccia, Quiceno, Zapata & Abad, 2006) explored QoL and its relationship with depressive and anxiety symptoms in 32 SLE patients. The results did not document statistically significant impairment in QoL. A similar study (Batalla, García-Doval, Peón & De la Torre, 2013) explored QoL in SLE patients. Their results mainly pointed out the importance of measuring QoL due to the possible interference of symptoms with patients' usual activities.

A qualitative study with ten participants (Mazzoni, Corne, Van Leeuw, Myllys, & Cicognani, 2017) sought to describe the process of "engagement" from the perception and experiences of SLE patients. The authors suggest that these data will inform clinicians and support staff to implement specific supportive actions for patients. The study involved in-depth interviews and a thematic analysis of transcripts. The findings suggest that "fully engaged" patients emotionally, cognitively, and behaviorally reframe their condition throughout its course. The success of that process reportedly depended on how patients succeeded at each point in time. The authors propose a model for understanding the engagement process so that healthcare professionals can apply it to the unique situation of SLE patients.

One study (Agarwal-Neellam & Kumar-Vinod, 2016) explored daily functioning in ordinary life. The results suggest that SLE symptoms can profoundly impact one's employment, especially among young people. Indeed, SLE is a leading cause of work disability in the United States, with 20% of patients losing their jobs. Participants who retained their employment reported that the condition impaired their work, self-management, QoL, and self-efficacy. The authors suggest that the findings facilitate identifying adaptation needs and design strategies emphasizing early interventions in the evolution of SLE.

Several authors, such as Sánchez-Sosa, & González-Celis (2006), Taylor (2003), and Ribes (2011), among others, propose studying QoL specifically in chronic patients. Knowledge about their conditions facilitates the acquisition of new coping skills in patients and professional interventions. In this context, Riveros, Sánchez-Sosa, & Del Águila (2009) developed a Mexican inventory to measure QoL concerning health.

Symptoms of depression and anxiety significantly mediate the perception of severity in SLE. Such perception may facilitate a clinically and statistically significant relationship with negative illness perception, requiring multidisciplinary attention (Garcia & Rodero, 2009; Nowicka-Sauer, Hajduk, Kujaswska-Denecka, Banaszkiewicz, Smolenska, Czuszynska & Siebert, 2018).

Other than the studies described, the applied international research literature contains very few studies evaluating the clinical effects of interventions on psychological suffering by lupus patients. Instead, the most recent contributions involve the development of scales to measure specific features of the disease (Askanase *et al*., 2019; Mathias *et al*., 2017), findings on specific medical symptoms such as myelitis (Monahan *et al*., 2020) or acute parkinsonism (Wantaneeyawong *et al*., 2022).

SLE's biological and psychological conditions point to the need for inclusive treatments that promote patients' well-being. Treatments promoting acceptance, restructuring dysfunctional beliefs (or changing the relationship with them), and promoting flexibility are required because patients seek to act according to their expectations. Thus, it is necessary to detect depressive symptoms or other manifestations of suffering or dysfunction for a comprehensive patient approach (Arias *et al*., 2010). SLE is often one of these diseases (Rivas-Larrauri & Yamazaki-Nakashimada, 2016), given that patients expect to improve both biologically and psychologically (Molloy, Noone, Cadwell, Welton & Newell, 2018).

Method

Participants

Once received the proper authorization by the hospital's research and ethics committee (resolution R-2017-3501-113), the study recruited 200 patients of both sexes, aged between 16 and 68 years (M = 33.52, SD = 10.37), with a confirmed diagnosis of systemic lupus erythematosus under the criteria (ACR, 1982 revised in 2010). The evolution of the disease varied from 1 to 42 years (M = 7.71, SD=6.88). All participants were users of the Rheumatology service of a high-specialty public hospital, and their participation was entirely voluntary.

Table 1 shows, in frequency and percentage, the sociodemographic and clinical characteristics of the patients at admission to the study pro-

tocol. Most patients were women (86%), 40% were single, 33% married, and 0.5% were separated. Regarding schooling (complete or incomplete), 39% had high school/college studies, and 34% had professional university studies. A total of 33.5% were employed, and 1.5% had no job. A total of 63.5% were from the city's metropolitan area (State of México), followed by 27% from México City.

Regarding clinical and social support data, the main symptoms were joint pain (38%), followed by a combination of more than three symptoms (22.5%). They had at least one relapse, 59%, and other diseases, and 69% reported none. The other conditions were mainly hypertension (10%) and hypothyroidism (8.5%). They receive support from their family 71%, and 7.5% do not receive support from anyone.

Table 1. Sociodemographic and clinical data: frequencies and percentages.

Characteristics	N	%	Characteristics	N	%
Sex			Supporter to treatment		
Female	172	86	Family	142	71
Male	28	14	Romantic partner	32	16
Civil status			Nobody	15	7.5
Single	80	40	Offspring	7	3.5
Married	66	33	Friends	2	1
Living together	40	20	Siblings	2	1
Divorced	11	5.5	Symptoms		
Widow(er)	2	1	Articular pain	76	38
Separated	1	0.5	Skin disorders	19	9.5
Schooling			Extreme fatigue	18	9
Elementary	8	4	Pain in organs	16	8
High school	35	17.5	Anemia	15	7.5
College	78	39	Fever > 38 degrees C.	6	7.5

University Profession	68	34	Ulcers	5	2.5
Graduate	11	5.5	More than 3 symptoms	45	22.5
Occupation			Relapses		
Employee	67	33.5	YES	118	59
Housewife	58	29	NO	82	41
U. Professional	36	18	Other chronic conditions		
Student	29	14.5	None	138	69
Pensioneer	7	3.5	Hypertension	20	10
No activity	3	1.5	Hypotyroidism	17	8.5
Residency			Kidney disease	6	3
México State	129	63.5	Diabetes	6	3
México City	54	27	Fanconi's Anemia	6	3
Morelos State	13	6.5	Rheumatoid arthritis	4	2
Hidalgo State	3	1.5	Hepatitis	1	0.5
Guanajuato St.	1	.5	Lung Fibrosis	1	0.5
			Breast cancer	1	0.5

Measurement

Participants completed the Quality of Life and Health Inventory (InCaVi-Sa) by Riveros, Sánchez-Sosa, & Del Águila (2009). The scales were developed by articulating components of several quality-of-life instruments for chronic diseases, with items adapted for a second health-related validation. The inventory consists of 53 Likert-type multiple-choice items, with six response options and a referent of proportion by percentage: never (0%), never or almost never (20%), rarely (40%), frequently (60%), almost always (80%), always (100%). The inventory assesses twelve areas of the patient's life.

- Concerns,
- Physical performance,
- Isolation,
- Body perception,
- Cognitive functions,
- Attitude to treatment,
- Leisure,
- Daily life,
- Family,
- Social networks,
- Medical dependence, and
- Relationship with physician.

Four items were added: type or absence of another condition and two questions on recent stressors such as unpleasantness, death of someone close, separation, and similar life-affecting events. Concurrent validity was already established with the WHO-QoL Brief in its version adapted for México (Sánchez-Sosa & González-Celis 2006). The internal consistency of each area was established with Cronbach's α coefficient; all areas showed adequate internal consistency ranging from 0.68 to 0.93.

Participants also responded to the Depression Inventory (BDI) developed by Beck (1972) and adapted and validated for México (Jurado, Villegas, Rodríguez, Loperena & Varela, 1998). It consists of 21 items in groups of four statements that go from the highest to the lowest depression index. Once the scores are summed, a category is assigned. Zero to 9 points represent minimal depression, from 10 to 16 as mild depression, from 17 to 29 as moderate depression, and from 30 to 63 severe depression. The inventory's total internal consistency from a sample of 1 508 adults aged 15 to 65 is 0.87 (Cronbach's α). As in the original version, a factor analysis yielded three factors: Negative attitudes toward oneself, Impairment of performance, and Somatic complaints.

Procedure

Once the project obtained authorization from the relevant hospital authorities, the data collectors invited the patients to participate while in the waiting room of the rheumatology outpatient clinic. The investigation generally included initial data on aspects of their disease that interfere with their daily life and psychological well-being and their main habits, feelings, beliefs, and attitudes about their health.

After hearing and reading the objective and logistics of the study, patients who agreed to participate signed a letter of informed consent and answered the questionnaires. Initially, patients provided sociodemographic and personal data related to SLE, carefully preserving their anonymity. They then answered the Quality of Life questionnaire, plus four questions associated with their health and 15 on frequent symptoms. Finally, the participants answered the depression inventory (BDI), recording how they had felt the previous week. When they had finished answering the questionnaire, they were thanked for their participation and dismissed.

Data analysis

Descriptive statistics were used for sociodemographic data (means and proportions) for data analysis. The normal distribution test and Shapiro-Wilk homogeneity test were applied for the dependent variables, which met the criteria required for their use, so the Pearson product-moment correlation and simple regression analysis were used.

Results

Table 2 shows the results of the data analysis on Quality of Life and Depressive Symptomatology.

Table 2. Correlation between Quality of Life and Depressive Symptomatology (Pearson r).

Quality of Life	Depressive Symptoms
Concerns	0.611**
Physical performance	-0.536**
Isolation	0.758**
Body perception	0.688**
Cognitive functions	0.536**
Attitude to treatment	0.622**
Family	-0.524**
Leisure	0.730**
Daily life	0.737**
Medical dependency	0.091
Rlationship with physician	-0.033
Social networks	-0.607**

$p < 0.01$**

The data revealed a prevalence of depressive symptoms (Beck's BDI) as follows: 85 (42.5%) with minimal level, 101 (50.5%) moderate, and 14 (7%) severe.

The table shows the correlation of depression scores with Quality of Life scores (InCaViSa) by factor. There was a statistically significant relationship between depressive symptoms and the following variables: worries ($r = 0.611$, $p < 0.01$), physical performance ($r = -0.536$, $p < 0.01$), body perception ($r = 0.688$ $p < 0.01$), cognitive functions ($r = 0.536$, $p < 0.01$), attitude towards treatment ($r = 0.622$, $p < 0.01$), family ($r = -0.524$, $p < 0.01$), free time ($r = 0.730$, $p < 0.01$), daily life ($r = 0.737$, $p < 0.01$) and social networks ($r = -0.607$, $p < 0.01$). The highest correlation occurred with isolation with ($r = 758$, $p < 0.01$). Medical dependence correlated ($r = 0.120$) and relationship with the physician ($r = -0.006$), with practically no association.

Table 3 shows the linear regression results representing how much effect the independent variable has on the dependent variable. The model presented a coefficient of determination for depressive symptomatology and quality of life ($r^2 = 0.747$, $p < 0.001$). This result would represent a 73.8% prediction rate in patients with SLE. The relative weight of the main predictors of deterioration in the quality of life in the regression analysis were feelings of isolation and cognitive difficulties ($p < 0.001$). In decreasing order, the following predictors were feelings of not having or not being able to enjoy free time ($p = 0.037$), attitude towards treatment ($p = 0.041$), and perception of body or physical appearance ($p = 0.051$).

Table 3. Linear Regression Analysis: Depressive symptoms and Quality of Life

Predicting Variables	B	Error	b	p	Modelo 1
Depressive Symptoms					R = 0.859
					$R^2 = 0.738$
Quality of life					Adjusted R = 0.721
Concerns	-0.041	0.102	-0.023	0.687	
Physical performance	-0.143	0.083	-0.083	0.084	
Isolation	0.416	0.125	0.234	0.001	
Body perception	0.195	0.099	0.118	0.051	
Cognitive functions	0.249	0.072	0.154	0.001	
Attitude to treatment	0.218	0.106	0.108	0.041	
Family	-0.136	0.107	-0.061	0.203	
Leisure	0.217	0.103	0.151	0.037	
Daily Life	0.214	0.115	0.138	0.065	
Medical dependence	-0.010	0.063	-0.006	0.874	
Relationship with physician	0.127	0.080	0.063	0.118	
Social networks	-0.178	0.094	-0.097	0.060	

Discussion

The present study sought to determine the association between quality of life and depressive symptoms in patients with systemic lupus erythematosus (SLE). We also sought to provide evidence applicable to treating a highly complex condition. The current line of research would allow making decisions that facilitate the design, application, and evaluation of preventive or assistance interventions in the face of a chronic autoimmune, degenerative diagnosis.

The results point to a significant association between symptoms of depression, SLE symptoms, and Quality of Life, represented by various reactions and surrounding conditions of the patients. In addition to associations with 10 of the 12 areas of the InCaViSa in the first analysis, isolation, cognitive difficulties, diminished enjoyment of leisure time, attitude towards treatment that is likely to be perceived as producing slight improvement, and perception of an unsatisfactory physical appearance appeared to be particularly troublesome.

Future analyses could examine more specific associations such as time of disease progression, pharmacological treatment, and age at diagnosis debut, per se. As some studies have pointed out, relatively recently, knowledge of psychological problems in this disease was minimal (Zuñiga & Vásquez, 2014).

In contrast to some findings (Martínez-Elizondo, 2003) that report a 10:1 female-to-male ratio, the present study documented a 9:2 female-to--male ratio. It is possible that, in the 19 years since the original study, the proportion of men with the disease has increased. In general, the ages of the participants in the present study and the time since SLE diagnosis do not suggest a survival of less than 20 to 30 years, which is consistent with such parameters in other studies (Barile & Olguín, 2003; Harris, Budd, Firestein, Genovese, Sergent, Ruddy & Slenge, 2006).

Levels of depression in SLE patients are somewhat higher than those associated with other chronic morbidities: 42.5% minimal, 50.5% moderate or medium, and 7% severe. While these levels are consistent with

those of other studies (Aspinwall & Taylor, 1992; Batalla *et al*., 2013; Nicassio, 2008), they continue to represent the need for preventive and careful attention. Indeed, without intervention, they may put themselves at additional risk for their medical treatment and further deteriorate their perception of their environment and health (Mazzoni *et al*., 2017; Nowicka-Sauer *et al*., 2018). Additionally, when patients adhere to their treatment, it decreases their psychological distress and likely increases their life prognosis, quality of life, and the way they accept the disease (Hotz *et al*., Mazzoni *et al*., 2017).

Some studies suggest that there are still no effective psychological interventions for patients with depression or anxiety concurrent with a chronic degenerative disease (Arias *et al*., 2010). As suggested by the present results, before intervening with drugs, patients should be psycho-educated on coping with the stress stemming from their condition and life situation. An educational intervention to cope with relapses or risk events would reduce stress, improve well-being and facilitate medical interventions (Silva-Ruz *et al*., 2022). A multidisciplinary health team is often the best option to improve the patient's health and psychosocial adaptation (Cantera, Cervantes & Blanch, 2008; Thurah, 2017).

Depressive symptomatology can have an immediate and progressive influence on patients (Coín-Mejías, Peralta-Ramírez, Callejas-Rubio & Pérez-García, 2007). Stress, anxiety, and depressive symptoms modify behaviors in patients' lives. The vast majority of chronic diseases drastically affect patients' perception of health, even when they believe they are in good health and have a good quality of life. This finding may indicate that patients learn to cope with stress related to their condition.

QoL remains a complex area encompassing many aspects most likely determined by the patient's development, social and interpersonal life, family support, environmental factors, economics, and resilience, among others (Sánchez-Sosa, 2002; 2022). The present study found no notable differences attributable to schooling or occupation. It is noteworthy that a high percentage of participants point to good family support as a determinant of well-being, as other studies have suggested (Arias *et al*., 2010).

In the present study, most participants reported an average quality of life, followed by those who reported it as high. Habituation to symptoms or natural acceptance of the disease has probably improved their well-being and therapeutic adherence. Currently, studies in other countries point out that measuring these variables is a helpful signal to identify opportunities for intervention (Gobbo, 2009; Agarwal-Neellam & Kumar-Vinod, 2016).

The family is an essential part of the patient's environment and should participate, as proposed by Mazzoni *et al*. (2017). These authors indicate that intervention can be beneficial, including support groups, the family, and appropriate and specific interventions. Supplementary, health personnel can provide greater well-being to the patient, and as Agarwal-Neellam and Kumar-Vinod (2016) also indicate, the absence of reasonable care can generate costs and affect the functioning of patients.

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