

Exploring the quality of life and comorbidity impact among patients with systemic lupus erythematosus in Saudi Arabia

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ABSTRACT

الأهداف: استكشاف جودة الحياة (QoL) للمرضى الذين يعانون من الذئبة الحمراء (SLE) والعوامل التي تؤثر عليها.

المنهجية: شملت هذه الدراسة المقطعية 269 مريضاً تم تشخيصهم بالذئبة الحمراء من مناطق مختلفة من المملكة العربية السعودية. استخدمنا أداة تقييم جودة الحياة LupusPRO1.8. بالإضافة إلى ذلك، تم جمع بيانات شاملة حول الخصائص الديموغرافية للمرضى، وميزات المرض، والأمراض المصاحبة لتحليلها.

النتائج: بلغ متوسط جودة الحياة الإجمالية 57.71 ± 11.97 ، حيث كان الوسيط (النطاق الربيعي) 56.82 (48.62-66.65). بالنسبة لجودة الحياة المتعلقة بالصحة (HRQoL)، كان المتوسط 57.09 ± 18.81 ، والوسيط (النطاق الربيعي) 55.63 (44.04-70.19). أظهرت النتائج أن مجالات الصحة العاطفية كانت الأكثر انخفاضاً، حيث بلغ متوسطها 44.67 ± 30.00 (النطاق الربيعي) 41.7 (16.7-66.7). يليها مجالي الإرهاق والألم، حيث بلغ متوسط الإرهاق 46.24 ± 29.18 والوسيط (النطاق الربيعي) 43.8 (25-68.8)، بينما بلغ متوسط الألم 48.65 ± 30.38 والوسيط (النطاق الربيعي) 50 (25-71.9). بالنسبة لجودة الحياة غير المتعلقة بالصحة (NHRQoL)، كان المتوسط 58.32 ± 15.52 ، والوسيط (النطاق الربيعي) 58.85 (48.18-70.83). سجل مجال الأهداف والرغبات أقل النتائج في هذه الفئة، حيث بلغ متوسطه 45.79 ± 31.41 والوسيط (النطاق الربيعي) 43.8 (21.9-68.8). أظهرت الدراسة أن وجود الأمراض المصاحبة كان العامل الوحيد الذي أثر بشكل كبير على جودة الحياة للمرضى الذين يعانون من الذئبة الحمامية الجهازية.

الخلاصة: تشير نتائجنا إلى أن المرضى الذين يعانون من الذئبة الحمراء لديهم جودة حياة أقل بشكل عام، وتشمل كل من مجالات الصحة وغير الصحة. كما أن وجود الأمراض المصاحبة يؤثر بشكل كبير على جودة حياة المرضى الذين يعانون من الذئبة.

Objectives: To explore the quality of life (QoL) of patients with systemic lupus erythematosus (SLE) and the factors affecting it.

Methods: In this cross-sectional study, 269 patients diagnosed with SLE from multiple centers across different regions of Saudi Arabia were included. We used the LupusPRO1.8 QoL assessment tool. Additionally, comprehensive data regarding patient demographics, disease features, and associated comorbidities were collected for analysis.

Results: The overall mean QoL score was 57.71 ± 11.97 , with the median value (interquartile range [IQR]) of 56.82 (48.62-66.65). The mean health-related QoL (HRQoL) score was 57.09 ± 18.81 , with the median (IQR) of 55.63 (44.04-70.19). Among HRQoL domains, the emotional health domain had the lowest score (44.67 ± 30.00 , median: 41.7 [16.7-66.7]). The second and third lowest scores were for fatigue (46.24 ± 29.18 , median: 43.8 [25-68.8]) and pain (48.65 ± 30.38 , median: 50 [25-71.9]). Regarding non-HRQoL, the mean score was 58.32 ± 15.52 and median (IQR) score was 58.85 (48.18-70.83). The desires-goals domain had the lowest score (45.79 ± 31.41), with the median value of 43.8 (21.9-68.8). The presence of comorbidities was the only factor affecting the QoL of patients with SLE.

Conclusion: Our findings indicate that patients with SLE have worse overall QoL, which includes both HRQoL and non-HRQoL domains. Furthermore, the presence of comorbidities was the only factor that influenced the QoL of lupus patients.

Keywords: comorbidities, domains, lupus, quality of life

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Systemic lupus erythematosus (SLE) is a systemic autoimmune disease that significantly affects many organ systems and increases both morbidity and mortality. The prevalence of SLE varies by region and population, with higher rates observed in specific ethnic groups, such as individuals of African descent, Latin Americans, and Asians, in comparison to Caucasians.¹ Globally, it is estimated that SLE affects between 20-150 people per 100,000.² The prevalence of SLE in Saudi Arabia is approximately 19 cases per 100,000 individuals.³

Despite notable recent advancements pertaining to the survival and prognosis of patients with SLE, the quality of life (QoL) of these patients remains compromised when compared to both healthy people and those with other chronic diseases.⁴ This discrepancy can be attributed to factors directly related to the disease itself and its associated factors, as well as to extrinsic factors such as the presence of comorbidities.^{5,6} Individuals with SLE frequently experience comorbidities such as hypertension, cardiovascular disease, diabetes, malignancies, and osteoporosis.⁷ The presence of these comorbidities in lupus patients has been linked with several negative outcomes, such as reduced QoL, lower work productivity, irreversible damage to organs, more frequent hospitalization and healthcare expenses, and higher mortality rates.⁸⁻¹⁰

Therefore, a comprehensive approach that addresses both medical and psychosocial aspects, including effective symptom management, psychosocial support, and coping and adaptation strategies is necessary to improve the QoL for individuals with SLE.¹¹ Furthermore, we should emphasize strategies to prevent or reduce the impact of comorbidities.⁶ It is important to note that traditional measures of lupus disease activity or damage might not fully capture the multifaceted nature of the challenges faced by individuals with SLE.¹²

The Outcome Measures in Rheumatology group advocates the incorporation of health-related QoL (HRQoL) measures into core data sets for both observational studies and clinical trials.^{13,14} Likewise, the European Alliance of Associations for Rheumatology advocates regular assessment of HRQoL at every patient visit.¹⁵ This emphasis stems from the recognition that HRQoL represents the true burden of lupus in individual patients. Thus, using QoL measures is essential for accurately assessing a patient's overall QoL in the context of SLE and other rheumatic diseases.

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LupusPRO version 1.7 (v1.7) is a patient-reported outcome tool that was developed for individuals with SLE. It is recognized as a valid and reliable disease-specific instrument, relevant to lupus patients of all gender and ethnicities.^{16,17} Moreover, it effectively captures fluctuations in health status reported by patients and aligns with assessments of disease activity carried out by physicians. In LupusPRO v1.8, the pain-vitality HRQoL domain has been updated to better track the impacts of lupus or its therapeutic interventions on sleep, pain, and vitality independently, thereby catering to both patient care and clinical trial contexts.¹⁸

This study aimed to use LupusPRO v1.8 to explore the QoL of patients with lupus and identify predictors linked with lower QoL among this population, including the presence of comorbidities. The results of this study can help improve QoL for patients with SLE by identifying factors associated with the disease. Understanding these factors can lead to better disease outcomes and increased life expectancy through targeted interventions.

Methods. This observational cross-sectional study, carried out between January and May 2023, included patients with SLE from multiple centers across different regions in Saudi Arabia. Participants were patients over the age of 18 who were diagnosed with SLE by their rheumatologist according to the 1997 American College of Rheumatology diagnostic criteria.¹⁹ The study excluded patients who were under 18 or over 80 years old. Additionally, pregnant patients, those with a follow-up duration of less than one year, and individuals with severe psychiatric illnesses were also excluded. Physicians distributed an online questionnaire via email to all patients with lupus interested in participating.

All participants provided informed consent before they enrolled in the study. They were informed regarding confidentiality measures and the emphasis on anonymizing the collected data. The response rate was 60%. Approval for this study was granted by the local ethics committee at the College of Medicine, Taibah University, Al-Madinah Al-Munawarah, Saudi Arabia, with the approval number: IRB00010413.

We employed a random convenience sampling method to recruit participants for our study. The sample size of approximately 291 participants was determined using the Cochran formula, based on a prevalence of 19 cases per 100,000 population in Saudi Arabia, with a 95% confidence level (CI) and a margin of error of 5%.²⁰

The questionnaire was designed to gather data on the demographic characteristics of the participants

comorbidities not related to SLE (if present early in disease course), disease duration, medications, and SLE-related damage in the last 6 months. To measure QoL, the LupusPRO v.1.8 tool, which is a well-established and validated instrument, was used. This tool has been validated in Arabic for patients diagnosed with SLE.²¹

LupusPRO functions as a patient-reported outcome tool specifically designed to evaluate the influence of SLE on individuals' HRQoL and non-HRQoL.

Utilizing a 5-point likert scale, where respondents rated from 0 (none of the time) to 4 (all of the time), and "not applicable" responses were recorded as 0 for scoring, the LupusPRO comprises 2 constructs: HRQoL and non-HRQoL. It includes 43 questions in 12 domains, with 8 focusing on HRQoL and 4 on non-HRQoL. The HRQoL includes lupus symptoms, cognition, effects of lupus medications, procreation, physical health, sleep, fatigue, pain, emotional health, and body image. The non-HRQoL comprises effects on desires and goals, social support, coping, and satisfaction with treatment.

To calculate the mean score for each domain, the scores of items within that domain were added together and then divided by the total number of items in that specific domain. The raw domain scores were converted to a scale of 0 (indicating the lowest QoL) to 100 (representing the highest QoL) using the formula: $(\text{mean raw domain score}/4) \times 100$. This transformation was applied only if responses were provided for at least 50% of the items within each domain. The overall HRQoL and non-HRQoL scores were generated by calculating the average of the transformed domain scores for each construct.

Statistical analysis. The Statistical Package for the Social Sciences software, version 28.0 (IBM Corp., Armonk, NY, USA), was employed to carry out data entry and statistical analysis. Assessment of the normality of continuous variables was carried out using the Shapiro-Wilk test.

Frequency and percentage have been used to summarize categorical variables, while mean \pm standard deviation (SD) were utilized to present numerical variables with a normal distribution. The median and interquartile range (IQR) were employed to summarize variables displaying abnormal distribution.

Depending on the data distribution, either the Mann-Whitney-U test or the independent 2-sample t-test was used to compare continuous variables between 2 groups. For comparisons involving more than 2 groups, the Kruskal-Wallis test or one-way

analysis of variance (ANOVA) was employed based on the distribution. The relationship between 2 continuous variables was examined using either Spearman's or Pearson's correlation coefficient, chosen according to the distribution.

Multivariate regression analysis was employed to determine variables influencing QoL while adjusting for potential confounders. A *p*-value of <0.05 was considered significant.

Results. A total of 269 patients with lupus were included, with the majority being female (91%). The mean age of the participants was 34.01 ± 11.01 years. The disease duration was less than 5 years in 35%, between 5-10 years in 38%, and more than 10 years in 27% of the included patients. The most frequently reported SLE symptoms included joint pain (91%), hair falling (82%), skin rash (61%), oral/nasal ulcer (55%), and leucopenia (54%, **Table 1**).

The prevalence of non-SLE related comorbid conditions was 45%. Renal insufficiency was the most frequently reported, affecting 19% of patients, followed by rheumatic diseases other than SLE, which accounted for 13.4% of cases, as shown in **Figure 1**.

The overall mean QoL score was 57.71 ± 11.97 , with a median (IQR) value of 56.82 (48.62-66.65). The mean HRQoL score was 57.09 ± 18.81 , and the median (IQR) value was 55.63 (44.04-70.19). The highest score was observed for the procreation domain (mean: 74.35 ± 30.99 and median [IQR]: 87.5 [50-100]), followed by the body image domain (mean and median [IQR] scores: 66.26 ± 33.84 and 75 [37.5-100]). The lowest score was reported for the emotional health domain (mean: 44.67 ± 30.00 ; median: 41.7 [16.7-66.7]). The second and third lowest scores were for fatigue (46.24 ± 29.18 , median: 43.8 [25-68.8]) and pain (48.65 ± 30.38 , median: 50 [25-71.9]). The mean and median HRQoL score for other domains were as following: lupus symptoms 55.02 ± 27.16 , median 28.3 (33.3-75), lupus medications 58.78 ± 33.2 , median 62.5 (37.5-87.5), sleep 511.27 ± 28.29 , median 50 (33.3-66.7), physical health 61.43 ± 28.29 , median 60 (40-85), and cognition 64.27 ± 32.31 , median 62.5 (37.5-87.5).

Regarding non-HRQoL, the mean score was 58.32 ± 15.52 and median (IQR) score was 58.85 (48.18-70.83). The highest and lowest scores were obtained for the coping domain (mean: 75.37 ± 28.76 ; median: 83.3 [58.3-100]) and the desires-goals domain (mean: 45.79 ± 31.41 ; median: 43.8 [21.9-68.8]). The

Table 1 - Baseline demographics, clinical features, and disease characteristics in systemic lupus erythematosus patients.

Variables	n (%)
Gender	
Male	23 (9.0)
Female	246 (91.0)
Age in years, mean±SD	34.01±11.01
Marital status	
Single	116 (43.0)
Married	125 (47.0)
Divorced	25 (9.0)
Widowed	3 (1.0)
Educational level	
Illiterate	11 (4.0)
Below secondary school	33 (12.0)
Secondary school/diploma	112 (42.0)
University/postgraduate	113 (42.0)
Job status	
Unemployed	150 (56.0)
Student	47 (18.0)
Employee	61 (23.0)
Business	6 (2.0)
Retired	5 (2.0)
Average family income (SR/month)	
<5000	199 (74.0)
5000-10000	38 (14.0)
10001-15000	21 (8.0)
>15000	11 (4.0)
Smoking status	
Never smoke	246 (92.0)
Current smoker	17 (6.0)
Ex-smoker	6 (2.0)
Body mass index	
Underweight	29 (11.0)
Normal	90 (33.0)
Overweight	74 (28.0)
Obese	76 (29.0)
Duration in years (n=260)	
<5	91 (35.0)
5-10	99 (38.0)
>10	70 (27.0)
Age at diagnosis (years)	
≤18	72 (27.0)
19-29	104 (39.0)
30-39	58 (22.0)
≥40	31 (12.0)
SLE manifestations at time of diagnosis	
Hair falling	221 (82.0)
Oral/nasal ulcers	147 (55.0)
Joint pain	246 (91.0)
Skin rash	163 (61.0)
Renal trouble	92 (34.0)
Difficult breathing	137 (51.0)
Chest pain	137 (51.0)
Epilepsy	20 (7.0)
Memory/concentration weakness	118 (35.0)
Leukopenia	146 (54.0)
Thrombocytopenia	110 (41.0)
Albuminuria	110 (41.0)
Venous/arterial thrombosis	24 (9.0)
Number of medications	
≤3	96 (36.0)
4-6	109 (41.0)
>6	64 (24.0)

Values are presented as numbers and percentages (%).
SD: standard deviation, SR: Saudi Riyals, SLE: systemic lupus erythematosus

mean and median non-HRQoL for other domains were as following: social support 53.07±33.79, median 50 (25-87.5), satisfaction with care 59.04±34.25, median 62.5 (25-87.5). **Figure 2** summarizes the HRQoL and non-HRQoL domains mean score among lupus patients.

None of the studied personal or demographic characteristics of the patients showed a significant association with the overall QoL. No significant associations were found between any of the investigated characteristics of SLE and the QoL scores. Similarly, none of the SLE complications showed a significant correlation with the QoL score (**Table 2**). Also, the dosage of corticosteroids ($p=0.22$), as well as the use

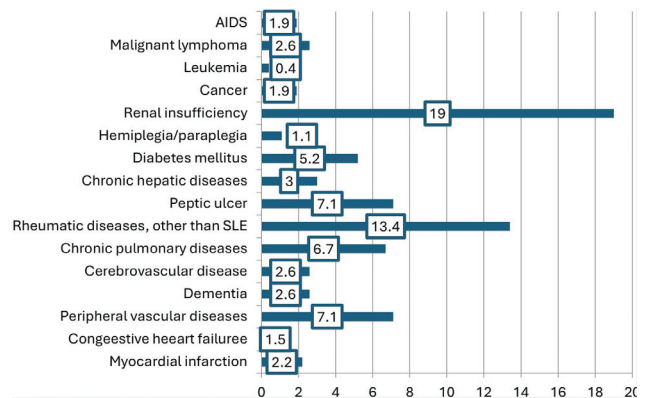


Figure 1 - The prevalence of non-systemic lupus erythematosus related chronic diseases among systemic lupus erythematosus patients. AIDS: acquired immunodeficiency syndrome, SLE: systemic lupus erythematosus

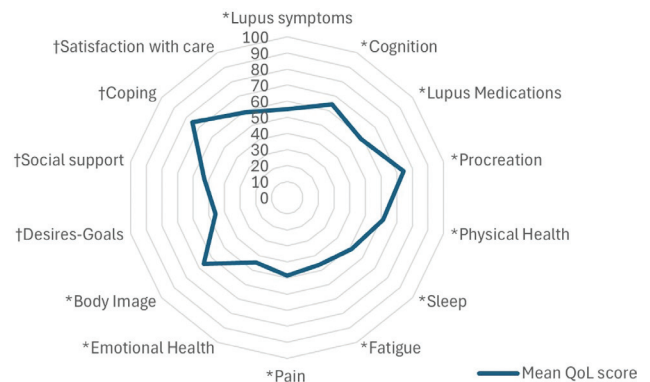


Figure 2 - Radar chart illustrating mean health-related quality of life (HRQoL) and non-HRQoL scores among systemic lupus erythematosus patients using LupusPRO v1.8. This radar chart displays the mean scores for each domain of the LupusPRO v1.8, scaled from 0-100, where higher scores indicate better quality of life. Each spoke of the chart represents a distinct domain of the LupusPRO v1.8. †Domains regarding HRQoL. *Domains related to non-HRQoL. QoL: quality of life

Table 2 - Comparison of the mean score of overall quality of life based on demographics, clinical characteristics of systemic lupus erythematosus patients and systemic lupus erythematosus related damage (results of univariate analysis).

Variables	Mean±SD	P-values
Gender		
Male	57.56±12.37	0.951*
Female	57.72±11.96	
Age in years	r= -0.053	0.384‡
Marital status		
Single	58.44±12.60	0.518**
Married	57.70±11.15	
Divorced	54.90±13.50	
Widowed	52.93±5.31	
Educational level		
Illiterate	58.69±10.42	0.850**
Below secondary school	56.41±13.74	
Secondary school/diploma	57.40±11.36	
University/postgraduate	58.29±12.27	
Job status		
Unemployed	57.93±11.70	0.975**
Student	57.68±13.57	
Employee	56.99±12.06	
Retired	60.22±6.06	
Average family income (SR/month)		
<5000	57.28±12.00	0.068**
5000-10000	62.08±11.70	
10001-15000	56.04±11.85	
>15000	53.48±10.06	
Smoking status		
Never smoke	58.19±11.87	0.084**
Current smoker	51.73±12.28	
Ex-smoker	54.98±12.43	
Body mass index		
Underweight	61.22±12.74	0.139**
Normal	56.99±12.21	
Overweight	59.06±11.37	
Obese	55.90±11.76	
Disease duration (years)		
<5	59.16±12.18	0.142**
5-10	55.90±11.77	
>10	58.53±11.94	
Number of medications		
≤3	56.68±11.53	0.561**
4-6	58.41±12.33	
>6	58.15±12.17	
Overall SLE damage in the last 6 months (no/yes)	58.35±11.76/56.30±12.37	0.192*
Ocular (no/yes)	57.69±12.25/57.79±10.59	0.959*
Neuropsychiatric (no/yes)	57.97±12.15/56.50±11.18	0.437*
Cardiovascular (no/yes)	57.74±11.96/57.03±12.65	0.835*
Pulmonary (no/yes)	62.08±10.64/57.34±12.03	0.081*
Renal (no/yes)	58.47±13.15/57.62±11.86	0.723*
Gastrointestinal (no/yes)	58.71±9.90/57.68±12.04	0.823*
Peripheral vascular diseases (no/yes)	57.70±12.21/57.74±10.71	0.985*
Skin (no/yes)	59.37±11.79/57.24±12.01	0.227*
Musculoskeletal (no/yes)	58.36±13.24/57.57±11.72	0.685*
Diabetes mellitus (no/yes)	57.77±12.02/56.70±11.57	0.730*
Malignancy (no/yes)	67.65±7.48/57.63±11.98	0.239*
Premature gonadal failure (no/yes)	59.19±12.92/57.40±11.78	0.357*

Values are presented as mean ± standard deviation (SD). *Independent 2 samples t-test.

**One-way analysis of variance test. ‡Pearson's coefficient of correlation. SR: Saudi Riyals, SLE: systemic lupus erythematosus

of cyclophosphamide (whether previously or currently, $p=0.45$), rituximab ($p=0.99$), or belimumab ($p=0.44$) during the course of the disease, did not show statistical significance.

However, the QoL score was notably higher among patients without comorbid chronic diseases than in those with comorbidities (59.94 ± 12.19 vs. 54.98 ± 11.15 , $p=0.001$).

When considering each chronic disease individually, patients with another rheumatic disease besides SLE had significantly lower HRQoL scores than those without such diseases (52.87 ± 10.13 vs. 58.45 ± 12.08 , $p=0.009$). Similarly, patients with peptic ulcers had lower QoL scores than those without peptic ulcers (52.33 ± 9.33 vs.

58.11 ± 12.07 , $p=0.042$), and patients with diabetes had significantly lower HRQoL scores than those without diabetes (50.68 ± 7.65 vs. 58.09 ± 12.06 , $p=0.024$; **Figure 3**).

Multiple linear regression analysis indicated that those with comorbidities had significantly lower QoL scores than those without comorbidities. This factor explained approximately 4% of the variability in the QoL score ($r\text{-square}=0.043$). However, presence of other rheumatic diseases in addition to SLE, peptic ulcers, and diabetes mellitus were not significantly associated with the QoL score in the multivariate regression analysis (**Table 3**).

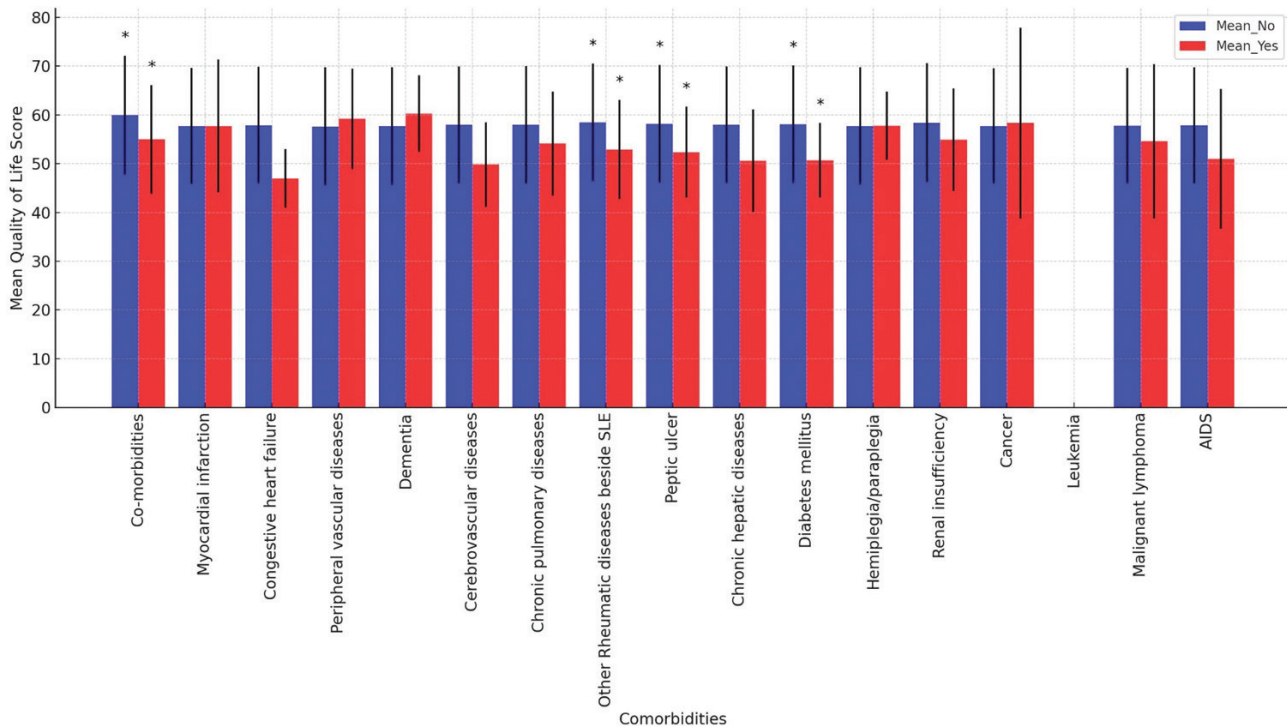


Figure 3 - Mean quality of life (QoL) scores in systemic lupus erythematosus (SLE) patients with and without comorbidities. This graph displays the average QoL scores for SLE patients, differentiated by the presence (red) or absence (blue) of comorbidities. Error bars represent the standard deviations. *Significant differences in QoL scores, are observed in overall comorbidities, other rheumatic diseases besides SLE, peptic ulcer, and diabetes mellitus, with p -values of less than 0.05. AIDS: acquired immunodeficiency syndrome

Table 3 - Best fitting multiple linear regression model for quality of life score among patients with systemic lupus erythematosus.

Variables	Unstandardized coefficients		Standardized coefficients	T-test	P-values	95% CI for B	
	B	Std. Error				Lower	Upper
Constant	59.938	0.965		62.129	<0.001	58.04	61.84
Co-morbidities not related to SLE (reference: no)	-4.963	1.438	-0.207	-3.450	0.001	-7.80	-2.13

R-square=0.043, adjusted R2=0.039. Model ANOVA: $F=11.905$, $p=0.001$. Variables entered and excluded: presence of other rheumatic diseases beside systemic lupus erythematosus, peptic ulcer, and diabetes mellitus. CI: confidence interval

Discussion. Our study revealed that patients with lupus experienced impairment in their QoL across all domains, as assessed using LupusPRO v1.8.

Previous studies have consistently demonstrated that lupus patients have a poorer QoL than the general population.²²⁻²⁴ The measuring tools utilized, the ethnicity of the patients, and the size of the study group do not affect the reduction in QoL.^{22,25,26} Neither physical nor mental health assessments show a decrease in QoL in SLE patients.²⁷ Furthermore, several studies have demonstrated an absence of any association between disease activity, damage index, and QoL in lupus patients.^{25,28} Additionally, the QoL in individuals with SLE is similar to that of people with other chronic illness including rheumatoid arthritis, Sjögren's syndrome, and acquired immune deficiency syndrome.²⁹

Emotional health was the most impaired domain, followed by the fatigue and pain domains. Individuals with lupus often encounter challenges in psychologically adapting to and managing their disease. A large cross-sectional study showed that the emotional health domain was the most significantly impacted aspect of life for both gender among individuals with lupus.³⁰ This finding emphasizes the significant psychological and emotional impact that lupus can impose on individuals, irrespective of their gender. Emotional health includes various factors such as mood, stress levels, coping mechanisms, and overall psychological well-being. Living with a chronic illness such as lupus can lead to increased levels of anxiety, emotional strain, and depression due to the uncertainty of the disease course, challenges in managing symptoms, and the potential impact on daily life activities.

Evidence from a systematic review and meta-analysis has shown that depression (30%) and anxiety (40%) are more prevalent among adult lupus patients, with changes in physical appearance being a common trigger.³¹ Additionally, data from prior studies have highlighted a negative relationship between self-esteem and SLE, suggesting that the influence of SLE on physical appearance and emotions can markedly decrease self-esteem.^{32,33} A systematic review and thematic synthesis of qualitative studies further illustrated the mental strain experienced by patients with SLE, including uncertainties regarding prognosis, feelings of being burdensome, a sense of hopelessness, fear of rejection, and experiencing social stigma.³⁴ These psychosocial issues can exacerbate SLE and contribute to a decline in the HRQoL. Addressing these psychosocial aspects of SLE care is crucial for improving patients' well-being and overall health outcomes.

Our research has shown that fatigue is an important domain that significantly affects patients' HRQoL, and more than half of patients with lupus reported it throughout their disease course.³⁵

In the existing studies, a well-established association between fatigue and a decrease in HRQoL is evident. For example, the EXPLORER trial demonstrated that FACIT-fatigue scores had a strong association with SF-36 domain scores ($r=0.52-0.68$), irrespective of disease activity.³⁶ Similarly, Bruce et al³⁵ discovered a noteworthy correlation between fatigue and SF-36 domains in individuals with lupus ($r= -0.5$ to $r= -0.82$). Moreover, in an analysis of pooled data from a phase Ib clinical trial involving lupus patients with moderate or severe disease, reductions in pain or fatigue reported by patients were associated with increases in the overall QoL.³⁷

Procreation was the least affected HRQoL domain among our patients with SLE. While lupus can influence numerous aspects of a patient's health and life, encompassing fertility and pregnancy, it is crucial to acknowledge that the impact on procreation varies among individuals. However, it is crucial to recognize that these effects can differ from patient to patient based on disease severity, specific manifestations, and individual factors. Procreation and parenting play significant importance for both gender. The findings of a previous study suggested that procreation was initially the least affected domain in patients with lupus. However, after controlling for age and matching patients under the age of 45 years, women were found to be more significantly affected in the procreation domain compared with men.³⁰ One potential explanation for procreation being identified as the least affected domain in our study is that a considerable proportion (53.5%) of the included patients were unmarried. This demographic characteristic suggests that many individuals within the study population may have been less inclined to actively contemplate fertility and pregnancy-related matters.

Among the non-HRQoL domains, the desires-goals domain was the most affected in our patients. Several studies have indicated that lupus can affect various aspects of patients' lives, including their ability to pursue personal goals and aspirations.^{38,39} It is important to recognize that the impact on the desires-goals domain varies among patients with lupus. Factors such as disease severity, symptom burden, social support, and socioeconomic status can influence how individuals perceive and adapt to the life changes associated with lupus.³⁹

In the current study, the presence of comorbidities was the only factor to be identified through the

multivariate regression analysis as being significantly linked with lower QoL in lupus patients. Earlier studies have underscored the negative repercussions of comorbidities in individuals with lupus. These findings align with the results of our study. Comorbidities in patients with lupus have been identified as being associated with a variety of poor outcomes, such as decreased HRQoL, lower work productivity, irreversible damage to vital organs, increased rates of hospitalization and healthcare expenditures, and increased mortality.^{9,40-43} Comorbidity is common in SLE, stemming from chronic inflammation, organ damage, anti-inflammatory medications, and psychosocial factors. The United Kingdom data show a significant burden of comorbidity in lupus patients in comparison to the general population.⁴⁴ Moreover, the increased risk of various comorbidities is present both before and after diagnosis.⁴⁵ Hence, comprehensive management strategies that address both lupus and associated comorbidities are essential for optimizing QoL outcomes and improving overall well-being in this patient population. These may include coordinated care, multidisciplinary interventions, psychosocial support, and strategies to improve self-management and coping skills.

Study strengths & limitations. Our study has several strengths, including a good sample size and being a pioneering research endeavor to explore QoL within the Saudi population. Another significant advantage is using a disease-specific QoL tool that integrates a non-HRQoL component. This feature facilitates comparisons that typically cannot be carried out using generic or other disease-specific tools, thereby enhancing the comprehensiveness of the findings. One limitation of our study is its reliance on a questionnaire-based survey that did not incorporate an assessment of disease activity. However, numerous previous studies have been unable to demonstrate a significant link between QoL and active disease.

In conclusion, our study found that patients with SLE experienced an overall decrease in QoL in many domains, including HRQoL and non-HRQoL. The presence of comorbidities was the only factor associated with decreased QoL. Therefore, to improve the QoL of lupus patients, it is critical to implement a comprehensive strategy that encompasses not just the medical components of the disease but also the mental, social, and economic issues. Comprehensive management strategies should involve clinical psychologists to address emotional well-being, lupus nurse specialists to provide ongoing clinical support and education, and social workers to help with social and socioeconomic

challenges. Personalized treatment plans that consider specific patient demands and lifestyle factors have the potential to greatly enhance overall health. Moreover, we should emphasize the significance of screening and addressing comorbidities in lupus patients to effectively improve their overall QoL.

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References

1. Hasan B, Fike A, Hasni S. Health disparities in systemic lupus erythematosus—a narrative review. *Clin Rheumatol* 2022; 41: 3299-3311.
2. Kumar R, Kumar A, Saroj U, Kumar M, Singh SK, Kumar A, et al. A cross-sectional study of clinical and laboratory characteristics of systemic lupus erythematosus in tribal region of Jharkhand at RIMS, Ranchi. *J Family Med Prim Care* 2022; 11: 7836-7841.
3. Almaghouth IA, Hassen LM, Alahmari HS, Bedaiwi A, Albarrak R, Daghestani M, et al. National systemic lupus erythematosus prospective cohort in Saudi Arabia: a study protocol. *Medicine (Baltimore)* 2021; 100: e26704.
4. Toloza SM, Sequeira W, Jolly M. Treatment of lupus: impact on quality of life. *Curr Rheumatol Rep* 2011; 13: 324-337.
5. Olesińska M, Saletra A. Quality of life in systemic lupus erythematosus and its measurement. *Rheumatologia* 2018; 56: 45-54.
6. Gergianaki I, Garantziotis P, Adamichou C, Saridakis I, Spyrou G, Sidropoulos P, et al. High comorbidity burden in patients with SLE: data from the community-based lupus registry of Crete. *J Clin Med* 2021; 10: 998.
7. González LA, Alarcón GS. The evolving concept of SLE comorbidities. *Expert Rev Clin Immunol* 2017; 13: 753-768.
8. Parker B, Urowitz MB, Gladman DD, Lunt M, Bae SC, Sanchez-Guerrero J, et al. Clinical associations of the metabolic syndrome in systemic lupus erythematosus: data from an international inception cohort. *Ann Rheum Dis* 2013; 72: 1308-1314.
9. Jönsen A, Clarke AE, Joseph L, Belisle B, Bernatsky S, Nived O, et al. Association of the Charlson comorbidity index with mortality in systemic lupus erythematosus. *Arthritis Care Res (Hoboken)* 2011; 63: 1233-1237.
10. Cao L, Tong H, Xu G, Liu P, Meng H, Wang J, et al. Systemic lupus erythematosus and malignancy risk: a meta-analysis. *PLoS One* 2015; 10: e0122964.
11. Córdoba-Sánchez V, Limonero-García JT. [Coping and quality of life in patients with systemic lupus erythematosus: a review]. *Pensando Psicol* 2015; 11: 129-139. [In Spanish].
12. Kiani AN, Petri M. Quality-of-life measurements versus disease activity in systemic lupus erythematosus. *Curr Rheumatol Rep* 2010; 12: 250-258.
13. Strand V, Gladman D, Isenberg D, Petri M, Smolen J, Tugwell P. Endpoints: consensus recommendations from OMERACT IV. Outcome measures in rheumatology. *Lupus* 2000; 9: 322-327.
14. Tugwell P, Chambers L, Torrance G, Reynolds D, Wolfson M, Bennett K, et al. The population health impact of arthritis. POHEM Workshop Group. *J Rheumatol* 1993; 20: 1048-1051.

15. Mosca M, Tani C, Aringer M, Bombardieri S, Boumpas D, Brey R, et al. European league against rheumatism recommendations for monitoring patients with systemic lupus erythematosus in clinical practice and in observational studies. *Ann Rheum Dis* 2010; 69: 1269-1274.
16. Jolly M, Pickard AS, Block JA, Kumar RB, Mikolaitis RA, Wilke CT, et al. Disease-specific patient reported outcome tools for systemic lupus erythematosus. *Semin Arthritis Rheum* 2012; 42: 56-65.
17. Giangreco D, Devilliers H, Annapureddy N, Block JA, Jolly M. THU0440 Lupuspro is responsive to changes in disease activity over time. *Ann Rheum Dis* 2014; 73: 335.
18. Azizoddin DR, Weinberg S, Gandhi N, Arora S, Block JA, Sequeira W, et al. Validation of the LupusPRO version 1.8: an update to a disease-specific patient-reported outcome tool for systemic lupus erythematosus. *Lupus* 2018; 27: 728-737.
19. Hochberg MC. Updating the American College of Rheumatology revised criteria for the classification of systemic lupus erythematosus. *Arthritis Rheum* 1997; 40: 1725.
20. Cochran WG. Sampling techniques, 3rd edition. [Updated 1991; 2023 Jan 7]. Available from: <https://www.wiley.com/en-us/Sampling+Techniques%2C+3rd+Edition-p-9780471162407>
21. Elkarakly NE, Nasef SI, Omar AS, Fouad AM, Jolly M, Mohamed AE. The Arabic LupusPRO: a cross-cultural validation of a disease-specific patient-reported outcome tool for quality of life in lupus patients. *Lupus* 2020; 29: 1727-1735.
22. Alarcón GS, McGwin G Jr, Uribe A, Friedman AW, Roseman JM, Fessler BJ, et al. Systemic lupus erythematosus in a multiethnic lupus cohort (LUMINA). XVII. Predictors of self-reported health-related quality of life early in the disease course. *Arthritis Rheum* 2004; 51: 465-474.
23. Lash AA. Quality of life in systemic lupus erythematosus. *Appl Nurs Res* 1998; 11: 130-137.
24. Thibault T, Rajjillah A, Bourredjem A, Corneloup M, Maurier F, Wahl D, et al. Health-related quality of life, remission and low lupus disease activity state in patients with systemic lupus erythematosus. *Rheumatology (Oxford)* 2024; 63: 1447-1455.
25. Hanly JG. Disease activity, cumulative damage and quality of life in systemic lupus erythematosus: results of a cross-sectional study. *Lupus* 1997; 6: 243-247.
26. Stoll T, Gordon C, Seifert B, Richardson K, Malik J, Bacon PA, et al. Consistency and validity of patient administered assessment of quality of life by the MOS SF-36; its association with disease activity and damage in patients with systemic lupus erythematosus. *J Rheumatol* 1997; 24: 1608-1614.
27. Rinaldi S, Doria A, Salaffi F, Ermani M, Iaccarino L, Ghirardello A, et al. Health-related quality of life in Italian patients with systemic lupus erythematosus. I. relationship between physical and mental dimension and impact of age. *Rheumatology (Oxford)* 2004; 43: 1574-1579.
28. Gladman DD, Urowitz MB, Ong A, Gough J, MacKinnon A. A comparison of 5 health status instruments in patients with systemic lupus erythematosus (SLE). *Lupus* 1996; 5: 190-195.
29. McElhone K, Abbott J, Teh LS. A review of health related quality of life in systemic lupus erythematosus. *Lupus* 2006; 15: 633-643.
30. Jolly M, Sequeira W, Block JA, Toloza S, Bertoli A, Blazevic I, et al. Gender differences in quality of life in patients with systemic lupus erythematosus. *Arthritis Care Res (Hoboken)* 2019; 71: 1647-1652.
31. Zhang L, Fu T, Yin R, Zhang Q, Shen B. Prevalence of depression and anxiety in systemic lupus erythematosus: a systematic review and meta-analysis. *BMC Psychiatry* 2017; 17: 70.
32. McElhone K, Abbott J, Gray J, Williams A, Teh LS. Patient perspective of systemic lupus erythematosus in relation to health-related quality of life concepts: a qualitative study. *Lupus* 2010; 19: 1640-1647.
33. Beckerman NL, Auerbach C, Blanco I. Psychosocial dimensions of SLE: implications for the health care team. *J Multidiscip Healthc* 2011; 4: 63-72.
34. Sutanto B, Singh-Grewal D, McNeil HP, O'Neill S, Craig JC, Jones J, et al. Experiences and perspectives of adults living with systemic lupus erythematosus: thematic synthesis of qualitative studies. *Arthritis Care Res (Hoboken)* 2013; 65: 1752-1765.
35. Bruce IN, Mak VC, Hallett DC, Gladman DD, Urowitz MB. Factors associated with fatigue in patients with systemic lupus erythematosus. *Ann Rheum Dis* 1999; 58: 379-381.
36. Lai JS, Beaumont JL, Ogale S, Brunetta P, Cella D. Validation of the functional assessment of chronic illness therapy-fatigue scale in patients with moderately to severely active systemic lupus erythematosus, participating in a clinical trial. *J Rheumatol* 2011; 38: 672-679.
37. Petri M, Kawata AK, Fernandes AW, Gajria K, Greth W, Hareendran A, et al. Impaired health status and the effect of pain and fatigue on functioning in clinical trial patients with systemic lupus erythematosus. *J Rheumatol* 2013; 40: 1865-1874.
38. Robinson D Jr, Aguilar D, Schoenwetter M, Dubois R, Russak S, Ramsey-Goldman R, et al. Impact of systemic lupus erythematosus on health, family, and work: the patient perspective. *Arthritis Care Res (Hoboken)* 2010; 62: 266-273.
39. Blomjous BS, Gajadin GRS, Voskuyl AE, Falzon L, Hoving JL, Bultink IEM, et al. Work participation in patients with systemic lupus erythematosus: a systematic review. *Rheumatology (Oxford)* 2022; 61: 2740-2754.
40. Rizk A, Gheita TA, Nassef S, Abdallah A. The impact of obesity in systemic lupus erythematosus on disease parameters, quality of life, functional capacity and the risk of atherosclerosis. *Int J Rheum Dis* 2012; 15: 261-267.
41. Baker K, Pope J, Fortin P, Silverman E, Peschken C. Work disability in systemic lupus erythematosus is prevalent and associated with socio-demographic and disease related factors. *Lupus* 2009; 18: 1281-1288.
42. Kim SK, Choe JY, Lee SS. Charlson comorbidity index is related to organ damage in systemic lupus erythematosus: data from KOREAN lupus Network (KORNET) Registry. *J Rheumatol* 2017; 44: 452-458.
43. Han GM, Han XF. Comorbid conditions are associated with emergency department visits, hospitalizations, and medical charges of patients with systemic lupus erythematosus. *J Clin Rheumatol* 2017; 23: 19-25.
44. Rees F, Doherty M, Grainge M, Lanyon P, Davenport G, Zhang W. Burden of comorbidity in systemic lupus erythematosus in the UK, 1999-2012. *Arthritis Care Res (Hoboken)* 2016; 68: 819-827.
45. Kuo CF, Chou IJ, Rees F, Grainge MJ, Lanyon P, Davenport G, et al. Temporal relationships between systemic lupus erythematosus and comorbidities. *Rheumatology (Oxford)* 2019; 58: 840-848.