

# Changes in Quality of Life Domains among Saudi Patients with Systemic Lupus Erythematosus before and during the COVID-19 Pandemic

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## Abstract

**Background:** Systemic lupus erythematosus (SLE) is the most prevalent form of lupus. In this autoimmune disease, the immune system attacks the body's tissues, causing systemic damage and inflammation. This research aimed to measure the quality of life (QoL) among adult SLE patients before and during COVID-19 in Saudi Arabia.

**Methods and Results:** A cross-sectional descriptive study was conducted in Riyadh City between November 2021 and March 2022. Data were collected from 192 patients (172 women and 20 men) with SLE via social media platforms (Twitter, Telegram, WhatsApp, and Instagram) using the Short Form-36 (SF-36) questionnaire. All eight QoL domains and overall health changes revealed significant differences before and during the COVID-19 pandemic. For all scales and the single health change item, there was a decline in QoL; moreover, most show a decrease in the range of 10 points on the 100-point scale. None of the correlations between age and QoL measures were high. For both men and women, general health was reported to be better before COVID-19 than during the pandemic, as expected. Due to a much larger number of women than men in the study, the significance of that decline in general health resulted in a higher significance level for women ( $t = 5.69, P < 0.001$ ) than for men ( $t = 2.07, P < 0.05$ ). However, the Hedges'  $g$  effect size estimate was higher for men ( $g = 0.47$ ) than for women ( $g = 0.30$ ).

**Conclusion:** The QoL of SLE patients was generally lower before and even more so during the COVID-19 pandemic. This change is not correlated with any sociodemographic factors. (International Journal of Biomedicine. 2024;14(4):673-678.)

**Keywords:** systemic lupus erythematosus • COVID-19 • SF-36 • quality of life • Saudi Arabia

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## Introduction

Systemic lupus erythematosus (SLE) is the most prevalent form of lupus. In this autoimmune disease, the immune system attacks the body's tissues, causing systemic damage and inflammation.<sup>1,2</sup> Systemic lupus erythematosus can affect people of all ages, but women of reproductive age are at the highest risk of developing the disease.<sup>1</sup> In addition, having another autoimmune disease increases the likelihood of developing SLE.<sup>2</sup>

As SLE is an unexpected disease, monitoring one's health and quality of life (QoL) becomes crucial. The WHO defines QoL as a person's assessment of their position in life, considering their cultural values, goals, expectations, standards, and concerns.<sup>4</sup> Essentially, it is how a person perceives life circumstances, considering aspects such as physical health, psychological state, social relationships, and the environment.

The QoL of healthy and diseased people within the general population is measured using generic questionnaires,

such as the Short Form 36 (SF-36), the most used in medical outcomes studies. The SF-36 is a 36-item self-reported questionnaire consisting of eight sub-scales comprising physical functioning, social functioning, role constraints due to physical difficulties, role restrictions attributable to emotional problems, mental health, energy/vitality, pain, and overall health. It does not account for disease characteristics but compares one's QoL across different disease domains.<sup>5</sup>

Some studies have indicated that SLE patients have a lower health-related overall QoL.<sup>6</sup> Compared with the other QoL domains, the physical one is the most affected among SLE patients.<sup>7</sup> Most SLE patients experience joint discomfort, restricting their everyday activities and increasing their clinic visits.<sup>7</sup> It has repercussions for both their employment and their ability to function socially and often leads to physical inactivity,<sup>8</sup> which increases the risk of cardiovascular disease, obesity, osteoporosis, and fatigue. Patients with SLE are more likely to experience skin damage and disease activity if they smoke tobacco.<sup>2</sup> SLE patients should be advised to have a diet high in polyunsaturated fatty acids, avoid a sedentary lifestyle, and engage in supervised activity.<sup>9</sup>

Regarding emotional issues, more than two-thirds of SLE patients suffer from emotional irregularities.<sup>10</sup> Research has indicated that such people experience sadness, depression, despair, worry, and rage.<sup>10</sup> Increasing social support and patient satisfaction with health services, as well as managing SLE disease activity and preventing organ damage, may enhance the health status of SLE patients.<sup>10,11</sup> Due to the signs of the disease, patients tend to have restricted social relationships at work, with friends, and with family.<sup>11</sup> Because most SLE patients experience fatigue, they worry about being a burden on their families.<sup>11</sup> This condition has the greatest impact on the quality of couples' relationships, with female patients being concerned about whether they may be able to fulfill their motherly and marital responsibilities effectively.<sup>6</sup>

There is a paucity of information about the course of inflammatory rheumatic illnesses, of which SLE is one, during the COVID-19 pandemic.<sup>12</sup> During this time, there was a decrease in hospital visits and a modest rise in patients who were not adhering to their treatment.<sup>12</sup> The severe negative effect on the continuity of rheumatology therapy, along with the scarcity of important medications, such as hydroxychloroquine, placed—and continues to place—patients at significant risk of symptom flare, thus affecting the disease outcome.<sup>13</sup>

The impact of the COVID-19 pandemic on the QoL of SLE patients might be much worse, given that it has negatively impacted QoL in terms of psychological, physical, social, and general health.<sup>14,15</sup> Compared with the pre-lockdown period, during lockdown the impact of forced confinement during the pandemic on the mental state of SLE patients revealed a significant difference across factors such as stress, sadness, anxiety, phobic anxiety, interpersonal sensitivity, and psychoticism.<sup>16</sup> Moreover, following hospitalization with COVID-19, patients with autoimmune disorders experienced increased rates of respiratory problems and 30-day death.<sup>17</sup>

Systemic lupus erythematosus influences multiple dimensions of an individual's life, including psychological,

physical, social, and general health, as well as financial and social conditions. The 2030 Saudi Vision Initiative pushes several private and public sectors to enhance the standard of living in Saudi Arabia.<sup>18</sup> However, no information is available on how COVID-19 have affected the well-being of Saudis with SLE.

This research aimed to measure the QoL among adult SLE patients before and during COVID-19 in Saudi Arabia.

## Materials and Methods

We assumed that Saudi patients with SLE would experience a decline in QoL throughout the pandemic across all domains. A cross-sectional descriptive study was conducted in Riyadh City between November 2021 and March 2022. Non-probability convenience sampling was used to recruit SLE patients. An online questionnaire was designed using Google Forms and distributed via social media platforms like Twitter, Telegram, WhatsApp, and Instagram. Participants were included if they were Saudi, had been diagnosed with SLE more than a year ago, and were older than 18 years. Patients with SLE and other chronic diseases were excluded to avoid confounding factors.

We calculated the sample size for this study using G\*Power software for Mac. The matched-paired test for difference between two independent means was employed. The effect size was 0.5, alpha error probability was set to 0.05, and the power was 0.8. The total sample size for two tails was 34.

The SF-36 questionnaire<sup>5</sup> yields two summary measures: physical and mental health. The physical health measure includes four domains: physical functioning, role-physical, bodily pain, and general health. The mental health measure comprises four domains: vitality (energy), social functioning, role-emotional, and mental health (emotional well-being).

Statistical analysis was performed using the statistical software package JMP, version 16. Baseline characteristics were summarized as frequencies and percentages for categorical variables and mean±SD for continuous variables. For data with normal distribution, inter-group comparisons were performed using Student's t-test. Pearson's correlation coefficient (r) was used to determine the strength of the relationship between the two continuous variables. A *P*-value of <0.05 was considered statistically significant.

## Results

Almost 50% of the study participants were aged between 18 and 30, and nearly 90% were female. Furthermore, more than 59% of the participants had university degrees (Table 1).

Cronbach's alphas for five of the eight scales were above the commonly accepted standard of 0.7 for both measures. The "during" scale was acceptable for pain, but the "before" scale was slightly low, at 0.57. Both "before" and "during" for general health and social functioning domains were slightly low; however, none of the scales showed alpha values less than 0.50 (Table 2).

**Table 1.**

**Sociodemographic characteristics of the study population (N=192).**

Variable		N (%)
Age	18–30	95 (49.48%)
	31–42	70 (36.46%)
	43–54	19 (9.90%)
	Over 54	8 (4.17%)
Gender	Female	172 (89.58%)
	Male	20 (10.42%)
Education level	School	53 (27.60%)
	Diploma	11 (5.73%)
	University degree	114 (59.38%)
	Postgraduate	14 (7.29%)

**Table 2.**

**Cronbach’s alphas for the eight scales before and during the COVID-19 pandemic.**

Scale	Before pandemic	During pandemic
General health	0.51	0.61
Physical functioning	0.90	0.90
Role physical	0.89	0.87
Role emotional	0.91	0.86
Vitality	0.74	0.72
Mental health	0.72	0.74
Social functioning	0.52	0.52
Bodily pain	0.57	0.75

All eight QoL domains and overall health changes revealed significant differences before and during the COVID-19 pandemic (Table 3). The increase in some of the scales indicated a decline in QoL. For example, the physical functioning scale measures deficits in physical functioning rather than positive functioning, indicating that the patient is experiencing more problems in physical functioning. Other domains, such as general health, measure positive health characteristics, and a decline suggests a decline in general health. For all scales and the single health change item, there was a decline in QoL; moreover, most show a decrease in the range of 10 points on the 100-point scale.

None of the correlations between age and QoL measures were high (Table 4). Only 2 of the 18 correlations were significant. During COVID-19, older SLE patients reported lower energy but also had greater scores in the emotional well-being domain.

**Table 3.**

**Paired t-tests of differences in scale results before and during the COVID-19 pandemic among SLE patients (N = 192).**

Scale	Before pandemic		During pandemic		t-value	P-value
	Mean	Variance	Mean	Variance		
General health	57.6	307.0	51.7	392.6	-5.77	<0.001
Physical functioning	57.6	817.5	63.0	718.6	3.94	<0.001
Role physical	47.5	1855.3	56.5	1796.9	3.36	<0.001
Role emotional	49.3	1901.2	59.4	1954.1	3.83	<0.001
Vitality	42.1	504.3	49.1	441.0	4.66	<0.001
Mental health	54.3	453.1	49.0	464.1	-3.44	<0.001
Social functioning	58.4	332.0	47.8	728.3	-4.49	<0.001
Bodily pain	54.6	897.4	61.3	850.3	3.32	<0.001
Health change (single item)	69.6	778.5	53.6	727.2	-7.30	<0.001

**Table 4.**

**Correlations between age and the eight scales and the item on health change (N=192).**

Scale	Before pandemic	During pandemic
General health	-0.05	-0.03
Physical functioning	0.03	0.02
Role physical	0.03	0.02
Role emotional	0.01	-0.02
Vitality	0.10	0.14*
Mental health	0.13	0.15*
Social functioning	-0.02	-0.01
Bodily pain	0.13	0.08
Health change (single item)	0.13	0.11

For both men and women, general health was reported to be better before COVID-19 than during the pandemic, as expected (Table 5). Due to a much larger number of women than men in the study, the significance of that decline in general health resulted in a higher significance level for women ( $t = 5.69, P < 0.001$ ) than for men ( $t = 2.07, P < 0.05$ ). However, the Hedges’ g effect size estimate was higher for men ( $g = 0.47$ ) than for women ( $g = 0.30$ ). A Hedges’ g of 0.3 is generally seen as a small effect size, while 0.5 is considered a medium effect size.

Table 5.

Results of paired *t*-tests both before and during the pandemic by gender.

Female	Mean	SD	N	t-value	Two-tailed P	Hedges' g
Before	57.41	17.18	172	5.69	<0.001	0.30
During	51.86	19.18	172			
Male	Mean	SD	N	t-value	Two-tailed P	Hedges' g
Before	59.50	20.64	20	2.07	<0.05	0.47
During	47.50	27.36	20			

## Discussion

The current study revealed that all eight QoL domains and overall health changed significantly before and during the COVID-19 pandemic. These results agree with those of a study conducted by Islam and Alharthy<sup>19</sup> in Saudi Arabia, which showed that the QoL of most Saudi households had been affected by the pandemic.

The changes in general health and decreased daily life activities—such as running, participation in strenuous sports, and lifting or carrying groceries—which, in turn, affect mental health, could be due to the situation caused by the lockdown. During the pandemic, the level of physical activity in terms of the time patients spent on work performance or other activities significantly decreased. This result is consistent with the study conducted by Planting et al.,<sup>20</sup> which reported that more than half of the participants became less physically active during the lockdown; this can be attributed to an increase in the use of electronic devices and watching television, which can lead to sedentary behavior.

Social and psychological health has also been significantly affected by COVID-19 due to the stressful situation worldwide, fear due to a lack of knowledge on how the disease gets transmitted, as well as unpredictable complications, especially for people who suffer from SLE. Another reason for decreased social and psychological activity is that SLE patients need to be extremely cautious of COVID-19, as they are vulnerable to being infected, according to the Lupus Foundation of America report.<sup>21</sup>

Regarding pain, this research found no significant difference between the amount of bodily pain before and during COVID-19, which could be attributed to the efforts and services of the Saudi Ministry of Health to help patients manage their health status through virtual appointments and medication delivery using Saudi post and phone consultations at any time.

As a result of the quarantine, feelings of calm, peace, and vitality levels decreased significantly. At the same time, tiredness increased, which could be due to the consequences of anxiety and depression during the pandemic. This has been shown in a study by Santos-Ruiz et al.<sup>16</sup> in Spain, which

reported a significant increase in emotional problems such as anxiety and depression between the pre- and post-lockdown periods.

The epidemiological evidence found that the prevalence of depression and/or anxiety in SLE patients ranged widely from 2% to 91.7% in different studies.<sup>22,23</sup> Patients with SLE show higher levels of perceived stress, as well as psychopathological symptoms, compared to the healthy population.<sup>24</sup> A study by Peralta-Ramírez et al.<sup>25</sup> showed that daily stress, but not stressful life events, is associated with the worsening of SLE. In addition, patients with SLE have a higher prevalence of anxiety and depression.<sup>26</sup> These findings may indicate an increased vulnerability of SLE patients to psychological disorders during a health emergency.

Sociodemographic factors such as age revealed weak correlations with QoL domains. During the COVID-19 pandemic, older patients reported lower vitality and greater scores in the emotional well-being domain. Likewise, in a study conducted in Turkey by Yilmaz-Oner et al.,<sup>27</sup> no correlation was found between age and health-related QoL among SLE patients, using the SF-36 questionnaire.

Regarding gender differences in general health before and during COVID-19, there was no significant change, although men seemed to have better health than women before COVID-19, while women reported better health during COVID-19. It may be worth seeking a more gender-balanced sample for follow-up research to determine if this effect was real or only partly factual. Moreover, the educational level also appears to not result in any significant difference in general health before or during COVID-19. Given the small numbers of all but university graduates in our sample, we combined school and diploma and university graduate and postgraduate students. This association of sociodemographic factors with QoL in the results is like those in the study conducted by Gaballah and El-Najjar<sup>28</sup> in Egypt, which illustrated that there is no association between sociodemographic characteristics and QoL in SLE patients.

## Conclusion

The QoL of SLE patients was generally lower before and even more so during the COVID-19 pandemic. This change is not correlated with any sociodemographic factors. Further research and follow-up studies employing different study designs regarding QoL in the Arab region are needed.

One limitation that must be noted is recall bias, as some participants could have recalled what happened during the pandemic very well, while others might not. Another limitation is the use of the non-probability sampling method when collecting the data; this may limit the generalizability of the results. Further, more demographic characteristics such as income, marital status, and working status might need to be analyzed.

## Ethical Considerations

The study protocol was reviewed and approved by the Ethics Committee at the Princess Nourah bint Abdulrahman

University (IRB Log Number 21-0447E). The data was only used for study purposes without individual details identifying the patient. Written informed consent was obtained from all the participants.

## Competing Interests

The authors declare that they have no competing interests.

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