Quality of Life among Patients with Systemic Lupus Erythematosus and its Association with Sociodemographic and Clinical Parameters in Karbala Governorate

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Abstract

Background: Systemic lupus erythematosus (SLE) is an autoimmune disease with a variety of clinical symptoms that primarily affect women of childbearing age causing a significant patient burden. The study aimed to assess health-related quality of life (HRQOL) among patients with SLE and to evaluate its association with different sociodemographic and clinical characteristics of SLE patients.
Method: Seventy-five patients with SLE who attended Imam Al-Hassan Al-Mujtaba Teaching Hospital, participated in a cross-sectional study. The Lupus quality of life (LupusQoL) questionnaire was used to assess disease-specific health-related quality of life, and the SLE disease activity index (SLEDAI) was recorded.
Results: The mean age of the studied patients was 38.12 years who were 97.3% female. All LupusQoL domains were reduced. Intimate relationship accounted for the highest QoL score (median-50), whereas fatigue represented the lowest score (median-25). LupusQoL was positively correlated to address, education, disease duration, occupation, and impact on the job especially in the physical health domain (r = 0.277, r = 0.342, r = 0.137, r = 0.240, r = 0.314 respectively). LupusQol was negatively correlated with age (r = -0.461), and with disease activity (r = -0.292), with p-values> 0.05. Renal and neuropsychiatric involvement of the disease did not statistically correlate with HRQOL.
Conclusion: Patients with SLE had low scores in all LupusQoL domains. There was a significant positive correlation between LupusQoL domains and address, education, disease duration, occupation, and impact on job, and a significant negative correlation with age, and disease activity.
Key words: SLE, health related quality of life, LupusQoL

Introduction

Systemic lupus erythematosus (SLE) is a chronic multisystemic autoimmune disorder with a variety of clinical symptoms that primarily affect young women of childbearing age [1]. The pathogenesis of SLE is highly complicated, involves both innate and adaptive immunity, and is primarily caused by two important families of mediators: autoanti-bodies that target nucleic acids and nucleic acid-binding proteins and type I interferon (IFN-I) [2]. The exact etiological cause of SLE is still unknown. Genetic predisposition, environmental variables, hormonal, and immunological factors all interplay in disease development and activity [3]. The strongest epidemiological evidence exists for increased risk of SLE associated with exposure to silica, cigarette smoking, use of contraceptives and postmenopausal hormonal therapy, UV light, certain infections, and heavy metals [4].

The incidence and prevalence of SLE have increased in all countries in recent decades, and this increase has been attributed to better diagnosis and the availability of data from international registries. Worldwide prevalence estimates range from 4 to 45 cases per 100,000 people in Asia-Pacific nations [5]. The 52 to 150/100000 cases in the United States affect females more often than males, with the incidence ratio varying between 8:1 and 15:1 and the greater incidence in African American populations, followed by Hispanic and Asian populations [6]. In Iraq, the prevalence of SLE is about 53.6 per 100,000 persons with a higher rate of 88.7 per 100,000 persons for women and the first case of SLE was reported in 1971, according to ALRAWI et al.,1983 [7], and AlBadri et al.,2008 [8]. SLE is

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associated with significant financial burdens in terms of the utilization of healthcare resources and productivity losses as a result of impairment of job capacity [9].

The most common clinical signs seen at the time of diagnosis are non-erosive arthritis, malar rash, and nephritis [10]. SLE is a heterogeneous disease, in addition to arthritis, can involve one or more organs including the nervous system, liver, kidneys, blood vessels, heart, and lungs, and take a chronic or relapsing and remitting disease course [11]. Patients with SLE face events related to the disease's activity, irreversible damage, and side effects from medications, all of which can have a detrimental influence on their HRQOL and ultimately lead to disability [12]. SLE Patients have major physical, psychological, and social challenges when their disease worsens. Many SLE patients have burdens associated with their medications, according to a study conducted on a sample of individuals with SLE in Iraq [13]. Numerous rheumatic disorders, including osteoarthritis (OA), rheumatoid arthritis (RA), and fibromyalgia syndrome have been associated with worse quality of life [14].

The World Health Organization (WHO) describes health-related quality of life (HRQoL) as a person's perception of their place in life in relation to their community and the value systems they live by, as well as their expectations, standards, goals, and concerns. It's a broad term that includes a wide range of factors such as an individual's physical and psychological well-being, level of independence, relationships with others, personal beliefs, and relationship to the key aspects of their environment [15]. By assessing a patient's quality of life, a physician can evaluate them holistically, considering not just their clinical condition but also their socioeconomic status, emotional and mental health, and overall well-being. Determining the quality of life is an essential part of diagnosing and treating chronic illnesses. It also maintains the appropriate physician-patient relationship and facilitates in the organization and planning of patient care.

The study aimed to evaluate the health-related quality of life among a sample of patients with SLE and assess the association between the health-related quality of life of SLE patients and different sociodemographic and clinical characteristics of SLE patients.

Materials and Methods

Patients
Patients with systemic lupus erythematosus who attended Rheumatology and Rehabilitation outpatient clinics in Imam Al-Hassan Al-Mujtaba Teaching Hospital participated in a cross-sectional observational study. The period of time for this study was from December 2022 to January 2024. Seventy-five patients who fulfilled the classification criteria of the American College of Rheumatology (ACR) [16], aged 18 years or older, with disease duration equal to or more than 6 months were enrolled in this study. Patients with SLE overlap with other rheumatic diseases such as rheumatoid arthritis or mixed connective tissue disease or with other existing comorbidities not related to SLE that may impact their quality of life were excluded from the study. The following formula was used to determine the study's sample size based on Dawson, 2004 [17].

$$n = (Z \alpha/2)2*P (1-P)/d2$$

n is the sample size, Z $\alpha/2$=Z is the statistic equivalent to the confidence level (1.96), the precision (which corresponds to the effect size) is d=0.1, P refers to anticipated prevalence (17%) according to Yousef et al., 2018 [18].

Study methods
The analysis of this study includes the final sample of 75 patients. After reviewing previous studies, a structured questionnaire was prepared for the study and evaluated by experts, in community medicine and rheumatology. Also, two external evaluators, specialists in internal medicine and community medicine, reviewed the questionnaire. The questionnaire consisted of the following data:

Sociodemographic data
Age, sex, residence, marital status, education, occupation, impact on job, and clinical characteristics such as disease duration, and erythrocyte sedimentation Rate (ESR) results. SLE disease activity index (SLEDAI) [19] was assessed, and a Lupus quality of life (Lupus QoL) questionnaire was used to assess health-related quality of life in adult SLE patients that was validated for use in the general population [20]. There is a validated linguistically translated Arabic version of LupusQoL that was used in the current study. Data was collected utilizing direct interviews conducted with patients, taking into account their privacy. Each interview took approximately 20-30 minutes. Four hours are needed for data collection every day. Clinical information was obtained from the patients through

history taking and physical examination. All of the patient's medical records were reviewed.

Ethical Approval

Ethical approval was taken from the Medical Research Bioethical Committee in the College of Medicine at the University of Kerbala (No. 8 on 4 Feb. 2023), and approval was taken from the Karbala Health Directorate. A facilitated letter was sent from the College of Medicine to Imam Al-Hassan Al- Mujtaba Hospital. Verbal consent was provided by the participants.

Statistical Analysis

The Statistical Package for the Social Sciences (SPSS 23.0) was used to enter and evaluate the data from the current study. Descriptive statistics are presented as frequency, percentage median, and IQR in appropriate tables and graphs. A possible association between normally distributed continuous variables was obtained through Pearson's correlation, otherwise, Spearman's correlation had been used. The significance level was considered if the P value < 0.05.

Results

The mean age of the patients was 38.12 years and females were predominantly (97.3%). More than two-thirds of the patients were of urban residence (Table 1).

Table 1. Sociodemographic characteristics of the participants

Characteristics		Number (%) N=75
Age (years)	Below 30	18 (24)
	30-49	46 (61.3)
	50 and above	11 (14.7)
Gender	Male	2 (2.7)
	Female	73 (97.3)
Residence	Urban	52 (69.3)
	Rural	23 (30.7)
Academic qualification	Illiterate	7 (9.3)
	Read & write	10 (13.3)
	Primary school	29 (38.6)
	Secondary school	15 (20)
	College and higher	14 (18.7)
Occupation	Housewife	62 (82.6)
	Employee	11 (14.7)
	Free work	2 (2.7)
Marital status	Single	14 (18.7)
	Married	61 (81.3)
Impact on job	Sick leave	11 (14.7)
	No	64 (85.3)

Eight percent of SLE patients had low disease activity or were in remission with a median of SLEDAI equal to 19 ranging from 11-27, and a median of ESR equal to 30 mm/hr ranging from 17-40 mm/hr (Table 2).

Table 2. Clinical and some laboratory parameters of the participants

Clinical characteristics		Number (%) N=75
Kidney and/ or neurological involvement	Present	24 (32.1)
	Absent	51 (67.9)
Disease duration (months)	Median (IQR)	60 (36-96)
SLEDAI	Median (IQR)	19 (11-27)
ESR	Median (IQR)	30 (17-40)

The median for the physical domain of lupusQOL was 40 with an IQR of 21.8-68.7. The median for the planning domain was 32.5 with an IQR of 25-65. The median for the pain domain was 33.2 with an IQR of 25-66.5. The median for the relationship was 50 with an IQR of 25-100. The median for the burden to others was 41.5 with an IQR of 25-83.2. The median for the body image domain was 35 with an IQR of 25-60. The median for the fatigue domain was 25 with an IQR of 6.2-50. The mean and SD of the emotional health domain were 53.7 (25-45), with a range of 4.1-100. (Table 3).

Table 3. Median and interquartile range of the LupusQol domains of the study patients.

Scale	Median	IQR	Range
Physical Health	40	21.8-68.7	3-100
Pain	33.2	25-66.5	0-100
Planning	32.5	25-65	0-100
Intimate Relationship	50	25-100	0-100
Burden to other	41.5	25-83.2	0-100
Emotional*	53.7	25.45	4.1-100
Body Image	35	25-60	0-90
Fatigue	25	6.2-50	0-100

Correlation of lupusQol with sociodemographic characteristics revealed statistically significant negative correlation between physical health domain and age (r = -0.461, p = 0.0005) and statistically significant positive correlation with address (r = 0.277, p = 0.016), education (r = 0.342, p = 0.003), occupation (r = 0.240, p = 0.038), and statistically significant positive correlation with impact on job (r = 0.314, p = 0.006). There was a statistically significant negative correlation between pain domain and age (r = -0.275, p = 0.017) and a statistically significant positive correlation with education (r = 0.330, p = 0.004) and with impact on the job (r = 0.358, p = 0.002). There was a statistically significant negative correlation between the planning domain and age (r = -0.368, p = 0.001) and a positive correlation with education (r = 0.243, p = 0.036). There was a

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statistically significant positive correlation between the body image domain and education (r = 0.339, p = 0.003). There was no statistically significant association with other sociodemographic characteristics of SLE patients (Table 4).

Correlation between lupusQOL with the clinical characteristic of SLE patients revealed a statistically significant negative correlation between burden to other domains and disease activity (r = -0.292, p = 0.011), and a statistically significant positive correlation between emotional health domain and disease duration (r = 0.291, p = 0.011) and statistically significant positive correlation between body image domain and disease duration (r = 0.239, p = 0.0391) (Table 5).

Discussion

Systemic lupus erythematosus is a chronic autoimmune disorder that may have different serious complications in all body organs. SLE patients' quality of life has been negatively affected as a result of these effects [21]. Therefore, determining these patients' needs and creating a complete treatment plan for them depends on assessing their quality of life [22].

The current study found that the vast majority of the studied patients were women, who were married. These findings corroborated those of Elmetwaly et al., 2021, who found that all of the patients were female [23]. A study conducted by Ferreira et al., 2023 found that women are more susceptible to stress and that female hormones like estrogen increase the risk of developing SLE [24]. Regarding marital status, more than half of the studied patients were married, and this result was in accordance with Mohamad et al., 2020 [25].

Table 4. Correlation of LupusQol domains with sociodemographic characteristics of the participants

	Age		Sex		Address		Education		Occupation		Marital status		Impact on job	
	r	P value	r	P value	r	P value	r	P value	r	P value	r	P value	r	P value
Physical Health	-.461	**.000****	-.088	.453	.277	**.016**	.342	**.003**	.240	**.038**	-.074	.526	.314	**.006****
Pain	-.275	**.017**	-.142	.223	.204	.078	.330	**.004**	.224	.054	-.080	.497	.358	**.002****
Planning	-.368	**.001****	.037	.753	.252	.029	.243	**.036**	.103	.378	-.077	.511	.210	.070
Intimate relationship	-.149	.297	.061	.668	.229	.107	.072	.618	.101	.482	-.162	.256	.202	.156
Burden to other	.010	.934	-.002	.987	.112	.337	.092	.434	-.021	.860	-.042	.718	.088	.452
Emotional	-.032	.784	-.096	.414	.080	.497	.108	.354	.143	.220	-.097	.410	.215	.063
Body Image	-.016	.890	-.084	.471	.099	.400	.339	**.003**	.093	.429	.013	.914	.180	.122
Fatigue	-.070	.549	-.048	.683	.160	.171	.111	.343	.135	.247	-.022	.850	.144	.217

Table 5. Correlation of LupusQOl domains with clinical characteristics of the participants

Variables	Disease duration		SLEDAI		ESR		Steroids		HCQ		Immuno-suppressant		Biology		Neuro-psychiatric		Renal involvement	
	r	p	r	p	r	p	r	p	r	p	r	p	r	p	r	p	r	p
Physical health	0.137	0.240	0.46	0.694	-0.011	0.922	-0.032	0.786	0.086	0.462	0.033	0.777	-0.060	0.607	-0.126	0.282	0.115	0.327
Pain	0.197	0.091	-0.032	0.787	-0.086	0.465	0.013	0.519	0.142	0.224	0.103	0.377	-0.035	0.769	-0.010	0.932	0.120	0.305
Planning	0.124	0.291	0.081	0.491	0.129	0.269	0.027	0.821	0.201	0.084	-0.024	0.835	-0.109	0.354	-0.023	0.843	0.076	0.514
Intimate relationship	0.129	0.366	-0.082	0.565	0.052	0.751	0.116	0.419	-0.009	0.950	-0.066	0.645	-0.061	0.668	-0.239	0.91	0.009	0.948
Burden to others	0.027	0.819	-0.292	0.011	-0.097	0.410	0.035	0.769	-0.085	0.471	-0.019	0.874	-0.063	0.594	-0.131	0.261	-0.154	0.187
Emotional health	0.291	**0.011**	-0.02	0.812	-0.06	0.603	-0.06	0.567	0.125	0.285	-0.00	0.947	-0.00	0.574	0.203	0.081	0.103	0.380
Body image	0.239	**0.039**	0.016	0.895	-0.01	0.905	0.035	0.764	0.199	0.087	0.148	0.206	-0.14	0.230	-0.05	0.639	0.067	0.566
fatigue	0.139	0.233	-0.013	0.913	-0.018	0.875	-0.048	0.683	0.064	0.587	0.138	0.238	-0.140	0.230	-0.006	0.959	-0.014	0.907

This could be because marriage adds more responsibilities, which raises stress levels and is one of the risk factors for SLE. In contrast to the study by Chalhoub et al. (2022) revealed that half of the studied patients were single [26].

The mean age of the participants according to the results of the current study was 38.12 years, this result was in accordance with results obtained by YilmazOner et al., 2016, who reported that the mean age of all participants was 40.6±11.9 years old on average [27]. This result was also consistent with the findings of Mohammedy et al, 2022, who reported that more than half of the studied patients were over 30 years old in their study [28]. One explanation might be that the highest quantities of estrogen are found in women of reproductive age, which increases the risk of SLE.

Regarding residence, the current study revealed that more than half of the studied patients lived in urban areas. Similar result to a study done by Mohamed et al. 2019 who showed that two-thirds of the patients in that study also lived in urban areas [29]. This is the outcome of bad behaviors like consuming fast food and being exposed to pollution. This result contradicts the findings of Elsayed et al., 2018, who stated in their study that most of the patients lived in rural areas [30].

All domains of LupusQOL were low and consistent with impaired quality of life, and the most impaired domains were fatigue, pain, and body image, consistent with other studies by McElhone et al., 2010 that revealed that every lupusQOl domain was impaired, with fatigue, being most significantly impacted [20]. Since we did not screen patients in the current study for fibromyalgia, fatigue may have a role in fibromyalgia. Skin involvement is common in SLE. Classic facial erythema, discoid rash, lesions that have a tendency to scar, skin atrophy, and hair loss are all considered unattractive and can have a negative impact on a patient's self-esteem. People with SLE frequently experience appearance-related embarrassment as a result of these symptoms. They also worry that using glucocorticosteroids may cause them to gain weight. Also, It is agreed with Gordon, 2013, who found the lowest score observed in the domain of fatigue and the highest observed in intimate relationships [31]. Intimate relationship was the least affected side. The sensitive nature of the question, however, can make the letter observation unclear. It is possible that patients are uncomfortable sharing this information, and studies on intimacy often contain incomplete or inaccurate data.

Concerning the relationship between LupusQol domain scores and sociodemographic characteristics, such as SLE patients' age, a statistically significant negative correlation was found in physical health, pain, and planning domains. In terms of physical health, the result agreed with Darvish et al., 2017, who found that the quality of life decreased with advancing age in SLE patients [32]. A possible explanation could be that older patients naturally have lower HRQOL because of longer disease duration and a higher incidence of organ damage, such as more degenerative joint disease, which impairs physical health [33]. A lot of studies showed that older age has a negative impact on HRQOL [34-36]. This contrasts with the others [37-38] which found no significant correlation between the mean scores of lupus quality of life questionnaire and age. This dissimilarity may be due to variable sample size, variable patients' ages, different disease durations, and regional, seasonal, or racial variations.

Regarding the gender effect on HRQOL, it has been found that there was no correlation in the current study. According to Mok et al., 2009, disease activity, depression, and anxiety both directly and indirectly impacted HRQOL, but socioeconomic characteristics such as age, sex, education, income/family, and work status did not directly affect HRQOL [39]. Unlike Jolly et al., 2019 who examined the sex differences in HRQOL among SLE patients and discovered that while men had more damage and worse social support, women had considerably worse symptoms, cognition, and procreation domains with tendencies for worse physical health and pain-vitality [40].

Regarding marital status effect on LQOL, the present study revealed an absent correlation, in contrast to a study that reported those who lived alone reported higher HRQOL than those who did not [36]. Moreover, sociodemographic factors such as level of education had a significant positive association with HRQOL. Higher levels of education were associated with improved physical health, Pain, and planning. According to McElhone et al., 2006 who reported that age, disease duration, low education, and low socioeconomic status have been reported as the main barriers to improving lupus prognosis [35]. This comes in contrast with Mok et al., 2009 who mentioned that there was no significant relationship between age, level of education, disease duration, and lupus quality of life [39].

Regarding residence, the present study revealed worse HRQOL in SLE patients in the physical

health domain for those living in urban areas. The possible explanation is that unhealthy lifestyles and the existence of comorbidities associated with increased disability led the patients to have lower QoL than in rural areas [41].

In regards to the relation between SLE patients' occupation and quality of life, the present study showed a statistically significant positive correlation between SLE patients' occupation and lupusQol in the physical health and pain domains. It may be related to the fact that housewives perform their usual daily activities of housing-related tasks, which may have an impact on SLE while performing these activities continuously. According to a study conducted by Aly *et al*., 2018 about the pattern of social support among SLE Patients, reported that most of the patients in their study were female, and more than half of them were housewives up to 30 years and more [42]. At the same time, a study by Yazdany *et al*., 2010 about the impact of SLE on the HRQOL and employment of SLE patients, showed a significant impact on HRQOL and observed with employment because of SLE, which has a substantial effect on a variety of domains involving symptoms, functional status, and general health perceptions [43]. Up to 90% of SLE patients suffer fatigue, which 50% of patients consider their most disabling disease symptom [44]. Physical limitation, pain, and fatigue were the most important factors commonly perceived as limiting work in all patients. Frequent sick leaves because of the worsening of the symptoms or being admitted to the hospital could be problematic.

In the findings of the present study, patients with sick leave had higher QOL scores and showed better general health than patients with no sick leave, which is in accordance with Schmeding *et al*., 2013 who revealed that sick leave due to SLE is commonly reported in patients and is associated with higher QOL scores [12].

According to the current study, the length of time that the patients from SLE suffered was positively correlated with their quality of life, demonstrating that HRQOL scores diminished as the duration of the disease increased. This finding was similar to [45-46], which found a statistically significant positive correlation between the duration of the disease and patients' quality of life. In the present study, longer disease duration was correlated with worse emotional health and body image domains. Whenever a patient was diagnosed with a new disease, their quality of life was adversely affected since they were anxious, didn't know how to handle it, and didn't know about any precautions.

Emotional issues affect about two-thirds of SLE patients [20]. The results contrasted with those who found no correlation between the duration of a patient's illness and their quality of life [37-38]. For newly diagnosed patients, educational programs covering all aspects of disease are offered with the goal of enhancing the quality of life.

LupusQOL is negatively impacted by disease activity in SLE patients, according to certain studies [47-48, 20]. In agreement with the current study, which showed a significant negative correlation with burden to other domains of LQOL, but was not significantly correlated with the other domains of LupusQOL. Other studies have reported that disease activity is a poor indicator of HRQoL in SLE like [12, 27], YilmazOner *et al*., 2016 found that there was no correlation between HRQOL and SLEDAI scores in Turkish lupus patients as measured by the Lupus QoL-TR and SF-36 [27]. This finding revealed that factors other than disease activity could affect QOL, particularly in patients who are clinically inactive or mildly active. The correlation between disease activity and HRQOL in SLE is still debatable [39]. This could be caused by a number of variables, including various study designs, the disease's heterogeneity, the different measures to assess disease activity, and the disease's fluctuating states. Regarding association with renal involvement, the present study did not demonstrate an association between renal involvement of the disease and the quality of patients' lives. This may be because renal disease in SLE disease is most often clinically silent and picked up primarily on investigations. A longitudinal study with multiple QOL evaluations of the same patients would have been ideal. Similar results were found by Golder et al, 2017 who found no significant association between active renal disease and any domains of SF-36 [49]. This finding was in contrast with the study of Jolly *et al*., 2018, who proved that the HRQOL domains of patients with active lupus nephritis are worse [50].

Strength and limitation of the study

There are important points that should be mentioned about the strengths and weaknesses of the current study. Because of the rare nature of the condition, the small sample size, time limitations, and the challenges in the data collection that was taken from a single study center. Also, because the study was cross-sectional in nature, a longitudinal follow-up study is recommended. Additionally, a number of significant variables that could have an impact on how the results are estimated were not examined in this study, including income level, anxiety, stress, and depression. Furthermore, we

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did not test for fibromyalgia, a condition that can alter a patient's HRQOL. The study's key strengths were its use of a validated, disease-specific questionnaire and its examination of the variables affecting quality of life (QoL) in various sub-dimensions in an appropriate sample size of Iraqi SLE patients.

Conclusions

Systemic lupus erythematosus has a major impact on the quality of life of patients. There was a significant positive correlation between LupusQol domains and sociodemographic characteristics such as address, education, occupation, and impact of the disease on the job, and a significant negative correlation with age in the physical health domain. There was a significant positive correlation with some clinical characteristics such as disease duration in the emotional health and body image domains, and a significant negative correlation between LupusQol and disease activity. Regular assessment of the quality of life of SLE patients and conducting this study again with a larger sample size drawn from various regions of the country are recommended to confirm the results and precisely identify risk factors.

Conflicts of interests: No conflicts of interests to be declared
Patient consent: The study was performed after the verbal consent was taken from the participants and each participant received an anonymous questionnaire sheet.
Author contributions: Conceptualization: S.S.A., Methodology: R.S.M., and Z.H.A., Formal analysis and investigations: Z.H.A., and R.S.M., Writing: R.S.M., Resource: R.S.M., Supervision: S.S.A., Z.H.A.

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