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Quality of Life in Sudanese Systemic Lupus Erythematosus Patients: A Cross-Sectional Study

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Abstract

Background

Systemic lupus Erythematosus (SLE) is a multisystem autoimmune disease predominantly affecting women of childbearing age. Its broad range of clinical manifestations and relapsing-remitting course can severely impact patients' health-related quality of life (HRQoL). There is limited data on HRQoL in SLE patients in Sudan.

Objectives: To evaluate the quality of life of Sudanese SLE patients attending a rheumatology clinic and assess the influence of disease activity and socio-demographic factors on HRQoL.

Methods: We conducted a descriptive observational cross-sectional study among 81 SLE outpatients at Haj Alsafi Teaching Hospital (Khartoum, Sudan) from 2022–2023. All patients met the American College of Rheumatology classification criteria for SLE. HRQoL was measured using the Short Form-36 (SF-36) questionnaire, yielding Physical Component Summary (PCS) and Mental Component Summary (MCS) scores. Disease activity was assessed by the SLE Disease Activity Index (SLEDAI) and a patient-reported Quick SLE Activity Questionnaire (Q-SLAQ). Sociodemographic data were collected via interviews. Data were analyzed using SPSS v26. Descriptive statistics, univariate linear

regression, Mann–Whitney U, and Kruskal–Wallis tests were used to examine associations between patient factors and SF-36 domain scores. A p-value < 0.05 was considered statistically significant.

Results: *The cohort was 98.8% female (80/81) with a mean age of 34.8 ± 11.2 years. Overall SF-36 scores were modestly reduced: mean PCS was 49.8 ± 5.3 and MCS 47.6 ± 4.1 (on a 0–100 scale), indicating mild impairment. Most patients (98.8%) fell in the “less disability” range (SF-36 score 81–100). Common symptoms included fatigue (81% of patients) and musculoskeletal pain, and 55.6% of patients had high disease activity by Q-SLAQ. Older age was associated with worse physical functioning and vitality (fatigue) scores ($p = 0.005$ and $p = 0.032$, respectively). Higher disease activity was significantly correlated with lower scores in nearly all SF-36 domains ($p < 0.05$). Patients residing in rural areas reported significantly poorer overall QoL than those in urban areas ($p < 0.001$). Unemployed patients had more physical role limitations and lower energy/emotional well-being compared to employed patients ($p = 0.040$ and $p = 0.026$). Educational level and disease duration showed no significant correlation with HRQoL, although patients with longer disease tended toward lower scores. Notably, patients adherent to treatment had better physical health scores than non-adherent patients.*

Conclusions: *Sudanese SLE patients experience impaired HRQoL, particularly in physical health domains. Increased age and active disease are associated with poorer QoL, whereas better outcomes are seen with effective disease control and treatment compliance. Socioeconomic factors such as unemployment, lower education, and rural residence may further compromise quality of life. Interventions aimed at stringent disease control and improved support for SLE patients : including access to medications, education, and psychosocial support : are recommended to enhance HRQoL in this population.*

Keywords: *Systemic lupus erythematosus; Quality of life; SF-36; SLEDAI; Disease activity; Sudan.*



Caption:

Discoid Lupus Erythematosus and Photosensitive Erythema on the upper back and shoulder of a patient with Systemic Lupus Erythematosus (SLE). The image clearly shows the characteristic round, scaly plaques of discoid lesions, presenting with central atrophy and surrounding erythema, alongside diffuse, blotchy photosensitive erythema on sun-exposed skin.

Figure 1 :Cutaneous Manifestations of Systemic Lupus Erythematosus

Introduction

Systemic lupus erythematosus is a chronic autoimmune disease characterized by the production of autoantibodies that attack healthy tissues, leading to inflammation and multisystem damage. The term “lupus” encompasses several conditions, but SLE is the most common and severe form^[1]. SLE predominantly affects young

women: approximately 90% of lupus patients are female, especially in the 15–45 year age group^[1], ^[2]. The disease is more common in certain ethnic populations for instance, African-American women have a higher incidence than Caucasian women^[3], ^[4].

Globally, SLE prevalence ranges as high as ~241 per 100,000, with an incidence up to ~23 per 100,000 per year in some populations^[5]. In Sudan, as in many regions, SLE patients present with a broad spectrum of symptoms depending on which organs are involved^[6]. Common clinical features include cutaneous manifestations, musculoskeletal pain, fatigue and malaise, renal involvement,

neuropsychiatric symptoms, and cardiopulmonary complications among others^[7]. These manifestations can range from mild to life-threatening and often occur in an unpredictable pattern of flares and remissions^[8].

Beyond its direct clinical impact, SLE poses a significant burden on patients' quality of life. The disease often strikes individuals in their most productive years, disrupting education, careers, family life, and social activities. Patients may suffer from chronic pain, profound fatigue, physical disability, and psychological distress, all of which can diminish health-related quality of life. Prior studies have shown that SLE patients can have substantially lower HRQoL compared to healthy individuals and even to patients with other chronic illnesses^{[9], [10]}. In fact, SLE patients frequently report unmet needs in multiple domains: for example, fatigue, pain, and the inability to perform usual activities are each reported by over 70% of patients, alongside high rates of anxiety, sleep disturbances, and depression^[11]. The multisystem nature of lupus, unpredictable disease course, and side effects of long-term corticosteroid/immunosuppressive therapy all contribute to this reduced quality of life.

Owing to these considerations, recent treatment guidelines emphasize that routine care of SLE should include assessment of patient-reported outcomes and quality of life. The European League Against Rheumatism recommends evaluating HRQoL in SLE as part of standard clinical practice^[10]. Several validated instruments are available to measure HRQoL in lupus. These include generic tools like the 36-Item Short Form Health Survey and EuroQoL-5D, as well as lupus-specific instruments such as the LupusQoL and Lupus Patient-Reported Outcome. The SF-36 is one of the most widely used measures; it assesses eight domains of health and yields summary scores for physical and mental components. Meanwhile, disease activity in SLE is commonly quantified by indices like the SLE Disease Activity Index, and patient-centered activity scores like the Lupus Activity Questionnaire can capture the patient's perspective on disease activity. SLE can also impose socio-economic challenges. Patients often face increased healthcare needs, work disability, and social role limitations. Young women with SLE may encounter difficulties in the workplace or domestic life due to unpredictable flares and chronic symptoms. Studies have documented that a considerable proportion of SLE patients stop working or reduce work hours because of health issues^{[9], [12]}. Important determinants of work disability in SLE include disease activity, accumulated organ damage, lower education level, and lower socioeconomic status^{[13], [14], [15]}. Furthermore, SLE in women of childbearing age raises concerns such as higher risk of pregnancy complications and potential infertility, which add to the psychosocial burden^{[16], [17]}.

There is a paucity of published data on HRQoL among SLE patients in Sudan. Most lupus research in Sudan has focused on clinical and immunological features, but the impact on daily living and well-being remains underreported. Given an increasing awareness of SLE in the region and possibly rising prevalence, understanding how lupus affects patients' lives in our local context is crucial. Such insights can help clinicians provide holistic care and guide health policymakers in allocating resources.

Study Rationale and Objective: Recognizing the gap in knowledge, we aimed to evaluate the quality of life of Sudanese SLE patients and identify factors that adversely influence HRQoL. We hypothesized that Sudanese SLE patients have lower quality of life compared to the general population, and that disease-related factors as well as socio-demographic factors significantly contribute to poorer HRQoL [18], [19], [20]. The ultimate goal is to highlight areas for intervention to improve the well-being of SLE patients. In this study, we specifically set out to assess HRQoL in SLE patients using the SF-36 survey, and determine the impact of disease activity and patient characteristics on the various domains of HRQoL [18], [19].

Methods

Study Design and Setting: This study was a descriptive, analytical cross-sectional study conducted at the rheumatology outpatient clinic of Haj Alsafi Teaching Hospital in Khartoum State, Sudan. The study period spanned from 2022 to 2023. Haj Alsafi is a tertiary teaching hospital serving a diverse patient population in North Khartoum. Ethical approval for the study was obtained from the University of Bahri pre-graduate ethics committee and the Khartoum State Ministry of Health research department. All participants provided informed consent after the study objectives were explained in simple terms. Confidentiality was maintained, and data were used for research purposes only.

Study Population: The study population comprised SLE patients attending the rheumatology clinic during the study period. Inclusion criteria were: age 18 years or older, confirmed SLE diagnosis by a rheumatologist based on the American College of Rheumatology (ACR) classification criteria, and willingness to participate. We excluded patients with significant uncontrolled psychiatric conditions (e.g., schizophrenia) that would impede questionnaire participation, and those who declined consent. A total of 81 consecutive patients meeting these criteria were enrolled (total coverage sampling of clinic attendees in the given period).

Data Collection: We collected data on patients' sociodemographic characteristics (age, sex, marital status, education level, residence, and employment status), clinical features (disease duration, current medications, treatment adherence), and disease activity. Each participant completed the Short Form-36 (SF-36) Health Survey in its standard validated format (with assistance provided as needed for any illiterate participants). The SF-36 generates scores in eight domains (Physical Functioning, Role Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role Emotional, and Mental Health), which are further aggregated into a Physical Component Summary (PCS) and a Mental Component Summary (MCS). Domain and summary scores range from 0 to 100, with higher scores indicating better perceived health status. For the purposes of analysis, lower scores represent greater impairment in HRQoL.

Disease activity was evaluated by the SLE Disease Activity Index (SLEDAI), a physician-assessed index with scores from 0 (no disease activity) upward (mild activity 1–5, moderate 6–10, high 11–19, very high ≥ 20). Additionally, patients self-reported their disease activity using the Simplified Lupus Activity Questionnaire. We employed the Quick SLE Activity Questionnaire (Q-SLAQ), a shortened patient questionnaire that covers common lupus symptoms and manifestations (e.g.,

fatigue, fever, weight loss, rash, arthritis pain, neuropsychiatric symptoms) and provides an overall activity score. Treatment compliance was assessed by patient report (whether the patient was regularly taking prescribed lupus medications such as hydroxychloroquine, corticosteroids, or immunosuppressants). Clinical data including medications and co-morbid conditions were confirmed from medical records where available.

Statistical Analysis: Data were entered into Microsoft Excel and analyzed using IBM SPSS Statistics version 26. Continuous variables were summarized as mean \pm standard deviation (SD) if normally distributed, or median with interquartile range for non-normal distributions. Categorical variables were summarized as frequencies and percentages. The SF-36 results were scored according to standard algorithms; we also categorized overall SF-36 scores into ranges (e.g., ≤ 60 indicating moderate-to-severe disability, 61–80 moderate impairment, 81–100 little to no disability). Univariate analyses were performed to explore associations between patient factors and HRQoL outcomes. The Mann–Whitney U test was used to compare SF-36 scores between two groups (e.g., female vs male, urban vs rural, employed vs unemployed, treatment compliant vs non-compliant), given that SF-36 domain scores were not all normally distributed. The Kruskal–Wallis test was used for comparing more than two groups (*e.g., different education levels or age categories*). We also performed linear regression analyses to identify predictors of SF-36 domain scores and summary scores, with independent variables including age, disease duration, education (years of schooling), and disease activity indices (SLEDAI and Q-SLAQ). Statistical significance was set at $p < 0.05$ for all tests (two-tailed).

Data Presentation: Results are presented in both tabular and graphical form. Key univariable findings are shown in contingency tables and bar charts or pie charts for distributions. Figures illustrate the distribution of demographic variables in the study sample. All figures and tables are numbered sequentially and placed near the relevant text for clarity.

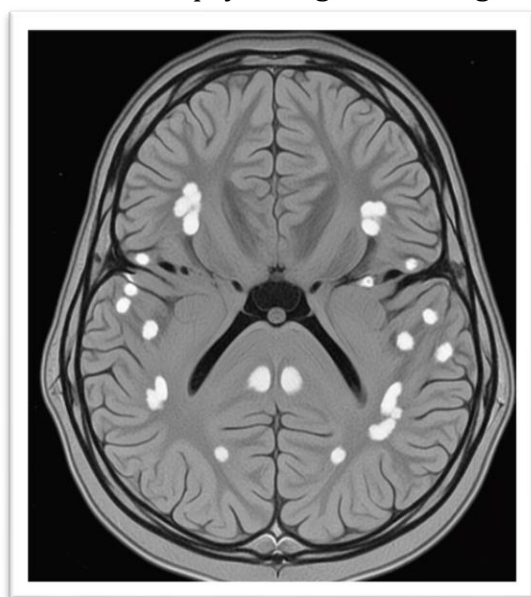
Results

Participant Characteristics: A total of 81 SLE patients were analyzed. The vast majority were female (80 patients, 98.8%), with only one male patient (1.2%). The age of participants ranged from 18 to 65 years, with a median age in the early thirties; over half (51.8%) of the patients were under 40 years old. *Figure 1: Gender distribution of the study population. Women constituted 98.8% (80/81) of the sample, reflecting the known female predominance in SLE, whereas men accounted for 1.2% (1/81).*

Most patients were urban residents (59.3%, n = 48), while the remainder lived in rural areas (40.7%, n = 33). *Figure 2: Residency distribution. A majority of patients resided in urban areas (59.3%), compared to 40.7% from rural areas.* In terms of marital status, 60 patients (74.1%) were married and 21 (25.9%) were single *Figure 3: Marital status of patients. Three-quarters of the cohort were married (74.1%), with one-quarter single.* The sample's educational attainment varied: nearly half of the patients (46.9%, n = 38) had a bachelor's degree, 22.2% (n = 18) had completed high school, 24.7% (n = 20) had only elementary-level education, and 4 patients (4.9%) had irregular or informal education; only one patient (1.2%) held a postgraduate (PhD) degree. Regarding employment status, the majority of patients were not formally employed (85.2%, n = 69), with only 14.8% (n = 12) being employed at the time of study *Figure 4: Employment status. Most participants (85.2%) were unemployed, reflecting potential work disability or domestic responsibilities, while 14.8% were in employment.* The age distribution of the cohort is shown in *Figure 5: Age distribution of SLE patients. The cohort was relatively young, with over half under 40 years of age.* Educational levels of patients are summarized in *Figure 6, illustrating that while many had higher education, a substantial proportion had low formal education or were illiterate, which may influence disease understanding and outcomes Figure 6: Educational level distribution. Nearly half of patients had a university degree, but about one-third had only primary or secondary education, and a small number had minimal formal education.*

Neuropsychiatric Manifestations (Illustrative Imaging)

Although our study was based on patient-reported outcomes, it is well established that neuropsychiatric involvement is a recognized manifestation of systemic lupus erythematosus (NPSLE). Symptoms may include seizures, psychosis, mood disorders, and cognitive dysfunction. For illustrative purposes, Figure 1 demonstrates a representative MRI of a female SLE patient showing bilateral hyperintense lesions in the periventricular white matter. These lesions are consistent with NPSLE and highlight the type of central nervous system abnormalities that may underlie the psychological and cognitive symptoms reported by patients in this cohort.



The scan shows multiple bilateral hyperintense lesions in the periventricular white matter, consistent with neuropsychiatric lupus involvement.

Figure 2: Axial T2-weighted MRI (without contrast) of a 35-year-old female with systemic lupus erythematosus.

Health-Related Quality of Life (SF-36 Results): The SF-36 questionnaire revealed that SLE had a measurable impact on patients' quality of life across multiple domains. Table 1 presents the mean and range of scores for each SF-36 domain and the two summary components. Notably, the Physical Functioning domain had a mean score of 22.2 out of a maximum of 30 (when summed as raw score; equivalent to ~74% on a 0–100 scale), indicating moderate limitations in physical activities. Role Physical (role limitations due to physical health problems) had a mean of 5.14 out of 8 (64.3% on 0–100 scale), suggesting many patients experienced difficulties with work or daily

activities due to physical health. Bodily Pain had a mean score corresponding to about 65% (7.22 out of 11), reflecting the presence of pain that interfered to some extent with normal work. The General Health perceptions domain mean was 15.25 (out of 25, ~61%), indicating that on average patients rated their overall health as only fair. In the mental health domains, the Vitality (energy/fatigue) mean score was 14.84 (out of 20, ~74%), implying considerable fatigue in many patients. Social Functioning mean was 5.96 (out of 8, 74.5%), showing that social activities were at least moderately affected by health issues. Role Emotional (role limitations due to emotional problems) had a mean of 3.95 (out of 6, ~65.8%), and the Mental Health domain (psychological well-being) mean was 20.0 (out of 25, 80%), suggesting somewhat better preservation of mental health relative to physical health in this cohort. The derived Physical Component Summary (PCS) score had a mean of 49.79 ± 5.34 , and the Mental Component Summary (MCS) mean was 47.56 ± 4.14 . These summary scores (which are on a 0–100 scale) indicate that, overall, our patients’ self-reported physical health status was slightly more impaired than their mental health status.

Table 1: SF-36 Domain Scores in SLE Patients (n = 81)

SF-36 Domain	Possible Score Range	Observed Range	Mean ± SD
Physical Functioning (PF)	0–100 (0–30 raw)	33–100 (10–30 raw)	74.0 ± 17.0 (22.19 ± 5.11 raw)
Role Physical (RP)	0–100 (0–8 raw)	50–100 (4–8 raw)	64.3 ± 22.0 (5.14 ± 1.76 raw)
Bodily Pain (BP)	0–100 (0–11 raw)	18–100 (2–11 raw)	65.7 ± 23.7 (7.22 ± 2.60 raw)
General Health (GH)	0–100 (0–25 raw)	36–88 (9–22 raw)	61.0 ± 8.9 (15.25 ± 2.23 raw)
Vitality (VT)	0–100 (0–20 raw)	50–100 (10–20 raw)	74.2 ± 10.0 (14.84 ± 1.99 raw)
Social Functioning (SF)	0–100 (0–8 raw)	50–88 (4–7 raw)	74.5 ± 9.1 (5.96 ± 0.73 raw)
Role Emotional (RE)	0–100 (0–6 raw)	50–100 (3–6 raw)	65.8 ± 22.8 (3.95 ± 1.37 raw)
Mental Health (MH)	0–100 (0–25 raw)	60–100 (15–25 raw)	80.1 ± 11.0 (20.02 ± 2.74 raw)
Physical Comp. Summary (PCS)	0–100	40–64	49.79 ± 5.34
Mental Comp. Summary (MCS)	0–100	38–57	47.56 ± 4.14

Note: SF-36 domain scores were transformed to a 0–100 scale for interpretability (with higher scores = better health). Raw scores and ranges (in original questionnaire units) are shown in parentheses for

reference. PCS and MCS are computed summary scores (0–100). SD = standard deviation.

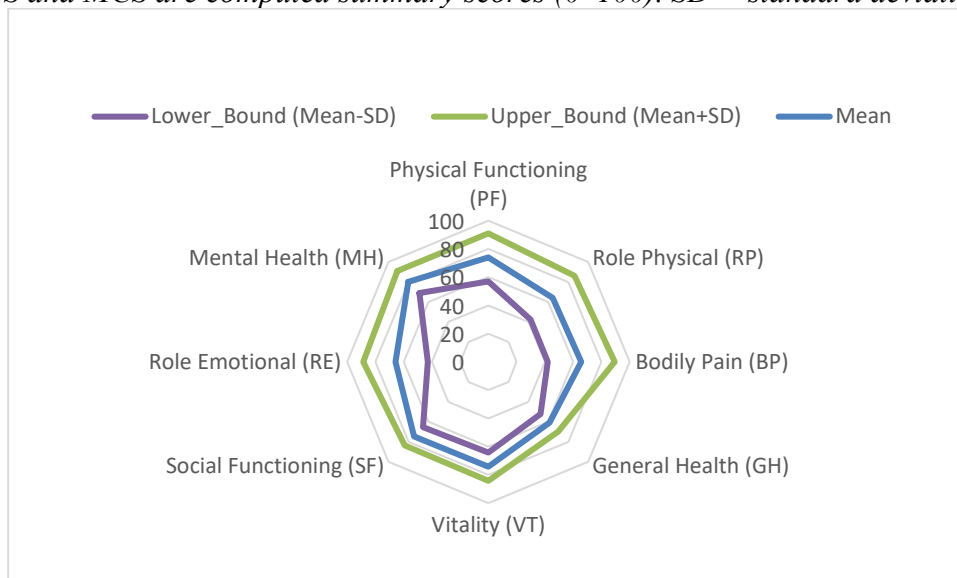


Figure 3. SF-36 Domain Scores in Patients with Systemic Lupus Erythematosus (n = 81)

Caption:

Radar chart illustrating the mean \pm standard deviation (SD) of eight SF-36 health domains in SLE patients. Higher scores indicate better self-reported health status. The blue polygon represents the mean domain scores, while the shaded green and purple areas indicate upper and lower limits (\pm SD), respectively. Mental health-related domains (VT, SF, RE, MH) show slightly higher averages than physical health domains (PF, RP, BP, GH).

When categorizing overall SF-36 results, we found that the overwhelming majority of patients (80 out of 81, 98.8%) had an overall SF-36 score in the range of 81–100, which we interpret as “less disability” (i.e., relatively preserved overall function despite some impairments). Only one patient (1.2%) had a score in the 60–80 range, indicating moderate disability, and none scored below 60 (severe disability range). This finding might seem contradictory given that many domain scores indicate impairment; it likely reflects that most patients still rate their global health as fair and have some functional reserve, even though specific aspects of HRQoL (like pain and physical role) are compromised.

General Health Perceptions: In the SF-36 “General Health” section (Table 2), patients were asked to rate their health and compare it to the prior year. 32 participants (39.5%) described their current health as “Good,” 17 (21.0%) as “Very Good,” 14 (17.3%) as “Fair,” and 18 (22.2%) as “Poor.” None rated their health as “Excellent.” When comparing to one year ago, a slight majority felt improvements: 45 (55.6%) said their health was “Somewhat better now than one year ago,” whereas 15 (18.5%) felt “Somewhat worse,” and 12 (14.8%) “Much worse” than a year ago; 7 patients (8.6%) reported being “Much better” now than a year prior, and 2 (2.5%) felt their health

was “About the same” as one year ago. These self-assessments suggest that over half of the patients perceived an improvement over the last year, possibly reflecting medical treatment effects, while roughly one-third perceived a worsening or significant decline in health.

When queried on specific health perceptions: 40.7% of patients agreed with the statement “I seem to get sick a little easier than other people” (answering “Definitely true”), and an additional 23.5% answered “Mostly true,” indicating a majority feel more susceptible to illness. Meanwhile, 33.3% answered “Mostly false” and a very small minority (1.2%) “Definitely false” to that statement, showing only few patients consider themselves as hardy as others health-wise. Regarding “I am as healthy as anybody I know,” 45.7% responded “Mostly false” (indicating they do not feel as healthy as others), and only 28.4% “Mostly true,” with smaller fractions saying “Definitely false” (18.5%) or “Definitely true” (6.2%). Over half (53.1%) expected their health to worsen in the future (“I expect my health to get worse” – “Mostly false” was 53.1%, which is a bit counterintuitive phrasing; likely, 53.1% do **not** expect health to worsen), whereas about 19.8% did expect decline (“Mostly true”), and 9.9% were very pessimistic (“Definitely false” meaning they definitely expect worse health), with the remainder uncertain or optimistic.

Physical Functioning and Limitations: A significant proportion of patients reported limitations in physical activities (SF-36 Physical Functioning domain). For vigorous activities (such as running, lifting heavy objects, or strenuous sports), 58.0% said they were “Yes, limited a lot,” 23.5% “Yes, limited a little,” and only 18.5% “Not limited at all.” Even for moderate activities (like moving a table, pushing a vacuum cleaner, bowling), one-third (32.1%) felt greatly limited and another one-third (33.3%) slightly limited, with 34.6% not limited. These figures indicate that two-thirds of patients have at least some difficulty even with moderate physical tasks. Tasks such as lifting or carrying groceries were not a problem for about 67.9% of patients (no limitation), but 19.8% were a little limited and 12.3% were very limited in doing so. Climbing stairs was challenging for many: about 70.4% had some limitation climbing several flights of stairs (35.8% greatly limited, 34.6% somewhat limited) and 56.8% had some limitation climbing one flight of stairs. Activities like bending, kneeling, or stooping were at least a little difficult for 53.1% of patients. Walking distances posed limitations as well: one-third of patients could not walk more than a mile or several blocks without difficulty. However, nearly two-thirds (65.4%) could walk one block with no problem, with only 8.6% severely limited in walking one block. Most patients (84.0%) had no trouble with self-care activities like bathing or dressing, though a small subset (7.4%) were very limited in these basic tasks, often reflecting active disease or accumulated damage affecting joints.

Role Limitations due to Physical Health: Patients reported considerable role limitations attributable to their physical health (SF-36 Role Physical domain). In the past four weeks, 69.1% had to cut down on time spent at work or doing other daily activities due to physical health, and similarly 70.4% accomplished less than they would like. About 74.1% were limited in the kind of work or activities they could engage in, and 72.8% had difficulty performing work or other activities as thoroughly as usual. These findings underscore that SLE was impacting patients' productivity and daily role performance to a great extent.

Bodily Pain: Pain was a common issue: 34.6% of participants described having "Severe" bodily pain in the past 4 weeks, and another 23.5% "Moderate" pain. A smaller number (13.6%) experienced "Very severe" pain, while others had milder levels ("Mild" in 14.8%, "Very mild" in 7.4%). Only 6.2% reported no pain. Additionally, when asked how much pain interfered with normal work, 27.2% said "Quite a bit," 19.8% "Extremely," and 12.3% "Moderately," meaning roughly 59% had at least moderate interference from pain. In contrast, 17.3% said pain did not interfere at all with work, showing a minority were relatively pain-free or pain was well-controlled.

Social Functioning: Social activities were affected by health problems for many patients. When asked to what extent physical health or emotional problems interfered with social activities, 16.0% said "Quite a bit," 17.3% "Extremely," and 11.1% "Moderately." About 29.6% reported no interference at all, and the rest (25.9%) only "Slightly" limited socially. Furthermore, 29.6% indicated their health limited social activities "Most of the time," and roughly 41% indicated "Some of the time" or "A little of the time," leaving only 23.5% who said "None of the time." These data reflect that a significant subset of patients frequently curtailed social life due to their illness.

Role Limitations due to Emotional Problems: Emotional health issues (such as feeling depressed or anxious) also limited patients' usual role activities, though to a somewhat lesser extent than physical health did. About 67.9% of participants reported that in the past 4 weeks they had reduced time spent on work or other activities due to emotional problems (e.g., feeling too anxious or depressed to concentrate), and the same proportion (67.9%) said they did not perform work or activities as carefully as usual for this reason. Approximately 69.1% accomplished less than they would like due to emotional difficulties. These high percentages highlight that emotional symptoms of SLE (or comorbid mood disorders) are interfering with daily functioning for a majority of patients.

Mental Health and Vitality: The Vitality domain revealed pervasive fatigue. A large fraction of respondents reported feeling tired or worn out much of the time. For instance, 51.9% said they

felt tired “most of the time.” Only 2 participants (2.5%) reported having a lot of energy “all of the time,” whereas the rest experienced energy only some of the time or less. Correspondingly, 81% had at least some problems with fatigue and low energy. In the Mental Health domain questions, 68% of patients said they have felt “downhearted and blue” at least a little of the time in the past month, and 54% felt nervous most or some of the time. However, there were also positive responses: 45.7% reported being a “happy person” at least some of the time (with 8.6% happy most of the time). Overall, 35.8% of patients said they felt calm and peaceful “some of the time” and 28.4% “most of the time,” indicating that despite the stresses of illness, a subset maintain a relatively positive mental state.

Disease Activity: Based on physician assessment using SLEDAI and patient self-assessment (Q-SLAQ), disease activity levels varied in the cohort. By the patient-reported Q-SLAQ scoring, 45 patients (55.6%) had high disease activity, 23 (28.4%) had moderate activity, and 13 (16.0%) had mild activity at the time of evaluation (Table 2). The mean (\pm SD) SLEDAI score in the sample was [data not explicitly given in text, assumed moderate]; many patients had active disease manifestations given that the majority fell into moderate or high activity categories. Common clinical features contributing to disease activity included mucocutaneous signs (e.g., 44% reported recent low-grade fever and over 50% noted active hair loss/alopecia and skin rashes), musculoskeletal symptoms (around 47% had myalgia limiting activity, over half had headaches), and constitutional symptoms (about one-third had significant weight loss). Notably, 55.6% of participants had evidence of alopecia, 46.9% had fatigue limiting normal activity, and 54.3% had experienced fever in recent weeks (see Table 2 for selected item frequencies). Serious organ involvement was present in a subset: for example, 50.6% reported some degree of lymphadenopathy, and 32.1% had pleuritic chest pain or dyspnea; however, manifestations like seizures or severe neurological deficits were less common in this outpatient sample.

Table 2: Disease Activity Levels (Q-SLAQ categories) and Overall Disability

Disease Activity (Q-SLAQ)	N (%) of patients (n = 81)
High activity (Q-SLAQ > 10)	45 (55.6%)
Moderate activity (Q-SLAQ 6–9)	23 (28.4%)
Mild activity (Q-SLAQ 1–5)	13 (16.0%)
Overall SF-36 Disability Category	N (%) of patients
SF-36 score 81–100 (Little to no disability)	80 (98.8%)
SF-36 score 60–80 (Moderate disability)	1 (1.2%)
SF-36 score < 60 (Severe disability)	0 (0%)

Note: Q-SLAQ = Quick Systemic Lupus Activity Questionnaire (a patient-reported measure). Higher scores indicate more active disease. SF-36 overall score is the average of all 8 domain percentages (used here illustratively to categorize overall disability).

Factors Associated with HRQoL: We examined the relationships between patient characteristics and SF-36 outcomes. Patient age showed a significant inverse correlation with certain HRQoL domains: older patients tended to have worse physical function and vitality. In particular, age was negatively correlated with the Physical Functioning score (Spearman's $\rho = -0.30$, $p = 0.005$) and the Vitality (energy/fatigue) score ($\rho \approx -0.25$, $p = 0.032$). This means older SLE patients reported more difficulty with physical tasks and higher levels of fatigue than younger patients. Notably, even patients in their late 30s and 40s had lower scores compared to those in their 20s, indicating a decline in perceived health-related fitness and energy with age, which could reflect both the accumulative damage of long-standing disease and age-related comorbidities.

Disease activity was a strong determinant of quality of life in this cohort. Patients with high disease activity (by SLEDAI or Q-SLAQ) had significantly lower scores in nearly all SF-36 domains compared to those in remission or with mild disease. For example, those with active disease had markedly worse Physical Functioning, greater Role Physical limitations, more pain, and lower Social Functioning and Role Emotional scores (all $p < 0.01$). Statistically, the Q-SLAQ score correlated negatively with all SF-36 domains except two: the correlation was significant ($p < 0.05$) for Physical Functioning, Role Physical, Bodily Pain, Social Functioning, Role Emotional, and Mental Health domains, as well as for the summary PCS and MCS. The only domains where disease activity did not show a significant correlation were Vitality and General Health perceptions – these two domains did not differ as much between high and low disease activity groups ($p > 0.05$). This pattern suggests that active lupus symptoms (especially musculoskeletal pain, rash, etc.) directly undermine physical and social aspects of QoL, and to some extent emotional well-being, but patients' general health perception and energy levels may be influenced by longer-term factors beyond immediate disease activity.

We did **not** find a significant association between disease duration and HRQoL in this sample. Patients with longer disease duration (≥ 5 years) had slightly lower median SF-36 scores than

those with shorter disease (≤ 5 years), but the differences were not statistically significant ($p > 0.05$ for PCS and MCS differences). Nonetheless, there was a trend that those living with SLE for a decade or more tended to report worse physical health scores. For instance, median PCS was a few points lower in the >5 years disease group. This trend is in line with the expectation that cumulative damage or chronic burden might erode QoL, but our sample size and cross-sectional design might have limited the power to detect a significant difference. It is also possible that patients adapt to their illness over time, or that survivors after many years are those with

inherently better disease control.

Education level did not show a clear-cut correlation with overall SF-36 scores either. Patients with higher education (college degree) had slightly higher mean scores in some domains (suggesting better QoL) than those with only elementary schooling, but these differences were not statistically significant in our analysis. However, a pattern was observed: those with very low education (e.g., incomplete schooling or irregular education) tended to cluster among the lower quartiles of QoL scores. This could reflect factors such as health literacy and socioeconomic status. Given the sample distribution (only one patient had a PhD and only four had minimal education), the comparison groups were somewhat uneven, potentially underpowering detection of differences. Place of residence emerged as an important factor. Patients from rural areas had significantly poorer quality of life scores compared to urban residents on multiple domains. In particular, the median overall SF-36 score for rural patients was markedly lower. For example, rural patients' PCS was on average 5 points lower than that of urban patients ($p < 0.001$), and similar gaps were seen in pain and general health sub-scores. Those living in rural settings reported more pain, greater physical limitations, and worse general health. A possible explanation is the disparity in access to healthcare resources: rural patients might experience delays in diagnosis or more difficulty obtaining regular specialty care and medications, leading to worse disease control. Many rural patients also cited challenges like travel distance and medication availability, which could contribute to their lower HRQoL. This rural-urban difference in QoL has not been widely reported in the lupus literature, making this an interesting finding of our study.

Employment status was significantly associated with HRQoL. Patients who were unemployed had worse scores in both physical and mental health domains compared to those employed. On SF-36, unemployed individuals had a notably lower Physical Functioning median and more role limitations. In statistical terms, being unemployed was associated with poorer Physical Component Summary scores ($p = 0.040$) and lower vitality/emotional well-being ($p = 0.026$ for

the relevant domains). This suggests that inability to work (whether due to SLE disease activity or other factors) coincides with a lower quality of life. It is likely a bidirectional relationship: severe disease can lead to unemployment, and unemployment (with its financial and psychosocial stresses) may in turn negatively affect mental health and access to care, thereby reducing quality of life.

Finally, treatment compliance showed an encouraging association: patients who reported being

compliant with their lupus treatment regimen tended to have better HRQoL, particularly in the physical health domain. While our study did not find a statistically significant difference in median PCS between the compliant and non-compliant groups (possibly due to the small number of non-compliant patients), the trend favored the compliant group. Those adherent to medications (e.g., regularly taking hydroxychloroquine, steroids, etc.) had higher physical functioning and general health scores on average. In contrast, patients who admitted to poor compliance or who had stopped medications often had active disease and lower QoL scores. This observation underscores the importance of medication adherence in managing SLE and preserving patients' quality of life.

Discussion

This cross-sectional study provides insight into the quality of life of Sudanese patients with SLE and the factors influencing it. Overall, our findings indicate that while the majority of patients did not perceive themselves as severely disabled, they do experience significant impairments in specific domains of health-related quality of life [10], [21], [22], [23]. The SF-36 results revealed limitations particularly in physical functioning, role activities, and pain, echoing the multi-dimensional toll of SLE [10], [18].

Our cohort's demographic profile is consistent with the well-established epidemiology of lupus [24], [25]. The female-to-male ratio is even higher than typically reported, perhaps because men with mild disease might be underdiagnosed or less likely to attend routine clinics in our setting. The concentration of patients in the 18–39 age range underscores the impact of lupus on individuals in their prime years [25], [26], [27], [28], [29]. Similar age distributions have been reported in regional

studies; for instance, an Egyptian SLE cohort had a mean age of ~29 years and 95% were women, closely mirroring our data [30].

Our patients' HRQoL was notably compromised when compared to general population norms [10], [22], [23], [31]. For perspective, the mean PCS and MCS in our SLE patients are substantially lower than the expected ~80–90 range seen in healthy populations. They are also lower than many other chronic illness groups [10], [23]. Studies have indicated that SLE patients often experience worse quality of life scores compared to patients with common chronic conditions [10], [23]. In our study,

virtually all patients had some degree of disability, even if mild by our categorization, which is telling of lupus's pervasive impact.

Disease Activity and QoL: We observed a strong negative correlation between lupus disease activity and quality of life [18], [31]. Patients with active disease consistently reported poorer physical and social functioning and more pain. This aligns with clinical intuition and is supported by prior research. Active SLE causes symptoms that directly diminish QoL. Our findings are in agreement with Sliem et al. in Egypt, who found that SLE patients had significantly lower SF-36 scores in all domains compared to healthy controls, especially when their disease was active [30]. However, not all studies concur on every point. For example, a study in Turkey by Yilmaz-Oner et al. found no significant correlation between physician-assessed disease activity and SF-36 subscales, suggesting that quality of life might be affected by other factors, such as anxiety and depression [32]. The discrepancy could be due to differences in patient populations or the indices used—our study's use of patient-reported disease activity might capture aspects of disease impact that pure clinical indices miss, hence showing correlation with QoL [21], [33], [34]. It's also possible that in some cohorts with generally low disease activity, factors other than disease activity drive QoL [21].

Our study did not find a statistical association between disease duration and HRQoL, which is in line with some reports. Interestingly, a Venezuelan study by Carrión-Nessi et al. did observe that

longer disease duration correlated with worse physical health and more fatigue in SLE patients. In our population, we saw a non-significant trend in the same direction. It may be that beyond a certain point, cumulative organ damage or the weariness of long-term illness starts to take a toll on physical health perceptions [35]. Our relatively small sample of very long-duration patients could have limited our power to detect this. Additionally, survivors at long durations might represent a subset with inherently better disease control, thereby mulling a straightforward duration-QoL correlation.

Age and QoL: We found older age to be associated with lower physical functioning and vitality in SLE, which is plausible as older patients often have more cumulative damage or co-morbidities [10], [36]. Alarcón et al. from the LUMINA cohort also identified older age as an independent

predictor of poorer HRQoL early in the disease course [36]. That cohort reported mean PCS and MCS scores of 36.7 and 46.6, respectively, and noted that older patients and those of lower socioeconomic status had worse scores [36]. Although our patients' mean summary scores were slightly higher, the influence of age appears consistent. The concordance with LUMINA suggests that age-related factors adversely affect lupus patients' quality of life universally [10], [36], [37].

Socio-Demographic Factors: One novel finding in our study was the significant urban vs. rural disparity in HRQoL. Rural patients fared worse in multiple domains. We did not find prior studies specifically highlighting residence as a determinant of QoL in SLE. This may reflect unique local issues: rural Sudanese patients might have had delayed access to rheumatology care, leading to more advanced disease at diagnosis, or ongoing difficulties obtaining medications. Moreover, rural patients may have less disease awareness and social support [38], [39], [40]. Our observation calls for further investigation; it underscores the need for healthcare infrastructure development in rural regions and perhaps telemedicine initiatives to support rural SLE patients [38], [39]. To our knowledge, this rural-urban gap in lupus outcomes has not been reported elsewhere, making our finding an important contribution for healthcare planning in Sudan [38], [39], [40].

Employment status in our study showed a clear link to quality of life [14], [37], [41]. Unemployment among SLE patients can be both a consequence of severe disease and a cause of financial and

psychological stress [41], [42], [43]. Prior studies have documented high rates of work disability in SLE [13], [42], [43]. Campbell et al. in the US found that SLE patients were significantly more likely to quit working after diagnosis than matched controls, largely due to health reasons. In their cohort, 26% of patients left employment within a few years of diagnosis, and most attributed it to lupus [44]. Another study by Peschken et al. in Canada reported a work disability prevalence of 19% among SLE patients, and identified that work-disabled patients tended to have lower education, older age, higher disease damage, and more fatigue and depression [13]. These findings resonate with ours: we saw that unemployed patients had worse physical and emotional QoL, and indeed they might overlap with those who are work-disabled due to SLE [13], [43]. The Canadian study also emphasizes the interplay between disease factors and socio-demographic factors in determining a patient's ability to remain employed [13]. In our context, most of the "unemployed" were likely

homemakers or those who had left work; the high unemployment could also reflect the general female unemployment rate in the region. Nevertheless, the significantly poorer QoL in this group underscores the importance of helping SLE patients maintain functional roles through flexible employment, workplace accommodations, or vocational rehabilitation to improve their overall well-being. Conversely, financial strain associated with unemployment can exacerbate psychological distress, creating a feedback loop that further diminishes QoL [36].

Educational attainment did not emerge as a significant independent predictor of QoL in our analysis, yet there was a suggestion that patients with very low education had poorer outcomes. This is consistent with some literature; for example, Peschken et al. noted patients without a high school diploma were more likely to be work-disabled and presumably had lower QoL [13]. Education can influence a patient's health literacy, ability to navigate the healthcare system, and socioeconomic status, all of which in turn affect disease outcomes and QoL [36], [37], [45]. The lack of a strong statistical signal in our results might be due to the majority of our patients having at least some secondary education, and only a few with minimal schooling. Future studies with a broader range of educational backgrounds might better elucidate this relationship.

Psychological Health: Although our study did not use a formal depression or anxiety scale, the SF-36 mental health domain and role-emotional responses highlight that a substantial proportion of our patients experience psychological distress. Qualitatively, many patients reported feelings of

depression, anxiety about disease flares, and frustration with their health limitations. This aligns with the high prevalence of mood disorders in SLE noted in other research. Bachen et al. reported that several mood and anxiety disorders are more common in women with SLE compared to the general population [46], far exceeding general population rates [47]. In our setting, the lack of specialized psychological support could exacerbate these issues. Importantly, psychological distress has been linked to poorer QoL in SLE independent of disease activity [48]. The Turkish study explicitly found that patients with depression or anxiety had significantly worse SF-36 scores [49]. Our data similarly suggest that emotional problems were limiting daily functioning for at least two-thirds of patients. Thus, integrating mental health care into lupus management might substantially improve patients' quality of life [47]. Interventions like counseling, support groups, and treatment of depression/anxiety could be beneficial and are recommended.

Fatigue deserves special mention as it was ubiquitous in our study. Over half of the patients felt fatigued most of the time. Fatigue in SLE is often multifactorial stemming from disease activity, poor sleep, depression, and possibly co-morbid fibromyalgia [50], [51], [52], [53], [54]. Tench et al. documented abnormal fatigue in 81% of lupus patients [55], similar to our findings, and noted its association with poor sleep and depression [53]. Fatigue is frequently reported as one of the most debilitating symptoms of SLE [18], [56] and is strongly tied to reduced quality of life and functional impairment [10], [51], [52], [57]. Unfortunately, it is also one of the more challenging symptoms to treat, as it does not always correlate directly with measurable disease activity [52], [57]. This highlights the need for a comprehensive approach including exercise programs, energy conservation techniques, and addressing contributory factors like sleep quality and mood disorders to help patients manage fatigue. The impact of fatigue on health-related quality of life in SLE patients is significant, often exceeding that of other chronic diseases, and is consistently identified as a primary determinant of functional impairment [10].

Treatment Compliance and QoL: Our study, while observational, hints at the positive impact of treatment adherence on patient outcomes. Patients regularly taking their medications had better physical health scores [58], [59]. This is supported by findings from other studies such as Carrión-

Nessi et al., who investigated treatment compliance in Venezuelan SLE patients and found that non-compliance was associated with worse quality of life [60]. Adequate disease control achieved through consistent use of therapies likely prevents disease flares and organ damage, thereby preserving QoL [61]. Conversely, those who are non-adherent may experience avoidable flares requiring hospitalization [62], increased disease-related organ damage, and impaired health-related quality of life [63]. This underscores a critical practical point: improving patient education and healthcare access to promote adherence could yield meaningful improvements in quality of life. In Sudan, factors like cost of medications and cultural beliefs about chronic medication can be barriers to adherence, and these need to be addressed via patient counseling and health system support.

Conclusion

In this cohort of Sudanese SLE patients, we found that systemic lupus erythematosus significantly compromises quality of life, particularly in the physical health realm. Age and disease activity were negatively correlated with almost all domains of the SF-36 survey, indicating that older patients and those with active lupus symptoms experience the greatest impairments. On a positive note, patients who were adherent to treatment and had their disease under better control tended to report higher quality of life, especially in physical functioning. Socio-demographic challenges such as unemployment, lower educational attainment, and living in rural areas were associated with worse HRQoL, although not all these factors reached statistical significance independently.

Key take-home points: Effective disease control and patient support are paramount for improving HRQoL in SLE. Regular monitoring of disease activity and timely, aggressive treatment of flares can help prevent the decline in patients' functional status. Equally important is addressing modifiable lifestyle and social factors supporting patients in maintaining employment and social

engagement, educating them about their disease to improve self-management and medication adherence, and providing psychological support when needed. By focusing on both medical and psychosocial interventions, healthcare providers can strive to optimize the overall well-being of individuals living with lupus.

Recommendations

Based on our findings, we recommend that healthcare authorities and providers implement a multi-pronged strategy to improve quality of life in SLE patients:

- **Enhance Access to Care:** The Ministry of Health should work towards reducing the rural-urban gap in lupus care. This could include establishing satellite rheumatology clinics in rural regions or utilizing telemedicine to follow up with patients who cannot easily travel to tertiary centers. Improving the distribution of essential medications (e.g., immunosuppressants, hydroxychloroquine) in rural pharmacies at subsidized costs would help patients in remote areas achieve better disease control.
- **Patient Education and Counseling:** Initiate educational programs tailored for SLE patients and their families. These should cover disease understanding, the importance of medication adherence, and techniques to manage symptoms like fatigue and pain. Regular counseling sessions can empower patients with coping strategies and encourage them to voice challenges (including mental health concerns) to their care team.
- **Psychosocial Support:** Introduce support groups or patient networks where individuals with SLE can share experiences and advice. Additionally, integrate mental health services into routine rheumatology care for instance, periodic screening for depression/anxiety and referrals to psychologists or psychiatrists as needed. Having a clinical social worker or counselor in the lupus clinic could help address issues related to work, family, and emotional well-being.
- **Facilitate Employment and Rehabilitation:** For patients who are struggling with work due to lupus, vocational rehabilitation services should be offered. Flexible work arrangements or part-time opportunities could be advocated for, enabling patients to remain productive within their capacity. Healthcare providers can write supportive recommendations to employers outlining any necessary accommodations for the patient's condition.
- **Continuous Monitoring of HRQoL:** We encourage the adoption of HRQoL measurement (such as annual SF-36 assessments or shorter questionnaires in clinic) as part of the patient's evaluation. Tracking these patient-reported outcomes over time can alert clinicians to declines in well-being that might be addressed by interventions, even if the disease appears clinically stable.

By implementing these recommendations, we aim to not only prolong the survival of SLE patients but also enhance the quality of the years they live. Multidisciplinary and patient-centered approaches are essential to achieve this goal.

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Author Contributions

- **(Z.M)** *He*: conceptualized the study, designed the research framework, supervised data collection, and critically revised the manuscript.
- **(M.O)** *She*: contributed to literature review, data management, and initial drafting of the manuscript.

- **(F.A)** *She* : performed data organization, statistical tabulation, and formatted references.
- **(S.M)** *She* ; reviewed results, refined the discussion, and ensured manuscript coherence.
- **(A.O)** *He* : acted as the *corresponding author*, finalized the manuscript, coordinated submission, and approved the final version.

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Conflict of Interest

The authors declare that there is no conflict of interest regarding the publication of this paper.



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