ADDIS ABABA UNIVERSITY

COLLEGE OF HEALTH SCIENCE SCHOOL OF MEDICINE

DEPARTMENT OF INTERNAL MEDICINE

Health-related quality of life among patients of Systemic Lupus Erythematosus and risk factors for poor HRQoL at health facilities in Addis Ababa, Ethiopia

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Declaration

I, Dr. Biruk Sisay, do hereby declare that this research thesis is a result of the works of my own making except where due is made in a review of previous literature in the content and by my knowledge, has never been submitted for any prior academic award or qualification in this Institution.

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Approval of thesis submission

I hereby certify that I have read this thesis prepared under my direction and recommend that it can be accepted as fulfilling the thesis requirement.

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LIST OF ACRONYMS/ ABBREVIATIONS

AAU	Addis Ababa University
ACR	American College of Rheumatology
ANA	Anti-Nuclear Antibody
ALP	Alkaline Phosphatase
ALT	Alanine transaminase
AST-	Aspartate transaminase
BUN	Blood Urea Nitrogen
CBC	Complete Blood Count
Cr	Creatinine
CRP	C - reactive protein
ECG	Electrocardiogram
ECHO	Echocardiogram
ESR	Erythrocyte Sedimentation Rate
ETB-	Ethiopian Birr
DM -	Diabetes mellitus
EULAR	European Alliance of Association for Rheumatology
HRQoL	Health Related Quality of Life
LDA	Low disease activity
PGA	*Physician Global Assessment*
MCS	Mental Component Score
PCS	Physical Component Score
QoL	Quality of Life
RFT	Renal Function Test

SF-36	Short Form 36
SLE	Systemic Lupus Erythematous
SLEDAI	Systemic Lupus Erythematous Disease Activity Index
SLEDAI-2K	Systemic Lupus Erythematous Disease Activity Index-2000
SLICC	Systemic lupus International Collaborating Clinics
TASH	Tikur Anbessa Specialized Hospital
USA	United States of America
IS	immunosuppression
$	dollar
%	Percent

Abstract

Background: Systemic Lupus Erythematosus (SLE) is a chronic autoimmune disease that significantly affects the health-related quality of life (HRQoL) of patients. Understanding the factors influencing HRQoL in SLE patients is crucial for improving patient care and outcomes.

Objective: To assess HRQoL and identify the factors associated with HRQoL in patients with SLE attending selected rheumatology clinics in Addis Ababa.

Methods: A multicenter, cross-sectional study was conducted in three rheumatology clinics in Addis Ababa, Ethiopia, from January 2024 to January 2025. The estimated sample size was 141. HRQoL was assessed using the SF-36 tool, and the overall HRQoL score, the Physical Component Summary (PCS), and the Mental Component Summary (MCS) scores were determined. Data were collected through chart reviews, electronic medical records, and phone interviews with patients. Data entry and analysis were performed using SPSS version 27.1. Multivariable linear regression was used to identify factors significantly associated with HRQoL, allowing for the evaluation of demographic, clinical, and socio-occupational influences on HRQoL among patients with SLE.

Results: The study included 121 SLE patients with a mean age of 35.4 ± 12.3 years, of whom 99.2% were female. The overall mean HRQoL score was 48.41 ± 5.7, with the mean scores for the Physical Component Summary and Mental Component Summary being 46.28 ± 8.4 and 50.54 ± 8.03, respectively. In multivariable linear regression analysis, age (B = -0.144, 95% CI: -0.277 to -0.010, P = 0.035), disease duration (B = -1.215, 95% CI: -2.161 to -0.268, P = 0.02), disease activity (B = -5.41, 95% CI: -9.578 to -1.287, P = 0.01), and occupation (housewives: B = -3.057, 95% CI: -5.670 to -0.444, P = 0.022) were significantly associated with poor HRQoL.

Conclusion and Recommendations: The HRQoL among SLE patients was found to be low. Disease activity and sociodemographic factors significantly influenced HRQoL. The findings underscore the importance of regularly monitoring disease activity and HRQoL, and suggest that interventions targeted at high-risk groups could improve the quality of life for these patients.

Keywords: Systemic Lupus Erythematosus, Health-Related Quality of Life, Disease Activity.

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1. INTRODUCTION

1.1. Background of the study

SLE is a chronic Systemic autoimmune disorder of unknown etiology that predominantly affects women of childbearing age (1). The estimated prevalence of SLE is around 30-50/100,000 which approximates to be 500,000 patients in Europe and 250,000 in USA (2). The incidence and prevalence of SLE are higher in black, Asian, and Hispanic patients, who tend to have more severe and active disease with early onset. As compared to whites, they are at increased risk of long-term organ damage and increased mortality (1). Despite the know;ledge of high burden of disease in individuals with African trait, the phenotype and the prevalence of the disease is not thoroughly studied in native sub-Saharan African countries (3). The pooled prevalence rate and mortality rate of SLE through systematic review and meta-analysis (hospital based studies) in native sub-Saharan African was 1.7% and 10.3%, respectively (4).

The natural course of SLE varies from persistent low-grade disease activity to unpredictable intermittent periods of increased disease severity, known as flares. Although presenting manifestations are diverse, common ones include constitutional symptoms, skin rash, and arthralgia. Patients can also present with severe organ-threatening complications, such as lupus nephritis, autoimmune cytopenia, or nervous system diseases (2).

There is no known cure for SLE. Therefore, to improve long-term patient outcomes, management should aim at remission of disease symptoms and signs, prevention of damage accrual and minimization of drug side effects, as well as improvement of quality of life (5,6). Complete remission (absence of clinical activity with no use of GC and IS drugs) is infrequent (6–10). To this end, newly defined low disease activity states (based on a SLEDAI score ≤3 on antimalarials, or alternatively SLEDAI ≤4, PGA≤1 with GC ≤7.5 mg of prednisone and well tolerated IS agents) have shown comparable rates with remission, regarding halting of damage accrual (OR 0.5–0.7 for increase in damage index) and prevention of flares(8,11-14). Measures of disease activity include; SLE disease activity index (SLEDAI)(15). British Isles Lupus Assessment Group (BILAG) disease activity index (16). And SLE Activity Measure (SLAM) (17). However, in addition to disease activity and damages, other important consequences of the disease include changes in Quality of Life (QoL) affecting employment and social functioning.

Therefore, in an effort to improve assessment of outcomes in SLE, the OMERACT (outcome measures in rheumatology clinical trials) group has recommended that trials of SLE include outcome measures of QoL, adverse events and economic costs, in addition to measure of disease activity and damage (18).

The most commonly used measure of HRQoL is the short form SF-36. The SF-36 is a generic, 36-item self-report questionnaire. It was designed to be used in a variety of conditions, populations, and settings. The SF-36 has been shown to be a valid and reliable instrument in SLE and has been used in numerous studies in SLE (20). It is also been proposed as an alternative goal in the treat-to-target strategy (19).

1.2. Statement of the problem

The EULAR recommendations for the management of SLE, 2019, recommends HRQoL outcome as part of treat to target approach so that physician and patient have a better targets based shared decision making for better health outcomes (1). The OMERACT trial group recommend trials will be done incorporating HRQoL outcome measure to better address patient concerns(18).

The incidence of SLE is reported to be one per 1000 in Caucasians, compared to four per 1000 in African-Americans (1). A review of rheumatic disorders in sub-Saharan Africa published in 2002, covering the period from the 1950s, found that SLE was increasing in the indigenous populations of East, Central and South Africa (13). A systematic review and meta-analysis, a global study, have showed patients with SLE had lower scores in all SF-36 dimensions compared with controls, especially in the physical role function (41).

In developing countries, SLE has a globally negative impact on patients' HRQoL, similar to that seen in developed countries (44). A case – control and cross sectional studies in Egypt and south Africa have showed poor HRQoL in SLE patients (32,43). In Ethiopia, A multicenter, cross-sectional study was conducted from May 2023 to November 2023 at TASH and Lancet General Hospital showed the prevalence of SLE flare in the first five years of SLE diagnosis was 38.9%, and most flares occurred within the first year of diagnosis(22). It is prudent to say the high frequency of flair would impact HRQoL significantly.

1.3. Significance of the study

The HRQoL related adverse effects of SLE is understudied in sub-Saharan African countries like Ethiopia. But, in clinical practice there is growing exposures of cases of SLE as a result of increasing number of rheumatologists in the country in last few years. In individuals of African trait, SLE is assumed to be more prevalent and more severe than individuals of Caucasian trait. Despite this, SLE continues to receive low public health priority, and there is barely any published data. In Ethiopia, there is no hospital-based study about burden of SLE in terms of HRQoL and factors influencing HRQoL

This study will summarize the Impact of SLE on Health-related quality of life and risk factors for poor HRQoL. Therefore, It will give directed systematic recommendations. Further, it will help to plan to further population-based studies.

2. LITERATURE REVIEW

2.1. Clinical pattern of SLE

Systemic lupus erythematosus (SLE) is a disease that can affect persons of all ages and ethnic groups and both sexes, but more than 90% of new patients presenting with SLE are women in the childbearing years. SLE is a disease that affects multiple systems (23). SLE is an autoimmune disorder characterized by multisystem disease with the generation of numerous autoantibodies, particularly antinuclear antibodies (ANA).

SLE patients present very widely. The most common pattern is a mixture of constitutional complaints with skin, musculoskeletal, mild hematologic, and serosal involvement, but some patients predominately have hematologic, renal, or central nervous system manifestations. The dominating pattern during the initial years of illness tends to prevail throughout the disease course (24). About 10% of the people with lupus confined to the skin will develop the systemic form of lupus (SLE) (25).

A study conducted in Asia revealed that common manifestations included mucocutaneous lesions (seen in 52- 98% of patients) and arthritis/musculoskeletal complaints (36-95%). The study also revealed that antinuclear antibodies were generally positive in 89-100% of patients. Renal involvement of the disease ranged from 18% to 100% with most of the articles reporting this in greater than 50% of their patients. Discoid lesions, serositis, and neurologic features were the least frequently seen symptoms (26).

The female-to-male ratio in a study done in Kenya was 32:1 (21,27). This is in keeping with most literature that reports a female predominance ranging from 83–97% (excluding studies that recruited only female or male patients). The female preponderance is also seen in all these reports from Africa e.g., Cameroun (F: M – 12:1); Zambia (29:0); Nigeria (10:1); South Africa (18:1); Tunisia (11.5:1); Kenya (13:0) (28-31). In a study done in Sudan, Sixty-two Sudanese adults with SLE were included, their mean age was 31 ± 10.9 years. Females made up 93.5% of patients. Arthritis was the dominant clinical manifestation seen in 85.5%, whereas renal involvement was seen in 66.1% of patients (27).

2.3. SLE Effect on HRQoL and determinates of poor HRQoL

Traditionally, SLE is a disease with a great impact on all aspects of health status. Its measurement has traditionally relied on the use of generic or disease-specific questionnaires. Generic questionnaires were developed for general use and may be used in a variety of diseases and populations. The most commonly used measure of HRQoL is the short form (SF)-36 which is a generic questionnaire. The SF-36 is a generic, 36-item self-report questionnaire. It was designed to be used in a variety of conditions, populations, and settings. The SF-36 is a valid and reliable instrument in SLE and has been used in numerous studies in SLE (20). also been proposed as an alternative goal in the treat-to-target strategy (19). However, disease-specific questionnaires are designed to measure outcomes in a specific disease (28). Only recently have disease-specific instruments been developed for use in SLE and these are not yet widely used (29).

A meta-analysis of 36 articles, multinational study, has showed pooled mean scores of SF-36 physical component summary and mental component summary were 46.10 and 50.37, respectively(33). A mixed method study evaluating SLE patients attending two tertiary hospitals in Johannesburg and Cape Town (south Africa) showed the mean mental and physical composite SF- 36 scores were poor (50.9 and 49.1 respectively) (43). In a case-control study in Egypt, SF-36 summary scores for the physical and mental components were decreased in the studied patients compared with controls; PCS was 28.81 ± 16.63, 77.25 ± 15.75 for cases and controls, respectively; and MCS was 32.75 ± 18.69, and 78.75 ± 10.63 for cases and controls, respectively ($p < 0.05$) (32).

A systemic review and meta-analysis of Forty articles representing of 6079 adult SLE patients has revealed mild to moderate negative correlations between disease activity and domains of these HRQoL measurements (correlation coefficient r ranging from -0.27 to -0.07). The pooled correlation coefficient is relatively higher in physical functioning related domains than mental health. In the region subgroup analysis, disease activity had strong negative correlations with SF-36 domains in African and European SLE patients vs Asian SLE patients ($p < 0.010$) (38).

In the USA, a cross-sectional study (single hospital-based) including 55 consecutive patients and using Short Form 36 (SF-36) and the EuroQol (EQ-5D). It concluded that the Perceived health status of patients with lupus was associated with disease activity, damage, role physical, bodily pain, capacity for usual activity, and mobility (34). Cross-sectional study concerning assessment of disease activity and HRQoL (using LupusQoL) in patients with SLE at Kenyatta National Hospital also showed a low HRQoL in those with active disease (37). Lai et al found that low-grade inflammation as reflected by low serum albumin and hemoglobin concentrations was associated with impaired HRQoL in patients with SLE, independent of other socio-demographic and clinical variables (35).

In Systemic Lupus Erythematosus (SLE), age appears to have a negative impact on Health-Related Quality of Life (HRQoL), especially regarding physical health, with advanced age being a risk factor for worse outcomes in various domains. A meta-analysis of 36 articles, including 6510 patients. found that mean age, proportion of female participants, and publication decades were negatively associated with some of the SF-36 domains(33). A cross-sectional study done in Venezuela has also revealed age and disease activity were negatively correlated with almost all domains of the LupusQoL (41).

In individuals with SLE, HRQoL is reduced. While disease activity and damage impact HRQoL, the effect of disease duration is complex and not fully understood, with some studies suggesting a positive impact of long quiescent disease courses. A Chinese study showed that the longer duration of illness exposure, the better the HRQoL of SLE patients (39). Patients with recent onset SLE ($\leq 1.2 \pm 0.6$ years duration) had worse HRQoL scores compared to those with longer disease duration [($> 8.5 \pm 5.2$ years duration) ($p = 0.07$)]. The authors speculated that improved disease perceptions and coping mechanisms were some of these reasons for the changes (40). However, a Brazilian study reported better HRQoL scores amongst participants with shorter disease duration compared to an SLE diagnosis of more than 5 years [87.3 vs 82.2% on the total WHOQoL score, ($p = 0.05$)] (40).

A study by Strand et al showed that the impact of SLE was evident - with decrements in HRQoL similar to those reported by patients with inflammatory arthritis, chronic congestive heart failure, and post-myocardial infarction (36).

2.4 Conceptual framework

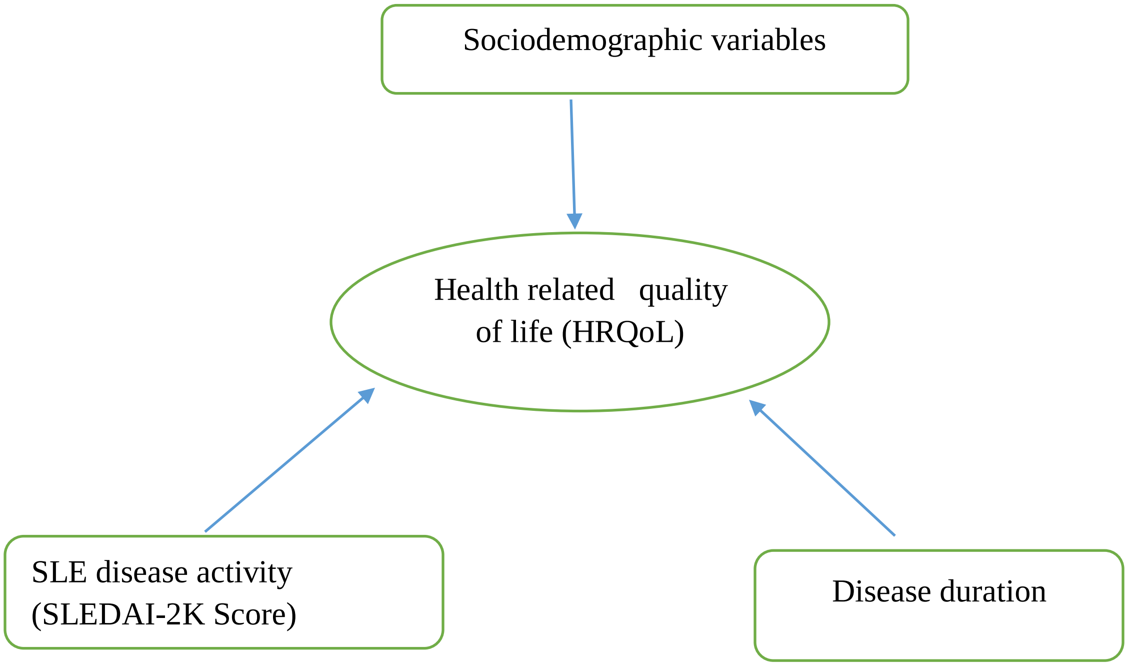

Figure 1: Conceptual framework

3. OBJECTIVE OF THE STUDY

3.1 General Objective

To assess the health-related quality of life and its determinants of poor HRQoL among patients with systemic lupus erythematosus (SLE) attending selected rheumatology clinics in Addis Ababa, Ethiopia, from January 2024 to January 2025.

3.2 Specific Objectives

1. To determine the level of health-related quality of life among SLE patients attending selected rheumatology clinics in Addis Ababa, Ethiopia.
2. To assess factors associated with the poor HRQoL among SLE patients attending selected rheumatology clinics in Addis Ababa, Ethiopia.

4. METHODS

4.1. Study area and period

The study was conducted at TASH and Rheum Specialty Clinic from January 2024 to January 2025. TASH is one of the largest teaching hospitals in Ethiopia, found in Addis Ababa, providing undergraduate, postgraduate, and fellowship programs in different fields of clinical medicine.The Internal Medicine department provides services in different subspecialties in both outpatient and inpatient department including emergency and intensive care units. The outpatient department is a medical referral clinic composed of subspecialty clinics, such as, Cardiac, Pulmonology, Neurology, Hematology, Nephrology and Rheumatology clinics. Rheum Specialty Clinic is a specialized private owned clinic providing rheumatology outpatient subspecialty service and other subspecialty services.

4.2. Study design and study period

Institution-based cross-sectional study was conducted from January 2024 to January 2025

4.3. Source population

The source population encompassed SLE patients who visited the rheumatology clinics of TASH, and Rheum specialty clinic.

4.4. Study population

The study population included SLE patients who had visited the rheumatology clinics and who fulfilled the inclusion criteria.

4.5. Inclusion and exclusion criteria

4.5.1. Inclusion criteria

This study included all SLE patients who comply with the 2019 ACR/EULAR criteria for the classification of SLE

4.5.2. Exclusion criteria

Patients with incomplete medical records

participants with any other rheumatic diseases, coexisting morbidity unrelated to SLE, such as diabetes (excluding steroid induced DM) or hypertension, cancer, dementia, psychosis (not related to SLE), or overlap syndrome to avoid confounding factors

4.6. Sample size determination & sampling technique

$$n = \frac{[z]^2 \times p(1-p)}{d^2}$$

Where:

n = the sample size

Z-score for a 95% confidence interval is 1.96

d = marginal Error taken as 5%

P = estimated proportion of the population that presents the characteristic (when unknown we use p = 50%)

Since the population size is <10,000, the following correction formula is used to reduce the sample size. The total number of patients treated and on follow-up for PTE at the two health facilities is taken as 167 after revision of the health management information system (HMIS) registry.

$$n = \frac{n0}{1 + \frac{n0}{N}}$$

Where,

n = Final sample size

n0 = Initial sample size =384

N= Source population size = 167

The sample size after taking N as 167 is 116, adding a ten percent nonresponse rate makes the final sample size 128. Since the target population was small in number, the researcher chosen consecutive non probability sampling method to incorporate as much study subjects as possible.

4.7. Study variables

4.7.1. Dependent variables

- HRQoL: - Global score, Mental component score, and Physical component score

4.7.2. Independent variables

- SLE disease activity.
- Disease duration
- Age, marital status, educational status, occupational status

4.8. Operational definitions

1. Low Disease Activity: Defined as SLE Activity Index (SLEDAI) ≤4, Physician Global Assessment (PGA) ≤1, with glucocorticoid (GC) use ≤7.5 mg of prednisone, and well-tolerated immunosuppressive (IS) agents.
2. Health-Related Quality of Life (HRQoL) It was assessed using the SF-36 (RAND version - 1) assessment tool, which is designed to capture the overall well-being of the patient by evaluating both physical and mental health components. The RAND-36 generates two key summary scores:
    - Physical Component Summary (PCS): The PCS reflects the patient's physical health, with a focus on aspects such as physical functioning, role limitations due to physical health, pain, and general health perceptions.
    - Mental Component Summary (MCS): The MCS assesses the patient's mental health, addressing aspects such as emotional well-being, role limitations due to emotional health, social functioning, and energy/fatigue.

4.9. Data source and collection method

Data was collected by the investigator with a pre-tested structured questionnaire which was adopted from previous studies. It was also collected primarily by reviewing electronic records, patient charts as necessary, and patient interviews through phone calls.

4.10. Method of data analysis

Statistical Package for Social Sciences (SPSS) version 27.1 was for data entry and analysis. Descriptive statistic was used to determine percentage of cases, mean, median, standard deviation and interquartile range. Factors related to the poor quality of life was determined using multivariable linear regression analysis. Normality assumption was assessed for model selections. The 95% confidence intervals were estimated for the coefficient (B) and statistical significance was set at $p < 0.05$.

4.11. Ethical consideration of the study

Ethical clearance was obtained from the Institutional Review Board (IRB) of Tikur Anbessa Specialized Hospital and a formal letter of permission was obtained from the hospital’s administration before starting the study. Before starting the data collection process, informed consent was obtained from all study participants.

4.12. Dissemination of result

The final result of the research will be submitted to Addis Ababa University School of Medicine. The results will be presented during the defense. The copies of the results will be available to the Internal Medicine Department in each hospital and the hospital’s administration. Publication in scientific journals will be attempted.

5. RESULT

5.1. Sociodemographic and Clinical Characteristics of SLE Patients

From an estimated 128 systemic lupus erythematous (SLE) patients, 121 participated, yielding a response rate of 94.5%. The overall mean age of participants was 31.2 ± 9.27 years, and the vast majority were female (99.2%).

Of the 121 patients, 18 (14.9%) had active disease, while 103 (85.1%) had low disease activities. The mean age did not significantly differ between active and inactive groups (29.6 ± 8.8 vs. 31.5 ± 9.9 years, respectively; $p > 0.05$). Similarly, sex distribution was comparable across groups ($p = 0.67$).

There were no statistically significant differences in marital status, education level, or employment status between the two groups ($p > 0.05$ for all). The most frequently reported clinical manifestations were constitutional symptoms (80.2%), mucocutaneous involvement (80.2%), and musculoskeletal symptoms (64.5%), with similar distribution across both groups.

Among laboratory parameters, only erythrocyte sedimentation rate (ESR) showed a significant difference, being higher in patients with active disease (25.6 ± 7.4 mm/hr) compared to those with inactive disease (17.0 ± 4.7 mm/hr; $p = 0.001$). No significant differences were observed in leukocyte count, hemoglobin level, platelet count, serum creatinine, ANA titers, or anti-dsDNA levels (Table 1).

Table 1. ***Sociodemographic, Clinical, and Laboratory Characteristics of SLE Patients in Selected Rheumatology Clinics in Addis Ababa, Ethiopia***

Variables	**Total cases (n=121)**	**Active disease (n=18)**	**Low disease Activity (n=103)**	**P-value**
Sex female (%)	120/121(99.2)	18(100%)	102(99.2)	0.67
Mean age ±SD	31.24±9.27	29.56±8.82	31.53 ±9.89	
Marital status				0.09
Ever married	56(46.3)	5(27.8)	51(49.5)	
Single	65(53.7)	13(72.2)	52(50.5)	
Educational status				0.72
Primary	12(9.9)	1(5.6)	11(11.7)	
Secondary	63(52.1)	8(44.4)	38(36.9)	
College and above	46(38.0)	9(50.0)	54(52.4)	
Employment status				
Employed	58(47.9)	8(44.4)	50(48.5)	
Housewife	30(24.8)	4(22.2)	26(25.2)	
Students	33(27.3)	6(33.3)	27(26.2)	
Clinical presentation				
Constitutional	97(80.2)	13(7.22)	84(81.6)	0.36
Musculoskeletal	78(64.5)	12(66.7)	66(64.1)	0.13
Mucocutaneus	97(80.2)	12(66.7)	85(82.5)	0.12
Serositis	19(15.7)	5(27.8)	14(13.6)	0.17
Renal manifestation	23(19.0)	5(27.8)	18(17.5)	0.31
Hematologic	21(17.4)	6(33.3)	15(14.6)	0.56
Neuropsychiatric	4(3.30)	1(5.60)	3(2.70)	0.56
Cardiovascular manifestation	10(8.30)	3(16.70)	7(6.80)	0.16
Respiratory manifestations	3(2.50)	1(5.6)	2(1.9)	0.36
Disease duration, Median (IQR)	3.0(2.0-5.0)	4(3.0-4.0)	3(2.0-5.0)	0.32
Laboratory				
Leukocytes, Mean (SD), cell/ **µ** l	4.88(±525)	4807.8(+349)	4903.7(+550)	0.47
Hemoglobin, Mean [SD], g/dl	11.97(±0.66)	11.9(+0.55)	11.99(+0.6)	0.43
Platelets, Mean [SD], cell/ µl	210.87(±463)	210.9(+498)	210.6(+459)	0.98
Creatinine, Mean [SD], mg/dl	0.92(±0.15)	0.94(+0.16)	0.92(+0.15)	0.54
ESR (SD), mm/1st hour	18.28(±6)	25.56(7.4)	17.01(+4.7)	0.001
ANA(n=58), Mean (SD)	879.1(320-1000)	500(320-1000)	1000(320-1000)	0.10
Anti-DNA (n=55), (IQR)	422.5(67.1539.2)	200(42-857)	245.6(73.1-473.2)	0.42

5.2 Health-related quality of life among SLE patients

The overall mean HRQoL score among patients with systemic lupus erythematous (SLE) was 48.41 ± 5.7, with scores ranging from 31.18 to 64.31**.** The mean scores for the physical component summary (PCS) and mental component summary (MCS) were 46.28 ± 8.4 and 50.54 ± 8.03**,** respectively. Among the eight domains of the RAND-36, the highest mean scores were observed in physical functioning (58.30 ± 11.3)**,** social functioning (53.78 ± 6.65)**,** and role limitations due to emotional problems (52.34 ± 27.83)**.** The lowest mean score was recorded in role limitations due to physical health (37.81 ± 21.6)**.**

Table 2. Health-Related Quality of Life Scores across RAND-36 Domains among SLE Patients in Rheumatology Clinics, Addis Ababa, Ethiopia

Eight components of the HRQoL		**Mean (SD)**	**Min**	**Max**
	General Health	44.45(7.1))	31.0	63.0
	Physical functioning	58.30(11.3)	20.00	85.0
	Role limitations due to physical health	37.81(21.6)	0.0	100
	Body pain	44.57(7.3)	20.0	67.3
	Role limitations due to emotional problem	52.34(27.83)	0.0	100
	Social functioning	53.78(6.65)	32.5	75.0
	Energy/Fatigue	46.91(5.67)	30.0	60.0
	Emotional well-being	49.16(5.21)	36.0	68.0
Summary of HRQoL				
	Physical component summary	46.28(8.4)	26.63	61.0
	Mental component summary	50.54(8.03)	29.13	68.75
Overall HRQoL				
	Overall HRQoL	48.41(+5.7)	31.18	64.31

5.3 Associated factors for poor HRQoL among SLE patients

The multivariable linear regression analysis revealed several significant factors associated with the overall health-related quality of life (HRQoL) among patients with systemic lupus erythematous (SLE). Age was negatively associated with HRQL, where each additional year of age resulted in a decrease of 0.144 points in HRQoL (P = 0.035, 95% CI: -0.277 to -0.010). This indicates that older SLE patients tend to experience lower quality of life scores. Additionally, the duration of disease was significantly associated with HRQoL; for every year increase in disease duration, there was a decrease of 1.215 points in HRQoL (P = 0.02, 95% CI: -2.161 to -0.268), suggesting that a longer disease duration negatively impacts patients' overall quality of life. Disease activity also played a critical role in HRQoL, with patients experiencing active disease reporting 5.41 points lower HRQoL than those with low disease activity (P = 0.01, 95% CI: -9.578 to -1.287). This highlights the detrimental effect of active disease on both the physical and mental well-being of SLE patients. Lastly, occupation was an important factor, with housewives reporting a 3.057-point lower HRQoL compared to individuals in other occupations (P = 0.022, 95% CI: -5.670 to -0.444).

Table 3 :Multivariable linear logistic regression to assess factors associated with physical component summary and mental component summary (n = 121)

Variables	Coefficient (B)	P-value	95.0% Confidence Interval for B	
			Lower Bound	Upper Bound
Age	-0.14	0.04	-0.28	-0.01
Duration of disease	-1.21	0.02	-2.16	-0.27
Disease activity				
Active disease	-5.41	0.01	-9.58	-1.29
Low disease activity	Reference	Reference	Reference	Reference
Occupation				
Housewife	-3.06	0.02	-5.67	-0.44
Others	Reference	Reference	Reference	Reference

6. DISCUSSION

This study aimed to determine the health-related quality of life (HRQoL) among patients with systemic lupus erythematous (SLE) who were receiving follow-up care at selected rheumatology clinics in Addis Ababa, Ethiopia. The overall mean HRQoL score among SLE patients was 48.41 ± 5.7, with the mean scores for the physical component summary (PCS) and mental component summary (MCS) being 46.28 ± 8.4 and 50.54 ± 8.03, respectively. The study identified several significant predictors of poorer HRQoL, including increasing age, longer disease duration, active disease activity, and being a housewife. These factors were associated with a decreased overall quality of life among SLE patients.

The mean overall HRQoL score in this study was 48.41 ± 5.7 with a physical component summary (PCS) score of 46.28 ± 8.4, and a mental component summary (MCS) score of 50.54 ± 8.03. These values indicate a moderate impairment in overall well-being, with a more notable reduction in Role limitations due to physical health. However, this score is notably higher than the severe impairment reported in Egypt (PCS: 28.81; MCS: 32.75) (32). This disparity may stem from differences in healthcare infrastructure (e.g., better access to biologics or multidisciplinary care in the current cohort), socioeconomic status, or cultural resilience (e.g., stronger familial support networks or stigma against reporting poor health). Variations in disease phenotypes, such as lower renal involvement in the current study, or genetic factors could also contribute to milder HRQL impacts. However, both PCS and MCS are almost similar to PCS and MCS of meta-analysis and south Africa cross sectional study, respectively (33,32). The physical component (PCS: 46.28 ± 8.4) scored lower than the mental component (MCS: 50.54 ± 8.03), aligning with studies from the U.S. (34) and China (33), where physical burdens like fatigue and joint pain dominate, though mental health remains suboptimal compared to healthy populations. The slightly higher MCS score relative to PCS in the current study may reflect a coping mechanism or psychosocial adaptation over time, despite persistent physical symptoms.

Active disease was a significant determinate of reduced HRQoL among SLE patients in our study. Similarly, a systemic review and meta-analysis of Forty articles representing of 6079 adult

SLE patients has revealed negative correlations between disease activity and domains of these HRQoL measurements (correlation coefficient r ranging from -0.27 to -0.07). The pooled correlation coefficient is relatively higher in physical functioning related domains than mental health. In the region subgroup analysis, disease activity had strong negative correlations with SF-36 domains in African and European SLE patients over Asian SLE patients (38). In addition, a hospital-based cross-sectional study in the USA utilizing the SF-36 and EQ-5D questionnaires revealed that disease activity, damage, physical functioning, pain, and mobility were key determinants poor HRQoL was in SLE patients (34). A Cross-sectional study in Kenya has also showed a low HRQoL in those with active disease (37). This reinforces the relationship between clinical severity and patient experience in SLE across diverse populations. Flares and uncontrolled inflammation amplify physical symptoms (e.g., pain, fatigue) and mental health struggles, directly impacting daily functioning. The absence of biomarker analysis (e.g., hypoalbuminemia) in this study, unlike Lai et al (35), leaves room for exploring subclinical inflammation's role in HRQoL disparities.

Longer disease duration correlated with poorer HRQoL in our study, a trend positively and negatively associated with some studies, e.g. Brazilian study (40) and Chinese study (39) respectively. This study's negative disease duration and HRQoL correlation may be due to the accrual of irreversible organ damage (e.g., glomerulosclerosis, joint deformities) and treatment-related complications (e.g., steroid-induced osteoporosis). Over time, persistent inflammation may dysregulate immune and metabolic pathways, accelerating comorbidities like atherosclerosis. Psychologically, chronic illness related fatigue and "burnout" from decades of managing flares could erode mental resilience, as seen in studies linking prolonged SLE to depression (34). Early, aggressive disease control is critical to mitigate this trajectory and preserve long-term HRQoL.

Advancing age was a significant predictor of reduced HRQoL, mirroring findings from the Chinese meta-analysis (33) and Venezuela cross sectional study (41). This association may arise from age-related physiological declines (e.g., reduced regenerative capacity, comorbid conditions like osteoporosis) that synergize with SLE-related damage. Older patients also face polypharmacy risks, amplifying side effects like fatigue or cognitive impairment. Psychosocial factors, such as retirement-related loss of purpose or financial strain from chronic illness, could further worsen HRQL— a dynamic less prominent in younger cohorts. These factors highlight the compounding burden of aging in SLE, where biological and social vulnerabilities intersect.

Being a housewife uniquely predicted poorer HRQoL, this finding not explicitly addressed in prior literature. Housewives may experience a higher physical and emotional burden due to limited social engagement, decreased economic independence, and potential lack of structured support systems. In the context of SLE, a disease characterized by chronic fatigue, pain, and functional impairment, the lack of occupational engagement or social reinforcement may exacerbate feelings of isolation, dependency, and low self-worth, thereby impacting both physical and mental health components of HRQoL.

7. Strength and limitations

This study has several strengths. It employed a standardized health-related quality of life (HRQoL) assessment tool, ensuring valid measurement and enabling comparison with global studies. The multicenter design across two rheumatology clinics in Addis Ababa enhances the generalizability to a broader urban SLE patient population. The comprehensive data collection approach, integrating chart reviews, electronic medical records, and interviews, ensures thorough capture of clinical and sociodemographic variables. Disease activity was assessed using objective markers allowing meaningful comparisons between active and inactive disease. However, the study has limitations. As a cross-sectional design, it cannot infer causal relationships between determinants and HRQoL. The relatively small sample size may reduce statistical power, limiting the ability to detect subtle associations. Recall bias from patient phone interviews may affect the accuracy of self-reported data. Additionally, excluding patients with common comorbidities like hypertension and diabetes mellitus may reduce the external validity, as these conditions are common in routine SLE clinical settings.

8. Conclusion and recommendations

In conclusion, this study found that the health-related quality of life (HRQoL) among patients with systemic lupus erythematosus (SLE) in Addis Ababa was significantly affected by disease activity, with patients exhibiting higher disease activity reporting poorer HRQoL. Sociodemographic factors, including age and socioeconomic status, were also identified as influencing HRQoL levels.

Based on the findings of this study, several recommendations can be made to improve the health-related quality of life (HRQoL) of SLE patients. Firstly, enhancing disease management strategies is crucial, as disease activity was found to significantly impact HRQoL. Timely and effective treatment should be prioritized, along with regular monitoring of disease status, to minimize disease activity and improve patient outcomes. Additionally, sociodemographic factors such as age, and socioeconomic status should be taken into consideration when planning and delivering care. Tailoring interventions to these factors may help address disparities in HRQoL among different patient groups. Furthermore, integrating regular HRQoL assessments into routine clinical practice could facilitate the monitoring of disease impact and enable healthcare providers to make necessary treatment adjustments. Patient education and support are also essential, as empowering patients with knowledge about their disease and management strategies can improve coping mechanisms and enhance their overall quality of life. Finally, further research is needed to explore the long-term effects of SLE on HRQoL and evaluate the benefits of targeted interventions

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