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Health-related quality of life and its associated factors in patients with systemic lupus erythematosus attending the Rheumatology Clinic at the National Hospital of Sri Lanka

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Abstract

Background: The aim of this study was to assess the health-related quality of life (HRQoL) and its associated factors in Systemic Lupus Erythematosus (SLE) patients attending the Rheumatology Clinic at the National Hospital of Sri Lanka.

Methods: A cross-sectional study was conducted in patients who were diagnosed with SLE based on 2012 European Alliance of Associations for Rheumatology/American College of Rheumatology (EULAR/ACR) criteria. The Short Form 36 health survey questionnaire (SF-36) which scores 0-100 for each of eight domains and summarised as Physical Component Summary (PCS) and Mental Component Summary (MCS), with higher values indicating better functions and an interviewer-administered questionnaire comprising Systemic Lupus Erythematosus Disease Activity Index 2000 (SLEDAI 2k) 30-day score, Systemic Lupus Erythematosus Collaborating Clinics/American College of Rheumatology (SLICC/ACR) damage index, and sociodemographic data were used to collect data. A SLEDAI score of less than 6 was considered as "mild disease activity" while a score equal or higher than 6 was considered as "moderate to high disease activity". SLICC damage index of 0 was considered as "no damage" and > 0 was considered as "damage present". Descriptive statistics, Pearson correlation coefficient (r) (r 0.0- 0.3 - No correlation, r 0.3-0.5 weak, r 0.5 - 0.7 moderate, r >0.7 strong), and Student T-Test were used for data analysis.

Results: Sixty participants were recruited from consecutive sampling, predominantly female (98.3%), with a mean age of 36.1 years (SD 12.96) and a mean disease duration of 6.01 years (SD 5.67). Forty-six (76.7%) of them had mild disease activity with a mean SLEDAI score of 5.08 (SD 8.39) and a mean SLICC damage index of 1.4(SD 1.21). Among the eight domains of SF-36 HRQoL of the total study group, the lowest score was in the general health domain with a mean value of 45.36 (SD 22.78), and the highest was in the social well-being domain at 74.01 (SD 26.53). The mean Physical Component Summary score (56.59, SD 27.04) was lower than the mean Mental Component Summary score of 65.69 (SD 25.08). Patients with moderate to high disease activity scored significantly lower ($p<0.05$) in all HRQoL domains and summary components compared to patients with mild disease activity. Physical and mental summary components negatively correlated with age (PCS r= -0.48, MCS r= -0.40) and Erythrocyte Sedimentation Rate (ESR) (PCS r = -0.38, MCS r = -0.39).

Conclusions: The disease had a negative impact on the quality of life of SLE patients with a higher disease activity causing a significant reduction in all aspects of HRQoL. Thus, actively assessing HRQoL, specially in those with above risks and managing accordingly will help to improve the overall outcome of SLE patients.

Key words: systemic lupus erythematosus, health related quality of life, SF 36 questionnaire, physical summary component, mental summary component

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Introduction

Systemic lupus erythematosus (SLE) is a multi-system autoimmune inflammatory disorder affecting predominantly females. It has a varying prevalence worldwide with prevalence in Asia being 30 to 50/100,000 population.[1] Over the years, with improvement of diagnosis and treatment, patient survival has improved reaching more than 95% 5-year survival and 85% of 10-year survival.[2] However, despite improvement in treatment and survival in SLE, quality of life remains to be lower than in general population.[3] This study aims to assess health related quality of life (HRQoL) in SLE patients and identify associated factors in a Sri Lankan setting, with the purpose of improving clinical practice and patient management.

Health related quality of life (HRQoL) is a multi-domain concept indicating the overall impact of a disease and its treatment on the individual's ability to function and their perceived well-being in the physical, mental and social life domains.[4] HRQoL in SLE can be measured by either generic questionnaires such as the Medical Outcomes Study (MOS) 36-Item Short Form Survey (SF-36) or disease-specific questionnaires such as LupusQoL, SLEQoL and Lupus-PRO.[5,6] SF 36 is widely used and considered equally effective as disease specific questionnaires in measuring HRQoL of SLE patients.[7,8] SF 36 questionnaire is validated for Sri Lankan population hence the reason this questionnaire was used in this study.[9]

HRQoL can be affected by various factors such disease activity, damage, duration, fatigue, fibromyalgia, depression, social support, education, and employment status.[10] SLE disease activity has shown direct negative relationship with HRQoL in many studies.[11]

Poor HRQoL negatively impacts treatment adherence, stress management, intimate relationships, and home and job-related activities.[12] HRQoL assessment should be an essential part of medical follow up as it facilitates the planning of patient care, a holistic approach toward patient management, and improving communication between the clinician and patient.

There are no published Sri Lankan data on the quality of life in SLE patients. The primary objective of this study was to assess the health-related quality of life in patients with SLE attending the Rheumatology Clinic at the National Hospital of Sri Lanka and to identify the factors that are associated HRQoL. Thus, we hope this study will provide new information in our local population which can be beneficial to the practicing rheumatologist to improve the care of patients with SLE.

Methods

This descriptive cross-sectional study was conducted from July 2022 to December 2022 at the Rheumatology Clinic of the Department of Rheumatology of the National Hospital of Sri Lanka. The study population included patients diagnosed with SLE based on the 2012 EULAR/ACR criteria with a disease duration of more than six months. Consecutive sampling was used due to the low prevalence of SLE. Although 180 SLE patients were registered in the clinic, during the time of the study the clinic attendance was poor due to the COVID pandemic.

Ethical clearance for the study was obtained from the Post Graduate Institute of Medicine and informed consent was taken from patients before being recruited.

HRQoL was assessed using the Medical Outcomes Study (MOS) 36-Item Short Form Survey (SF-36). SF-36 scores 0 - 100 for each of eight domains and higher values indicate better function. The eight domains were summarised into physical and mental cumulative summary components. Additional data were collected using an interviewer-administered questionnaire consisting of 3 components; socio demographic data and information on disease; SLEDAI 2k data collection sheet applied for last 30 days; and SLICC damage index. A SLEDAI score of less than 6 was considered as "mild disease activity" while a score equal or higher than 6 was considered as "moderate to high disease activity" and these two groups were compared in analysis. SLICC damage index of 0 was considered as "no damage" and > 0 was considered as "damage present". Homemakers (housewives) were defined as married women who are not employed but primarily responsible for managing the household and caring for the family.

Data were analysed using Statistical Package of Social Sciences (SPSS) 19. Descriptive statistics, Pearson correlation coefficient (r) (r 0.0-0.3 - No Correlation, r 0.3-0.5 weak, r 0.5-0.7 moderate, r >0.7 strong), was used to identify correlations between HRQoL and associated factors and Student's t-test was employed for group comparisons. A p-value of <0.05 was considered statistically significant.

Results

Demographic and clinical characteristics

The study included 60 patients, predominantly female (98.3%). The mean age was 36.15 years (SD 12.96), with a mean disease duration of 6.01 years (SD 5.74). 68.33% were married while 26.67% were unmarried. The majority have studied up to O/L (50%).

41.67% of the group were employed while 40% were home makers. A minority were unemployed (16.67%). Most patients had mild disease activity (76.7%), with a mean SLEDAI score of 5.08 and a mean SLICC damage index of 1.4 (Table 1).

The mean HRQoL was calculated for each domain based on the SF 36 (Figure 1), and was summarized as physical and mental summary components. The mean scores for each domain were; Physical functioning: 63.17 (SD 28.88), Role physical: 55.42 (SD 44.17), Pain: 62.41 (SD 28.66), General Health: 45.36 (SD 22.78), Vitality: 56.78 (SD 23.37), Social Well-being: 74.01 (SD 26.53), Role Emotional: 68.47 (SD 44.44), Emotional Well-being: 63.51 (SD 63.51). The physical summary component (PCS) was 56.59 (SD 27.04) while the Mental summary component was (MCS): 65.69 (SD 25.08) (Figure 1).

Table 1. Demographics and disease characteristics

Parameter		*Number (SD/Percentage)*
Age Years (SD)		36.1 (± 12.96)
Sex n (%)	Female	59 (98.3%)
	Male	01 (1.7%)
Disease duration Years (SD)		6.01(± 5.74)
Marital status	Married	41 (68.3%)
	Unmarried	16 (26.6 %)
	Divorced	3 (5.0 %)
Education level n (%)	Never gone to school	2 (3.3%)
	Up to grade 5	2 (3.3%)
	Up to Ordinary Level	30 (50%)
	Up to Advanced Level	16 (26.7%)
	Graduate	9 (15.%)
	Post graduate	1 (1.67%)
Employment state n (%)	Employed	25 (41.7%)
	Homemaker	24 (40%)
	Unemployed	10 (16.6%)
	Self Employed	01 (1.7%)
ESR Mean (SD)		39.41 (±28.84)
Comorbidities[a] n (%)	Present	38 (47.5%)
	Absent	31 (52.5%)
DMARDS[b]	On DMARDs	59 (98.3%)
	Not on DMARDs	01 (1.7%)
SLEDAI score Mean (SD)		5.08 (±8.39)
SLICC damage index		1.4 (±1.21)

[a] Comorbidities – hypertension, thyroid disease, other autoimmune diseases, psychiatric diseases, other.

[b] DMARDS – Disease Modifying Anti Rheumatoid Drugs – Hydroxychloroquine, Methotrexate, Mycophenolate mofetil, Cyclophosphamide, Azathioprine, Biologics.

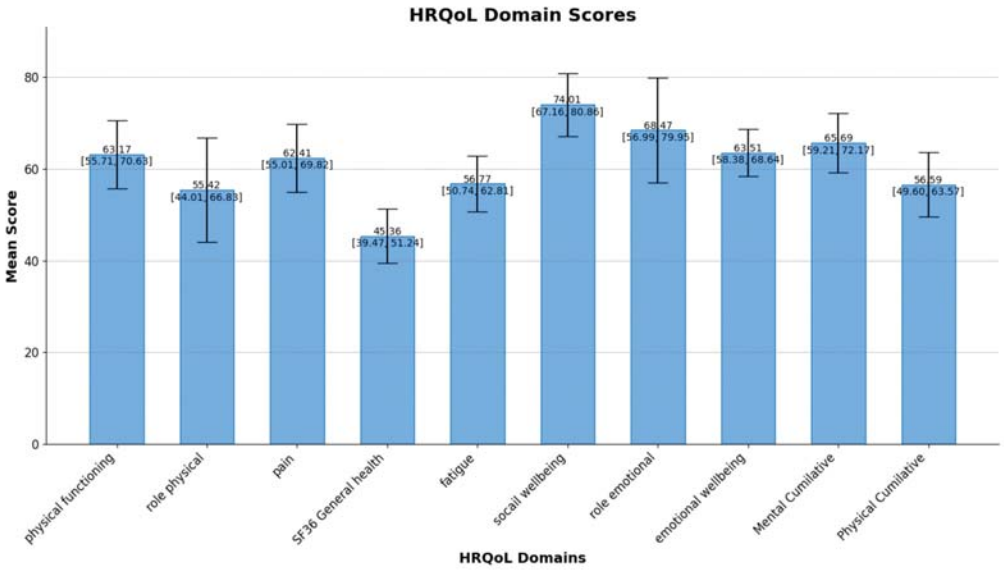

Figure 1. Correlation between HRQoL and SLEDAI score were assessed using Pearson Correlation test.

The Table 2 illustrates the association between the HRQoL domains and SLEDAI score.

Table 2. Correlation between HRQoL and SLEDAI score

HRQoL domain	*Correlation coefficient*	*P value*	*95% CI lower*	*95% CI upper*
Physical functioning	-0.38	0.0024	-0.5798	-0.1465
Role Physical	-0.38	0.0024	-0.5781	-0.1395
Pain	-0.47	0.00015	-0.6450	-0.2467
SF36 General Health	-0.47	0.00016	-0.6448	-0.2465
Fatigue	-0.42	0.00083	-0.6089	-0.1859
Social Wellbeing	-0.44	0.00043	-0.6232	-0.2122
Role emotional	-0.42	0.00083	-0.6078	-0.1884
Emotional Wellbeing	-0.43	0.00054	-0.6166	-0.1976
Physical Cumulative (PCS)	-0.46	0.00020	-0.6397	-0.2383
Mental Cumulative (MCS)	-0.43	0.00054	-0.6180	-0.2042

There was a negative weak corelation between HRQoL domains and SLEDAI score but with a P value <0.05.

In the group comparison to compare HRQoL between patients with mild disease activity and moderate to high disease activity groups, patients with moderate to high disease activity group scored lower than the mild disease activity group for all HRQoL domains with P values of <0.05 as illustrated in the Table 3.

Table 3. HRQoL domain Means for moderate to high disease activity and mild disease activity groups

HRQoL Domain	*Moderate-high diseaseactivity (Mean)*	*Mild disease activity (Mean)*	*P value*
Physical functioning	47.50	67.93	0.0191
Role Physical	19.64	66.30	0.0003
Pain	36.04	70.44	0.00003
SF36 General Health	24.64	51.66	0.000037
Fatigue	42.07	61.25	0.0061
Social Wellbeing	49.82	81.37	0.000035
Role emotional	30.94	79.89	0.00015
Emotional Wellbeing	53.43	66.58	0.0287
Physical Component Summary (PCS)	31.96	64.09	0.000036
Mental Component Summary (MCS)	44.07	72.27	0.000106

There was no significant association between SLICC damage index and the HRQoL domains in the group comparison between ‘damage present’ and ‘damage absent’ and all the p values were >0.05.

Out of the other factors that were analysed for associations with HRQoL, Age and ESR showed a negative weak correlation with both PCS and MCS with a p value of <0.05 (Table 4).

Table 4. Correlation between Age, ESR with Physical Component Summary (PCS) and Mental Component Summary (MCS)

Variable	*Outcome*	*Correlation coefficient*	*P value*	*95% CI lower*	*95% CI upper*
Age	PCS	-0.47	0.00014	- 0.6504	- 0.2513
Age	MCS	-0.40	0.00163	-0.5947	- 0.1642
ESR	PCS	-0.38	0.00302	-0.5779	-0.1392
ESR	MCS	-0.39	0.00259	-0.5822	-0.1455

When analysed for employment status, homemakers had lower HRQoL than the employed and unemployed group. However, there were significant differences in mean ages between the groups hence the findings were corrected for age. Correction was done by fitting a linear regression model, calculating the residuals and adding the mean age effect back and when corrected there was no significant difference in HRQoL among the homemakers and employed or unemployed groups (Figure 2).

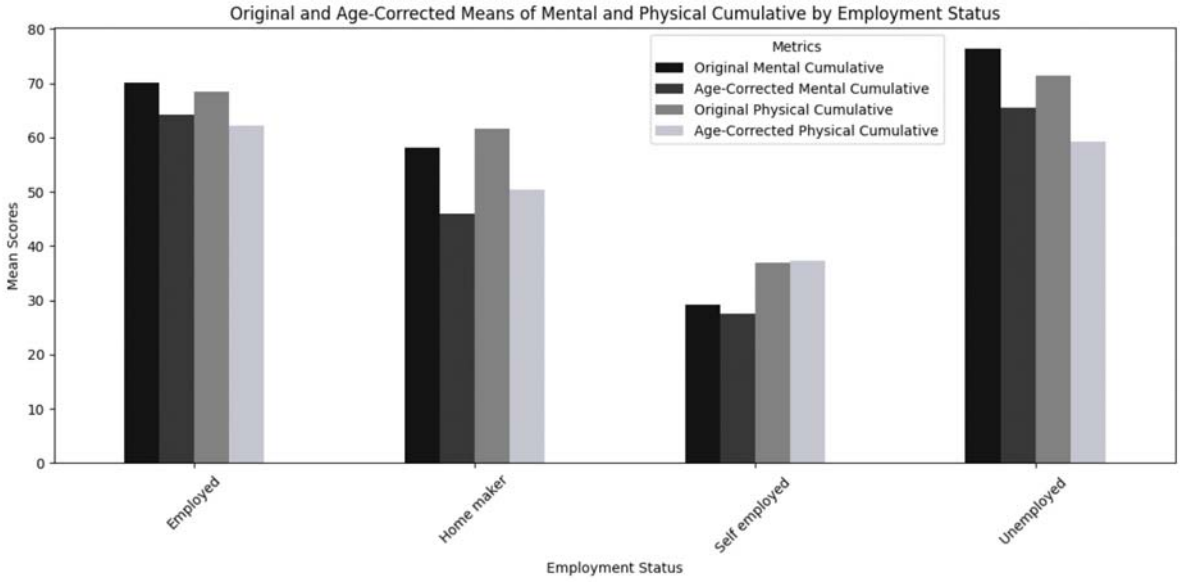

Figure 1.

Pearson correlation coeffect (r) was calculated to find the association between HRQoL and disease duration (PCS r = 0.08, MCS r = 0.001), however results did not reveal a corelation between the two parameters.

Discussion

This study provides a valuable insight to health-related quality of life in patients with SLE in a Sri Lankan cohort and demonstrates that SLE negatively impacts physical and mental domains of HRQoL. The physical component is more affected than the mental component in our study group. The most affected physical domain was the general health, and the mental domain was the vitality. The least affected physical domain was physical functioning, and the mental domain was social wellbeing. Out of all 8 domains, general health scored the lowest while the social wellbeing domain scored highest. Our results are comparable to results from a systematic review and metanalysis by Gu et al, done to assess impact of the SLE on HRQoL measured by SF 36.[13] This metanalysis included 36 articles and 6,510 SLE patients, and included only studies with a sample size more than 50. Among all of the 8 domains lowest score was in the general health domain while the highest score was in the social wellbeing/functioning. In physical domains the highest score was in physical functioning and the lowest in the general health, and in the mental domains highest score was in social functioning and lowest was in vitality, similar to our study. The pooled physical component summary was lower than the mental component summary as well.

SLE patients have a high prevalence of fatigue, depression and fibromyalgia according to previous studies, thus a low score for vitality (fatigue) domain is an explainable finding as demonstrated in our group.[14] In an European survey by Cornet et al to assess the burden of living with SLE in 2020, on 4375 SLE patients, fatigue was the most commonly reported symptoms accounting to for 85.3% and fatigue and weakness were the most common symptoms patients wished to go away.[15] Elena et al did a cross sectional study of 233 patients with SLE to assess the impact of fatigue on HRQoL and found that SLE patients had more fatigue than matched healthy controls and fatigue reduced all domains of HRQoL with vitality domain affected the most.[16] They did not find as association with fatigue and disease severity, duration or treatment, but fatigue was more prevalent in patients with fibromyalgia. This evidence is reflective of how SLE patients scores low on vitality domain of HRQoL, similar to the results of our study.

When analysing associated factors of HRQoL, we found a significant corelation between the HRQoL domains and the disease activity as measured by SLEDAI score. The comparison between low disease activity group and moderate to high disease activity group based on SLEDAI score, revealed a statistically significant difference in the HRQoL domains between the two groups, with low disease activity group scoring higher in all HRQoL domains. ESR level which is also a marker of active SLE had a negative correlation with both physical and mental summary components of HRQoL in our group. Our results are comparable to a recent study by García et al which revealed statistically significant association between disease activity and HRQoL in SLE patients.[17] In this study 70 patients were included and 42 were followed up for a period of 12 months. HRQoL was measured by four different generic questionnaires, and all revealed that disease had a significant impact on HRQoL. In another recent observational study with 11 years of follow up by Parodis et al, low disease activity and being sustainedly in Lupus Low Disease Activity Status (LLDAS) was associated with favourable HRQoL, fatigue, and overall health experience irrespective of organ damage.[18]

This significant association of disease activity with HRQoL underscores the importance of ongoing monitoring and management of disease activity to improve quality of life.

We also found that age had a weak yet significant correlation with both the physical and mental summary component of HRQoL, with older age associated with poorer HRQoL scores. In the meta-analysis by Gu et al, the mean age was negatively associated with physical health domains and also the social wellbeing domain of the mental health component.[13] Similarly in a cross sectional study by Carrión-Nessi et al of 100 SLE patients, advanced age correlated with worse HRQoL measured by LupusQoL, though correlations were weak similar to our group.[19] It is possible that with advancing age patients may experience greater physical and functional limitation and the cumulative effect of morbidity, co morbidities and medication side effects worsens, compromising HRQoL. This implies the importance of individualized interventions addressing the specific needs of older patients with SLE.

We did not find a significant corelation between disease damage or disease duration with HRQoL domains in our study group. However, employment status emerged as affecting the HRQoL with homemakers scoring lower than both employed and unemployed groups in mental cumulative summary. But, after correcting for age, the differences between employed, unemployed, and homemaker groups were not statistically significant. This suggests that younger age and lower disease activity, rather than employment status alone, might be contributing to the observed differences in HRQoL. In a study by Shen et al on 170 Chinese patients, age, socio demographic factors such as employment, income, age, education did not directly corelated with HRQoL but indirectly affected HRQoL through other factors such as depression, anxiety and disease activity.[21] Nevertheless, the potential benefits of employment, such as financial stability, social interaction, and a sense of purpose, should not be overlooked in the management of SLE patients.

The main limitations of the study were, a small sample size and its single-center design, which may limit the generalization of the findings to the rest of the Sri Lankan population. Sample size was mostly reduced because of the COVID pandemic, where the patient attendance at clinics were markedly reduced. Future research should include larger, multi-centre studies to validate these results and explore additional factors influencing HRQoL in SLE patients.

Conclusions

In conclusion, SLE adversely affects HRQoL, with physical health more impacted than mental health. Disease activity, age, ESR are significant influencers of HRQoL in SLE patients. Regular assessment of HRQoL, as an integral part of the medical consultation during follow up of the disease and a comprehensive, holistic approach towards patient care are essential for improving outcomes in SLE.

Author declaration

Ethics approval

Ethical approval was obtained from Ethical Review Committee of the Post Graduate Institute of Medicine and informed consent was obtained from the patients.

Competing interests

Authors has no conflicts of interests. This study was self-funded.

Authorship criteria

DW designed the protocol, obtained ethical approval, collected data, analysed data and drafted the manuscript. DM as the primary supervisor, supervised and helped the study and approved the final manuscript.

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