Quality of Life of Systemic Lupus Erythematosus Patients and its Relationship to Disease Severity in Lagos, Nigeria.

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ABSTRACT

Background: Systemic lupus erythematosus (SLE) impairs the quality of life of patients. Studies on this quality of life (QoL) impairment are few. The study aimed to document the QoL of SLE patients, its determinants, and to correlate QoL with disease activity using the SLEDAI-2K.

Methodology: A prospective cross-sectional study of QoL was conducted on 70 SLE patients at the rheumatology clinic of the Lagos State University Teaching Hospital over 7 months. Clinical and sociodemographic data were documented. Quality of life was assessed using the SLE quality of life instrument (SLEQOL). The activity of SLE was assessed with the SLE disease activity index 2000 (SLEDAI-2K). Data was entered and analyzed using the IBM Statistics version 22 and a p-value <0.05 was considered significant.

Results: The mean age of the patients was 35.0 ±11.8 years and 98.6% were female. The mean duration of SLE was 3.6±3.3 years. Systemic Lupus erythematosus as depicted by SLEDAI-2K $\geqslant$ 6 was active in 87.1% with a mean SLEDAI-2K of 8.6± 7.6. SLE Activity was $\leqslant$ 6 in 36(51.4%) and $\geqslant$ 6 in 34(48.6%). Quality of life was impaired in 98.6% of the patients. SLEQOL scores ranged from 40-214 and the median (IQR) SLEQOL was 84(57,130). None of the sociodemographic and clinical factors were significantly associated with QoL impairment and there was no correlation between SLE activity and quality of life impairment.

Conclusion: Quality of life is impaired by SLE. However, this QoL impairment is independent of sociodemographic, clinical factors, and SLE activity.

Keywords: Systemic lupus erythematosus, Quality of life, SLEQOL, SLEDAI-2k, Disease severity

Qualité de vie des patients atteints de lupus érythémateux disséminé et sa relation avec la gravité de la maladie à Lagos, au Nigéria.

Abstrait

Contexte: Le lupus érythémateux disséminé (LED) nuit la qualité de vie des patients. Les études sur cette altération de la qualité de vie (QV) sont peu nombreuses. L'étude visait à documenter la qualité de vie des patients LED, ses déterminants, et à corréler la qualité de vie avec l'activité de la maladie à l'aide du SLEDAI-2K.

Méthodologie: Une étude transversale prospective de la QV a été menée sur 70 patients atteints de LED à la clinique de rhumatologie de l'hôpital universitaire de l'État de Lagos sur une période de 7 mois. Desdonnées cliniques sociodémographiques ont été documentées. La qualité de vie a été évaluée à l'aide de l'instrument de qualité de vie SLE (SLEQOL). L'activité du LED a été évaluée à l'aide de l'indice d'activité de la maladie du LED 2000

(SLEDAI-2K). Les données ont été saisies et analysées à l'aide de la version 22 d'IBM Statistics et une valeur de p <0,05 a été considérée comme significative.

Résultats: L'âge moyen des patients était de 35,0 ±11,8 ans et 98,6 % étaient des femmes. La durée moyenne du LED était de 3,6±3,3 ans. Le lupus érythémateux disséminé tel que décrit par SLEDAI-2K ⩾ 6 était actif dans 87,1% avec une moyenne SLEDAI-2K de 8,6± 7,6. L'activité de LED était de ⩽ 6 dans 36 (51,4%) et ⩾ 6 dans 34 (48,6%). La qualité de vie était altérée chez 98,6% des patients. Les scores SLEQOL variaient de 40 à 214 et la médiane (IQR) SLEQOL était de 84 (57 130). Aucun des facteurs sociodémographiques et cliniques n'était significativement associé à une altération de la qualité de vie et il n'y avait aucune corrélation entre l'activité du LED et l'altération de la qualité de vie.

Conclusion: La qualité de vie est altérée par le LED. Cependant, cette altération de la qualité de vie est indépendante des facteurs sociodémographiques, cliniques et de l'activité du LED.

Mots-clés: Lupus érythémateux disséminé, Qualité de vie, SLEQOL, SLEDAI-2k, Gravité de la maladie

Introduction

Systemic lupus erythematosus is a multi-systemic autoimmune inflammatory disease with a predilection for individuals aged 18 to 74 years.[1,2] The prevalence of Systemic lupus erythematosus (SLE) in Africa is said to be 0.3/100,000 person per year,[3] accounting for 0.1 to 1% of dermatological diseases and 5.4 to 91% of rheumatological diseases.[1,4-7] Systemic lupus erythematosus is more common in females, particularly those of childbearing age.[1,6,8,9]

Quality of life (QoL) in affected individuals is negatively affected by SLE.[2,10-13] Individuals who have SLE have a worse QoL when compared with healthy individuals as well as impaired physical functioning compared to family members.[12,13] Also, QoL is more impaired in SLE patients with cutaneous manifestation than in patients with other cutaneous diseases such as acne, psoriasis, eczema, and non-melanoma skin cancer.[11] In addition, patients with cutaneous SLE have a worse QoL than those who do not have.[11]

The impairment of QoL by SLE involves several aspects of their lives. These include physical functioning (walking, shopping, laundry, caring for children) social functioning (family and sexual relationships), emotional wellbeing, and work (absence from work, choice of work, career progression).[14] Patients worry about their skin lesions and other SLE symptoms getting worse, losing hair, and spending time outdoors.[11,14]

Studies of QoL of SLE patients show it to be affected by sociodemographic factors, SLE disease factors, activity of SLE and treatment.[2,10,11,15] Socio-demographic factors include gender,[2,11,16,17] age at onset,[2,11,16,18-20] age at presentation and age at diagnosis.[2] Additional factors are the duration of SLE,[2,16,19,20] level of education,[2,19,21] a low socioeconomic status and ethnicity.[20,21]

Disease factors include treatment, organs affected by SLE, the presence of cutaneous lesions and their distribution, and SLE disease activity.[11,22] The other implicated SLE disease factors are; fatigue, pain, emotional wellbeing, cognition, inability to conduct daily activities, physical and social functioning, and work productivity.[10,14,19] Quality of life impairment is worsened by specific organ damage, hair loss, and SLE flares.[18,22-26]

Some factors have been found to contribute to improvement in QoL.[2,15] These include the male gender, initiation of treatment, and disease remission.[2,15,16,27,28] Initiation of treatment leads to an improvement in QoL in 58% of SLE patients. However, this improvement occurs only in the first 2 years of treatment with no further improvement thereafter.[2,15]

Both generic and disease-specific instruments are used in the assessment of QoL of SLE patients and disease-specific instruments are more sensitive to the different aspects that QoL impacts.[2,29,30] One of such disease-specific instruments is the SLE quality of life (SLEQOL) which has specific questions related to SLE and its effect on emotion, physical and social functioning, and other aspects of life.[30]

Systemic lupus erythematosus patients are attended to at both rheumatology and dermatology clinics.

Frequently QoL issues due to both SLE (physical functioning and work-related issues) and its treatment are observed but not documented. Sometimes, the QoL issues become the dominant complaint of the patients. Currently, there are no studies of the QoL of SLE patients in Nigeria nor of its association with disease activity. The aim of this study was to document the QoL of our cohort of SLE patients - to determine what affects their QoL (age, duration of disease, alopecia, organ system involvement) and to correlate QoL with disease activity using the SLEDAI-2K.

Materials and Methods

Ethical approval for this prospective cross-sectional study of the QoL of 70 SLE diagnosed patients conducted at the rheumatology clinic of the Lagos State University Teaching Hospital was given by the ethics review committee of the hospital. The study was conducted over 7 months (February, July-December 2020). The study was interrupted by the COVID-19 pandemic. All consecutive consenting already diagnosed SLE patients who attended the Rheumatology clinic within the study period were studied. Excluded from the study were any SLE patients aged less than 18 years, patients who had psychological diseases, other dermatological diseases, and patients who had other autoimmune or medical diseases that could affect QoL (hyper/hypothyroidism, hypertension, diabetes mellitus). All the patients were clinically evaluated for hair loss and cutaneous lesions.

A questionnaire designed for the study was administered to the patients by the researchers. Sociodemographic data, systems affected by SLE, and disease duration were documented. Quality of life was assessed using the SLE quality of life instrument (SLEQOL).[2,29,30] The SLEQOL is based on activities over the previous one week and consists of 40 items which assess 6 domains: physical functioning (6 items), activities (9 items), symptoms (8 items), treatment (4 items), mood (4 items) and self-image (9 items). Each item has a 7-point Linkert scale ranging from 1 ("not difficult at all," "no trouble at all," or "not often at all") to 7 ("extremely difficult," "extremely troubled," or "extremely often"). The sum of the scores ranges from 40 to 280 and the higher the scores the poorer the QoL.[2,29,30]

The activity of SLE was assessed with the SLE disease activity index 2000 (SLEDAI-2K).[31-33] The SLEDAI-2K has 24 items covering 9 organ systems affected by SLE with score points calculated for each organ.[31,32] These points are weighted; 8 points for the central nervous system and the vascular system; 4 points for the renal and the musculoskeletal systems; 2 points for the serosal, dermal and immunologic systems; 1 point for constitutional and hematological parameters. Points were assigned if an item is present at the time of the patient's visit or within the preceding 30 days. The total SLEDAI-2K score is a sum of score points of the 24 items with a minimum score of 0 and a maximum score of 105.[31-33] SLEDAI-2Kscore is graded as: no, mild, moderate, and severe activities with scores of 0, 1-5, 6-10 and ⩾ 11 respectively[33,34] and SLE is said to be active when SLEDAI-2K score is ⩾6.[34,35]

Data was entered and analyzed using the IBM Statistics version 22. Test for normality was done for numerical variables. Numerical variables that were not normally distributed were expressed as median, range, and interquartile range while categorical variables were expressed as frequencies. Numerical variables of two or more independent groups were compared using the Mann Whitney U and Kruskal Wallis test while categorical variables were compared using the Chi-squared test. The confidence interval was set at 95% and a p-value <0.05 was considered significant.

Results

The mean age of the patients was 35.0 ±11.8 years (range 18-75 years). The patients were 98.6% female and 1.4%, male. The mean duration of SLE was 3.6±3.3 years. Fifty-six (80%) of the patients had commenced treatment with a mean treatment duration of 3.1±3.0 years. Cutaneous manifestations were observed in 17(24.3%). The type of cutaneous SLE was acute in 12(70.6%), subacute in 3(17.6%), and chronic in 2(11.8%). Details of specific cutaneous lesions are as in table 1. Other system involvement noted were renal in 26(37.1%), CNS in 8(11.4%), and musculoskeletal in 44(62.9%). Hair loss was observed in 48.6%. Other details are shown in table 1. Systemic Lupus erythematosus was active as depicted by SLEDAI-2K in 87.1% with a mean SLEDAI-2K of 8.6± 7.6. SLE flare (SLEDAI-2K ⩾6)

was observed in 34(48.6%). Details of SLEDAI-2K are as shown in table 2.

Quality of life was impaired in 98.6% of the patients. SLEQOL scores ranged from 40-214 and the median (IQR) SLEQOL was 84(57,130). The domains most affected were daily activities, symptoms, and self-image. Details are in table 3.

None of the sociodemographic and clinical factors were significantly associated with QoL impairment. Gender, p=0.286, duration of SLE, p=0.864, SLE activity, p=0.961. There was no correlation between SLE activity and quality of life impairment. Table 4

Discussion

Systemic lupus erythematosus is a multi-systemic disease that often affects the QoL of affected individuals.[2,10,19,30] Studies of SLE QoL show it to be affected by sociodemographic, clinical, and treatment factors.[2,12,19] This study reveals a predominant involvement of women by SLE and that the affected women were in their childbearing age. Studies of SLE in keeping with ours show SLE to have this predilection.[12.] It is thought that testosterone has a protective effect in males making females more predisposed to SLE.[36,37]

Cutaneous lesions were found in a low proportion of the patients and this was mostly the acute type. Studies of SLE reveal a varying prevalence of cutaneous manifestations depending on whether the study is retrospective or prospective, and whether the study was specifically about the cutaneous manifestation of SLE.[6,13,38] The low proportion of cutaneous SLE is within what has been reported and the finding of mostly acute cutaneous SLE is in keeping with reports of cutaneous SLE being mostly the acute type.[6,38,39]

Apart from the cutaneous manifestation, SLE was found to affect other systems and this was mostly the musculoskeletal system (MSS). Systemic LE being a multi-systemic disease is known to affect every organ of the human body.[12,24] Our study in consonance with other studies, shows the MSS to be affected in a high proportion of SLE patients.[10,12] Hair loss was also observed in almost half of the patients. Although the number of patients in our study with hair loss was not high, it was within what has been reported in other studies.[6,9] Hair loss, although not a specific feature of SLE, is said to be a marker for SLE severity and activity and to be associated with a poor QoL.[9]

The SLEDAI-2K is an activity of SLE measuring tool for recording various parameters of SLE over 30 days.[32-34] An increase in SLEDAI-2K gives an inkling of a flare of SLE. The mean SLEDAI-2K in this study was comparable to that in other studies.[15,27] In our cohort of patients, SLE was active in almost all the individuals although the degree of activity was low in half of the patients. The clinical implication of these results is that SLE was not yet controlled in these patients. Sliem et al similar to our study reported a low activity of SLE in their patients despite SLE being active in a lot of their patients.[12]

Quality of life was impaired in almost all the patients. Quality of life is a subjective phenomenon and is affected by various factors including symptoms and treatment. This makes it an issue of concern in a lot of SLE patients[3,10,13]

We found a SLEQOL range of 40-214. SLEQOL scores typically range from 40-280 with higher scores reflecting a worsening of QOL.[30] The SLEQOL unlike most QoL instruments cannot be stratified into mild, moderate, and severe.[30] This is because according to the developers of the instrument, different domains are variably affected in patients. A patient may have a mild involvement in the domain of daily activity simply because they do not have MSS symptoms while having severe involvement in the domain of renal disease because they have lupus nephritis. Thus, comparison of the degree of QoL affectation between individuals is not done with this instrument.[30]

The SLEQOL domains of daily activity, symptoms, and self-image were more affected in the patients. The domain of daily activity involves interference with work, school, earning a living, and socializing. A number of the patients in this study had involvement of the MSS which would have made daily functioning difficult. The domain of symptoms includes fatigue, joint pain, and loss of appetite. Fatigue and symptomatic neuromuscular disease is known to impair the functioning of SLE patients and impair their QOL.[10,14,19]

Self-image was another domain of SLEQOL impairment. This domain looks at self-esteem,

embarrassment because of SLE, being a financial burden to the family, concern that drugs may not work, and concern about side effects of drugs. Drugs used in the treatment of SLE are not without side effects.[40] The combination of symptoms of the SLE, the socioeconomic implication of treatment, cutaneous lesions, and embarrassment combine to impair the self-image of patients.

Similar studies on the QoL of SLE patients show daily activities, symptoms, and self-image to be the affected domains of SLEQOL impairment.[2,14,30] Physical functioning which involves bathing one's self, shopping was not an impaired domain and this is similar to the study by Klein et al.[11] We were unable to demonstrate any significant association between age, gender, duration, treatment, and SLE disease activity with QoL impairment. Social functioning was not impaired by SLE unlike what Sliem et al found in Egypt.[12]

Like this study, some researchers were unable to demonstrate a significant relationship between SLE duration and QoL impairment.[13,19,20] This is however contrary to what Ishiguro et al found in Japan, where a long duration of SLE negatively affects QoL.[16]

Also, this study did not demonstrate any effect of renal disease, MSS disease, CNS disease, or cutaneous lesions on QoL. At variance with our report, neurological, renal, and MSS disease are reported to influence QoL negatively.[12,24] We did not find age to affect QoL. This is contrary to reports from other studies where an older age affects QoL. [2,15,19,22] Most of our study participants were young. This may have accounted for this disparity in the influence of age on QOL.

Commencement of treatment and treatment duration did not significantly contribute to QoL impairment. Contrary to our study, treatment is reported in other studies to impair QoL[10,22] A high pill burden, cost of drugs, multiple schedules of drug administration were reported to be responsible for this poor QoL.[22] Increased activity of SLE has been reported to be associated with a low QoL but our study did not find this.[2,15,19,22] Increased activity is an indication of a flare in SLE with increased symptomatology, making functioning difficult. However, similar to our findings, a study done by Heijke et al did not find any relationship between the activity of SLE and the QoL of the patients.[41]

This study was limited by being a single-centred study and the inability of the SLE QOL instrument to stratify the degree of QoL impairment in the patients. The strength of the study was it being a prospective study and the use of a specific SLE QOL questionnaire.

In conclusion, QoL is impaired by SLE. However, this QoL impairment is independent of sociodemographic and clinical factors. Furthermore, in this study, there was no significant relationship between the degree of SLE activity and QoL impairment.

Conflict of Interest: None

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Table 1. Socio demographic and clinical details of participants

Variable	frequency (n= 70)	%
Age group (in years)		
< 20	5	7.1
20 - 29	21	30.0
30 – 39	26	37.1
40 – 49	11	15.7
50 – 59	4	5.7
⩾ 60	3	4.3
Duration of SLE (in years)		
< 1	15	21.4
1 – 5	40	57.1
>5	15	21.4
Treatment duration (Year)**	**n = 56**	
< 1	13	23.2
1 – 4	27	48.2
>5	16	28.6
Specific skin lesions		
Malar rash	3	17.6
Ulcer	4	23.5
Blisters	2	11.8
Discoid lesion	3	17.6
Oral ulcers	1	5.8
Scaly patches	8	47.1
Scarring alopecia	1	5.8
Photosensitivity	3	17.6
Nailf old telangiectasias	2	11.8
Raynauds phenomenon	1	5.8
Post-inflammatory hyper pigmented patches	2	11.8
Hair loss on examination		
Yes	34	48.6
No	39	51.4

**Fourteen (14) patients were newly diagnosed and yet to start treatment.

Table 2. SLEDAI-2K Scores

Variables	n = 70	%
Median SLEDAI-2K scores (IQR)	6 (2, 14)	
SLEDAI-2K categories		
No activity	9	12.9
Mild	19	27.1
Moderate	22	31.4
Severe	20	28.6
SLEDAI-2K domains		
CNS	12	17.1
Musculoskeletal	23	32.9
Renal	27	38.6
Cutaneous	35	50.0
Serositis	3	4.5
Immunologic	11	15.7
Haematologic	2	2.9
Vasculitis	1	1.4
Fever	4	5.7

Table 3. SLEQOL Domain Scores

Domain	Mean (SD	Median (IQR)	Range
Physical functioning	11.6(8.3)	8 (6, 13)	6 – 42
Daily activity	22.6 (13.6)	18 (10, 34)	9 – 57
Symptoms	17.6 (8.8)	15 (10, 23)	8 – 43
Treatment	10.3 (5.7)	9 (5, 14)	4 – 26
Mood	10.1 (7.1)	8 (4, 13)	4 – 32
Self-image	22.6 (10.7)	20 (13, 31)	9 – 56
Overall scores	**94.9 (42.9)**	**84 (57, 130)**	**40 - 214**

Table 4. Factors Associated With SLEQOL

Variable	n	median (IQR)	p
Age group (in years)			
< 20	5	83 (60, 104)	0.501##
20 - 29	21	100 (59, 131)	
30 – 39	26	81 (54, 136)	
40 – 49	11	79 (48, 96)	
⩾ 50	7	118 (62, 140)	
Hair loss			
Yes	34	100 (61, 136)	0.117#
No	36	78 (52, 117)	
Cutaneous involvement			
Yes	19	100 (65, 144)	0.119#
No	51	79 (57, 121)	
On treatment for SLE			
Yes	56	84 (57, 132)	0.843#
No	14	84 (54, 119)	
Treatment duration (Years) n =56			
< 1	13	99 (61, 136)	0.402
⩾ 1	43	81 (54, 131)	
Renal involvement			
Yes	26	96 (67, 130)	0.251#
No	44	81 (54, 129)	
CNS involvement			
Yes	8	103 (97, 130)	0.213#
No	62	80 (55, 132)	
Musculoskeletal involvement			
Yes	44	80(57, 117)	0.177#
No	26	103 (61, 144)	
SLE FLARE (SLEDAI-2K)			
⩾ 6	36	81 (58, 135)	0.597#
#>6	34	92 (55, 122)	

NB: # = Mann Whitney U test
= Kruskal Wallis test