Research Article

An evaluation of quality of life in ambulatory patients with systemic lupus erythematosus attending rheumatology clinic in Kenyatta National Hospital

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Abstract

Background: Systemic Lupus Erythematosus (SLE) is a chronic autoimmune disease that affects all organs of the body. It is becoming increasingly clear that SLE is not as rare in Kenya as was previously thought. Due to its chronicity SLE has been known to affect the quality of life of those affected by it. There is minimal data on SLE in East Africa and especially in Kenya. The quality of life of SLE patients in this country has never been assessed.

Objectives: To document the quality of life of patients with SLE in Kenyatta National Hospital using LUPUS QOL questionnaire. We also sought to correlate HRQOL with duration of illness, drugs used and age of the patient.

Design: This was a cross sectional study done on patients attending Rheumatology Clinic in Kenyatta National Hospital.

Methods: Patients who satisfy the ACR criteria were consecutively recruited. All patients with SLE attending the clinic were included in the study. Consent was obtained from the patients after which their demographic data was obtained. Patients were examined for the presence of malar rash, discoid rash, arthritis/athralgia, photosensitivity, CNS symptoms, serositis and oral ulcers. The patients then filled the LUPUS QOL questionnaire. The information acquired was then analysed using SPSS version 17.0 using student t test and regression analysis. The quality of life was calculated and then correlated with age, duration of illness and drug management.

Results: Sixty two patients were analysed (60 females 2 males). Mean age of the population was 37.3 years (range 14-71 years). All patients had some level of education with 61.3% of the population having some form of secondary education. Most patients 54.8% were married. Mean age of diagnosis was 34.5 years with mean duration of illness 1.5 years. Majority (88.7%) had arthritis/ athralgia, oral ulcers (62.9%), malar rash (59.7%), photosensitivity (58.1%), serositis (32.3%), CNS symptoms (27.4%) and discoid rash (17.7%). Patients scored globally low in all domains of LUPUS QOL. Highest domain was planning 63.7 (29.3), emotional health 61.3 (26.5), burden to others 58.9 (31.2), fatigue 57.5 (30.0), pain 56.6 (29.6), physical health 54.0 (23.3), body image 47.1 (24.2) intimate relations 41.1 (38.4).The most common drug in use in our population was prednisone at 74.2%. This was followed by HCQ at 69.4%, NSAIDS 54.8%, azathioprine 37.1%, methotrexate 22.6%, mycofenolate mofetil 8.1%, CCB 11.3%, cyclosporine 3.2%. HRQOL correlated positively with advance in age for the domains. Physical health, burden to others, emotional health and fatigue. There was no correlation between HRQOL and duration of illness or drugs used by the population.

Conclusion: The HRQOL of our SLE patients was found to be low in all domains and to correlate with advance in age in the domains of physical health, burden to others, emotional health and fatigue. However there was no correlation with duration of illness or the drugs used by the patients.

Introduction

According to WHO, health is defined as the individual's perception about his/her physical, mental, and social well being, and not merely the absence of disease or infirmity[1]. It comprises of several domains i.e. physical health, psychological status, degree of independence, social relationship, beliefs, relationship with the environment, financial gain, and freedom. Measures of QOL consider the effects of the disease or its treatment from the patient's perspective and determine the need for social, emotional and physical support during illness.

Systemic lupus erythematosus is characterized by periods of active disease and remission with better healthcare. The survival of SLE patients has significantly improved over the past years [2,3].

It is now becoming clear that disease status in chronic conditions is not only measured by the physical condition of the patient but also psychosocial factors such as pain, apprehension, difficulty in fulfilling personal and family responsibilities, financial burden and diminished cognition[4]. Assessing the Quality of Life (QOL) is thus an important measure to assess how much the disease process and its treatment is affecting an individual. Khanna *et al*[5] found that higher disease severity was associated with a lower quality of life score especially in the physical and psychological aspects but no significant correlation with social and environmental domains in the QOL. Patients with clearly active and probably active disease had significantly lower scores in the physical and psychological domains than patients with inactive disease. However, no significant difference was found in the domains of social and environmental QOL. Age or disease duration did not affect the QOL in any of the domains.

LUPUS QOL was developed to measure disease specific Health-Related Quality of Life (HRQOL) in adults with Systemic Lupus Erythematosus (SLE). It was developed and validated in the UK by McElhone *et al*[6] in 2007. It has 8 individual subscales physical health (8 items), emotional health (6 items), body image (5 items), pain (3 items), planning (3 items), fatigue (4 items), intimate relationships (2 items), burden to others (3 items). The Questionnaire has a 5-point Likert scale response format (0 all the time, 1 most of the time, 2 a good bit of the time, 3 occasionally, and 4 never). It has a recall period of the prior 4 weeks. It is available in both written and electronic versions. Scores range from 0 (worst HRQOL) to 100 (best HRQOL). The score ranges from 0 (worst HRQOL) to 100 (best HRQOL).

Materials and Methods

Patients diagnosed with SLE as by the ACR criteria and confirmed by a rheumatologist and gave informed consent (assent for minors), were recruited into the study. Those who declined to participate in the study were excluded. The patient's demographic data and last prescription was acquired from the file. The patients were then taken through some counseling to ascertain what they knew about their disease and to clear any misconceptions they may have had concerning their illness and treatment. Patients' clinical history was taken and a physical exam was then done. An observation was made for the presence of malar rash, discoid rash, arthritis/athralgia, serositis, photosensitivity. These were defined as per the ACR criteria[7]. After this the patient was given the LUPUS QOL questionnaire to fill. All the patients who attended the clinic were included in the study.

Data management and statistical analysis: Data was collected using structured questionnaires and was cleaned for errors and conflicting answers, missing entries and duplicate entries. The cleaned data was then exported to SPSS version 17.0 for analysis. Demographic variables (age) were summarized into means/ medians while gender, marital status were presented using percentages. Correlation of HRQOL and age, duration of illness and medication used was done using regression analysis.

Results

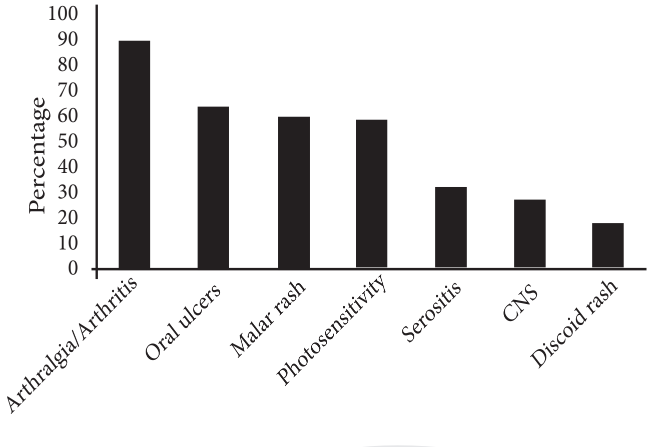
Demographic characteristics: Sixty seven patients were screened according to patients' records. The patients were then contacted by telephone and asked to participate in the study. Three had passed away, two declined to participate. Therefore 62 patients were recruited into the study. Table 1 shows the baseline characteristics of our population.

Table 1: Baseline characteristics of our population

Variable	Frequency (%)
Age, mean (SD)	37.3 (12.2)
Min-Max	14-71
Gender	
Female	60 (96.8)
Male	2 (3.2)
Level of education	
Primary	8 (12.9)
Secondary	16 (25.8)
Tertiary	38 (61.3)
Marital status	
Single	26 (41.9)
Married	34 (54.8)
Divorced	1 (1.6)
Missing	1 (1.6)
Age at diagnosis, mean (SD)	34.5 (12.2)
Duration of illness in years, median (IQR)	1.5 (0.08-12) (0.8-3.0)

Distribution of common lupus clinical features in our population: Majority of the patients (88.7%) had arthritis or athralgia. This was followed by oral ulcers at 32.3%, malar rash (59.7%), photosensitivity (58.1%), serositis (32.2%), CNS (27.4%). The least common clinical feature was discoid rash (17.7%). Figure 1 shows the distribution of the clinical features in the population

Figure 1: Distribution of clinical features of lupus in the population



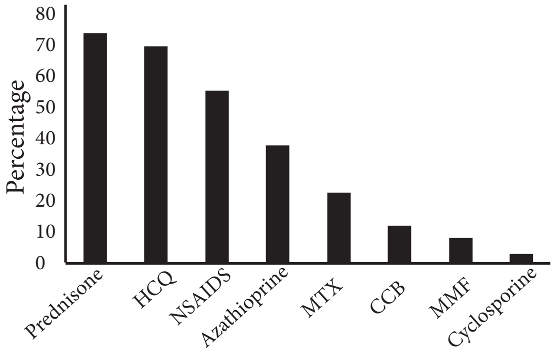
Health Related Quality of Life: On assessment of the HRQoL, Our population scored globally low in all the domains. The domain with the highest scores was planning (63.7), followed by burden to others ,(58.9), fatigue (57.5), pain (56.6), physical health (54.0), body image (47.1) and the lowest intimate relationships (41.1) as elaborated in Table 2.

Table 2: LUPUS QOL scores of our population

Domain	Mean (SD)
Physical health	54.0 (23.3)
Pain	56.6 (29.6)
Planning	63.7 (29.3)
Intimate relations	41.1 (38.4)
Burden to others	58.9 (31.2)
Emotional heath	61.3 (26.5)
Body image	47.1 (24.2)
Fatigue	57.5 (30.0)

Current drug management in our population: The patients' last prescription was recorded. Most common drug in use by our population was prednisone at 46(74.2%). This was followed by hydroxychloroquine (HCQ) at 43(69.4%). NSAIDS were the third most prescribed drug with 34 patients (54.8%). Twenty three patients were on azathioprine (37.1%). Methotrexate (MTX) was used by 14 (22.6%). The other drugs used by the patients were; Mycofenolate Mofetil (MMF) 5(8.1%) CCB 7 (11.3%), cyclosporine 2(3.2%). Of note is that the seven who were using CCB were all using it at antihypertensive doses. No one was using it for Reynaud's phenomenon. Figure 2 shows this distribution.

Figure 2: Distribution of drug use in the population



Correlation of HRQOL with age: Quality of life scores of the population was correlated with age for each domain. Positive correlation was found between physical health (r 0.306 p value 0.016), burden to others (r=0.272 p= 0.032) and emotional health (r=0.315, p= 0.013) and advance in age.

Correlation of HRQOL score and duration of illness: There was no significant association between HRQOL and the duration of illness, as shown in Table 4.

Table 3: Correlation of HRQOL score and age in our population

Variable	Pearson coefficient (r)	β (95% CI of β)	P value
Physical health	0.306	0.58 (0.11-1.05)	0.016
Pain	0.128	0.31 (-0.31-0.93)	0.321
Planning	0.197	0.47 (-0.14-1.08)	0.125
Int. Relation	0.025	0.08 (-0.74-0.90)	0.848
Burden to others	0.272	0.72 (0.06-1.39)	0.032
Emotional heath	0.315	0.682 (0.15-1.21)	0.013
Body image	0.147	0.29 (-0.22-0.80)	0.258
Fatigue	0.268	0.58 (0.03-1.14)	0.039

Table 4: Correlation of HRQOL score and duration of illness

Variable	Pearson coefficient (r)	β (95% CI of β)	P value
Physical health	0.191	2.04 (-0.69-4.77)	0.140
Pain	0.035	0.47 (-3.04-3.98)	0.791
Planning	0.067	0.89 (-2.57-4.35)	0.609
Int. Relation	0.135	2.38 (-2.22-6.97)	0.305
Burden to others	0.129	1.91 (-1.92-5.74)	0.322
Emotional heath	0.049	0.60 (-2.56-3.76)	0.707
Body image	0.160	1.77 (-1.09-4.63)	0.221
Fatigue	0.072	0.88 (0.55-0.59)	0.587

Association between QOL and drugs used: The study looked for any association between HRQOL and medication used in our population and also looked at the three most common drugs used i.e. prednisone, HCQ and NSAIDS. Again we found no significant correlation with the drugs used. Table 5 shows our findings.

Table 5: Association between HRQOL and prednisone

	Prednisone		P value
	Yes (n=46)	No (n=16)	
Physical health	53.1 (23.1)	56.6 (24.5)	0.609
Pain	55.1 (29.5)	60.9 (30.4)	0.501
Planning	61.4 (28.6)	70.3 (31.5)	0.300
Int. Relation	39.8 (37.9)	44.8 (40.9)	0.660
Burden to others	59.1 (33.4)	58.2 (30.9)	0.926
Emotional heath	60.9 (27.6)	62.4 (24.0)	0.849
Body image	46.3 (24.7)	49.2 (23.6)	0.686
Fatigue	58.4 (26.6)	55.1 (28.8)	0.682

Table 6: Association between HRQOL and NSAIDS

	NSAIDS		P value
	Yes (n=34)	No (n=28)	
Physical health	51.6 (23.7)	57.0 (22.9)	0.364
Pain	51.2 (29.2)	63.1 (29.3)	0.115
Planning	58.6 (30.6)	69.9 (27.0)	0.130
Int. Relation	39.1 (36.2)	43.5 (41.4)	0.666
Burden to others	58.5 (34.6)	59.3 (30.5)	0.926
Emotional heath	63.8 (27.6)	58.3 (25.3)	0.422
Body image	47.3 (22.6)	46.8 (26.5)	0.939
Fatigue	58.3 (25.9)	56.5 (28.7)	0.803

Table 7: Association between HRQOL and HCQ

	HCQ		P value
	Yes (n=43)	No (n=19)	
Physical health	52.8 (23.7)	56.9 (22.9)	0.526
Pain	54.9 (28.6)	60.5 (32.1)	0.493
Planning	58.3 (30.3)	75.9 (23.6)	0.029
Int. relation	39.3 (39.4)	45.2 (36.9)	0.583
Burden to others	58.0 (35.5)	60.8 (25.3)	0.761
Emotional heath	58.1 (26.6)	68.5 (25.5)	0.154
Body image	44.3 (24.7)	53.8 (22.4)	0.164
Fatigue	55.8 (27.3)	61.5 (26.5)	0.459

The rest of the drugs were being used by too few people to make any correlations. It was also not possible to make correlation between HRQOL and gender as there were only two men.

Discussion

Our population mean age was 37.3 years with youngest being 14 and oldest 71. This could be because diagnosis takes time in our setting, either due to reduced awareness of the disease or due to limited laboratory and imaging tests needed to make the diagnosis. Lupus is also sometimes difficult to diagnose and even in the best of settings and the most experienced clinicians, diagnosis may still take time. Most of our patients reported they had symptoms, for up to 3 years in some, before the diagnosis of lupus was finally made.

Lupus is mostly a disease of females of child bearing age and so it is not surprising that our population of 62 had only 2 males, (M:F 1:30). Our M:F ratio was also higher than in other studies, e.g , Wadee *et al*[8] in South Africa found a male:female ratio of 1:18[8]. Our smaller population may account for the higher ratio in our population.

Duration of illness in our population was 1.5 years (range 1 month - 12 years), much lower than in other populations. This reflects recent advances in our healthcare with more people being aware of the disease and having better laboratory and imaging techniques required to diagnose lupus. Other studies give a longer duration of illness. Benchmark study in the US had a duration of illness of 9.2[9]. Mexican study had a duration of illness of 8.2 years[10].

Clinical features of lupus: The most common clinical feature in our population was arthritis/athralgia, oral ulcers, malar rash, serositis, CNS symptoms and discoid rash. At the time of being included in the study, most patients still had early disease. Stefanidau *et al*[11] in Greece found the most common clinical feature in the females was also arthritis/ athralgia. Taylor[12] in Zimbabwe also found the most prevalent clinical feature to be arthritis/ athralgia. This was also replicated in Tunisia (78%)[13] and in Nigeria by Adelowo *et al* (87%)[14].

Health Related Quality of Life: The study found that our population scored globally low in all the domains of the LUPUS QOL. The domain with the highest was planning 63.7(SD 29.3). Our scores could be low because the fatigue experienced by patients with lupus may prevent them from planning for future events or committing themselves to social arrangements. Some of the clinical features like pain, athralgia, oral ulcers may also limit patients appearance in public due to the altered physical appearance.

Emotional health, though it had a low score (61.3, SD 21.5), was one of our higher scoring domains. This could be because most of our patients (54%) were married and the support from the spouse could have contributed to better emotional health. Also for the single people their immediate family could have still provided them with the emotional support needed to handle their condition. The domain on burden to others was our third highest scoring domain (58.9 SD 38.2). Our population probably still had active disease, especially those with short duration of illness and had to rely on others for help with their daily activities.

Pain had a low score of 56.6. Physical health (54.0 SD 23.3). Again our patients had early disease that was probably still active. Considering that the clinical feature we found most prevalent was arthritis and athralgia present in 88.7% of our population, this could have contributed to our low scores in these two domains.

Again having scored low in pain domain and physical health, it is not surprising that intimate relations had the lowest score (41.1SD 38.4). The pain they were experiencing, poor physical health, low body image and presence of fatigue, all could have affected their desire and/or enjoyment of sexual relations.

Body image was one of the lowest scoring domains, 47.1 (SD 24.2). A large proportion of patients had mouth ulcers (62.9%) along with discoid rash and malar rash. These may have adversely altered the body image of our patients.

Fatigue is a common symptom of lupus and can sometimes present on its own for years before diagnosis of lupus is finally made. Though we did not look specifically for the presence of fatigue in our population, many studies have found fatigue to be one of the most common and most debilitating feature in lupus. Robb-Nicholson *et al*[15] found in his study a prevalence of 81%. He also found out that most of them had active disease.

Current drug management: While the most common drug in lupus treatment is HCQ (LUMINA)[16], the most common drug in our population was prednisone with majority (74.2%) being on it. This was followed by HCQ (69.4%) then NSAIDS (54.8%). Active disease is treated by prednisone and therefore majority of our patients probably had active disease.

Azathioprine, Methotrexate (MTX), Mycophenolate Mofetil (MMF) cyclosporine is used for organ specific disease and the fact that few patients were on them may reflect the fact that few had organ specific disease, though we did not look for that in our study. Of note is that the 7(11.3%) patients using CCB were using for HTN and not for Reynaud's phenomenon. In our correlation analysis we did not find the use of any of the drugs to correlate significantly with HRQOL.

Correlating HRQOL with age: Positive correlation was found when HRQOL was compared with age in the domains; Burden to others, emotional health, fatigue. The study found that our patients scores in these domains increased with advance in age. Jolly *et al*[9] consistently found that advance in age correlated negatively with these domains, our population was different. A possible explanation for this could be emotional health improves in the older patients with lupus because they have had a longer duration of illness therefore they are more stable. It could also be because they may have learnt coping mechanisms by then that better help them accept their disease. Accepting and learning to cope may also have contributed to them being less of a burden to others. However a different study that looks specifically at this correlation to find out which factors directly affect these domains would be warranted to better explain these findings.

Conclusions

This study demonstrates that HRQOL in patients with lupus using the LUPUS QOL is globally found in all domains. In this study, advance in age was found to positively correlate with HRQOL in the domains of burden to others, fatigue, physical health and emotional health. There was no correlation between HRQOL and duration of illness and the drugs used.

Limitations

The cross sectional design of our study meant that it was not possible to measure any changes that may have occurred over time, as quality of life is dynamic and subject to change. The small sample size also made it impossible to do some of the correlation analysis, eg for gender and HRQOL.

Recommendations

We recommend a study looking at the disease severity of the patients and correlating it with HRQOL. We also recommend another study looking into the specific factors in our population that would make those with more advanced age have a better HRQOL than their younger counterparts.

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