Research article

Quality of life of women followed up for systemic lupus erythematosus in Abidjan, Côte d'Ivoire: a cross-sectional study of 51 cases

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Abstract

Objective: To determine the quality of life of Systemic Lupus Erythematosus (SLE) patients attending Cocody University Teaching Hospital in Abidjan using the SF 36 tool.
Design: A descriptive and analytical cross-sectional prospective study.
Methods: The study was carried out at the Rheumatology Department of Cocody's University Teaching Hospital in Abidjan, Côte d'Ivoire over a period of seven months from January 2019 to July 2019. Women diagnosed with SLE fulfilling American College of Rheumatology 1997 criteria and/or Systemic Lupus International Collaborating Clinics classification (SLICC) 2012 criteria for SLE were included. These patients completed the SF-36 questionnaire. The SF-36 scores reflected the degree of achievement in each domain. The lower the SF 36 scores the lower the quality of life. Quality of life was altered for any score below 40. For the disease activity, we used the systemic lupus erythematosus disease activity index. We looked for an association between the characteristics of the patients and the disease and the domains of the QOL.
Results: The study included 51 women and with a mean age of 35.88 ± 12.37 years. The patients were mostly single (65.38%) with a university level of education (59.62%). Most of them had low monthly income (82.69%) and they were without health insurance (51.92%). The mean duration of SLE was 76.79 ± 59.37 months. The mean disease activity score (mean SLE disease activity index) was 9.92. The affected domains of the SF-36 questionnaire showing altered quality of life were "physical role" (37.02) and "vitality" (39.99). Patients with lower quality of life were found to be young women, not married, have high disease activity, had skin and haematological manifestations, very high disease activity (SLEDAI) and without treatment.
Conclusion: In Abidjan, SLE patients attending Cocody University Teaching Hospital have a lower quality of life. Determinants of low quality of life are: young women, not married, secondary-educated level, mucocutaneous and haematological manifestations, very high disease activity (SLEDAI) and patient without treatment.

Key words: Assessment, Quality of life, Systemic lupus erythematosus, Abidjan

Introduction

Systemic lupus erythematosus (SLE) is a fairly rare but well-known autoimmune disease worldwide[1]. It is characterized by rather benign cutaneous-mucosal and articular manifestations but also serious manifestations that can be life-threatening [2,3]. It is a chronic disease with a heavy price with psychological and social implications and therefore a significant impact on the Quality of Life (QOL) of patients which remains an essential element to better understand the disease. A poor QOL may itself contribute to the prognosis of patients; thus justifying its assessment in lupus patients. Many studies focusing on the subject have been conducted in developed countries[4-7]. In low income countries, especially in sub-Saharan African context, there are scarce data on this subject [8-11]. It was the quest for data that prompted the realization of this study, the objective of which was to look at the quality of life of patients suffering from SLE in Abidjan.

Materials and methods

A descriptive and analytical cross-sectional prospective study was conducted at the Rheumatology Department of the Cocody

University Teaching Hospital, Abidjan over a period of seven months from January 2019 to July 2019. The study included women diagnosed with SLE and meeting the American College of Rheumatology 1997 criteria and/or Systemic Lupus International Collaborating Clinics classification (SLICC 2012) criteria for SLE[12]. Patients who did not respect the doctor's consultation days or in whom there was a lack of key information were not included. We carried out a consecutive and exhaustive sampling. These patients were administered both a standard questionnaire and the SF-36 questionnaire. The study was conducted by face-to-face interview (doctor-patient). The data collection was done in two phases. The first phase consisted in a narration by the patient of his pathology from the beginning of his symptomatology until the day of the interview; this allowed us to validate the applicability of the questionnaire to our study population. During the second phase, patients self-administered the questionnaire and the data that could not be provided by them were collected from their medical file.

In the standard questionnaire, the captured data were:

(i) *Socio-demographic data*: Age, sex, marital status, education level, monthly income, the presence of health insurance.

(ii) *Clinical and paraclinical data*: Duration of disease progression, clinical and para clinical manifestations, disease activity using the Systemic Lupus Erythematosus Disease Activity Index (SLEDAI)

(iii) *Therapeutic data:* Symptomatic and specific treatment.

The data was collected and analysed using the EPI-INFO software version 7.2.2.16. Quantitative variables were described using means, Standard Deviations (SD) and ranges as well as number and percentage. The ANOVA test was used to compare the variables and to look for an association between the characteristics of the patients and the disease on the one hand and on the other hand the domains of the QOL. The Pearson correlation test was performed to confirm the strength of the association between the factors alternating the QOL. Any variable was statistically significant for a value of P strictly less than 0.05.

The Socio Economic Level (SEL) was considered low if the monthly income was less than 150.000 CFA francs (230 euros), average if this income was between 150.000 CFA francs and 300.000 CFA francs (460 euros) and high if the monthly income was more than 300.000 CFA francs.

The SF-36 questionnaire is a 36-item scale, which measures 8 domains of health: physical functioning, physical health, emotional health, physical pain, mental health, social functioning, vitality and general health. The normalized score for each domain is between 0 (poor QOL) and 100% (best QOL)[13]. The scores were obtained by summing up the total values of the items for each domain. The scores reflected the degree of achievement for each domain. The lower the scores, the more SF-36 domains are reached and the more QOL is altered. The QOL is altered for any score below 40. To obtain the scores, we used the SF-36 calculator software[14]. The study was done in accordance with the Helsinki declaration on ethical principles.

Results

Fifty one women were recruited. The mean age was 35.88 ± 12.37 years [range: 9-67 years]. The mean duration of the disease was 76.79 ± 59.37 months. The baseline characteristics of patients are listed in Table 1. The disease activity was mild (38.46%), moderate (28.85%), high (19.23%) and very high (13.46%) with a mean activity score of 9.92 ± 6.96 (according to SLEDAI score).

Table 1: Charactéristics of the patients

Socio-demographic characteristics	No. (%)
Marital status	
Married	18 (34.62)
Not married	33 (65.38)
Level of education	
Primary	04 (7.69)
Secondary	14 (28.84)
University	31 (59.62)
Unschooled	02 (3.85)
Health insurance	
Present	24 (48.08)
Employment status	
Unemployed	19 (38.46)
Employed	32 (61.54)
Socioeconomic level	
Low	31 (59.64)
Average	12 (23.08)
High	18 (17.28)
Clinical characteristics	
Musculoskeletal	51 (100)
Mucocutaneous	47 (92.15)
Haematological	46 (90.19)
Respiratory	16 (31.13)
Renal	07 (13.72)
Clinical manifestations	
Neuropsychiatric	13 (25.49)
Cardiovascular	13 (25.49)
Therapeutic charateristics	
Corticosteroids	47 (92.31)
HCQ	29 (57.10)
HCQ + MMF	02 (04.46)
Drugs	05 (09.52)
HCQ + AZA	06 (11.90)
AZA	06 (11.90)
Cyclophosphamide + AZA	
Cyclophosphamide	02 (04.76)

HCQ=Hydroxychloroquine; MMF=Mycophenalte mofetil; AZA=Azathioprine

Table 2 summarizes the standardized scores for the SF-36 domains and the assessment method. The different domains of the SF-36 questionnaire are illustrated in Figure 1.

Table 2: Standard scores of the SF-36 domains

Domains	Mean normalized score	Standard deviation	Interval
	Physical summary score		
Physical health	43.46	±25.19	[5-100]
Physical functioning	58.21	±27.39	[0-100]
Physical role	37.02	±33.29	[0-100]
Body pain	50.38	±30.69	[0-100]
	Mental (psychic) and social summary score		
Emotional role	49.36	±46.43	[0-100]
Social functioning	66,79	±28.50	[0-100]
Mental health	52,79	±22.62	[12-100]
Vitality	39,99	±24.87	[0-100]
Change from the previous year	53,36	±36.38	[12-100]

Figure 1: Scores of SF-36 domains

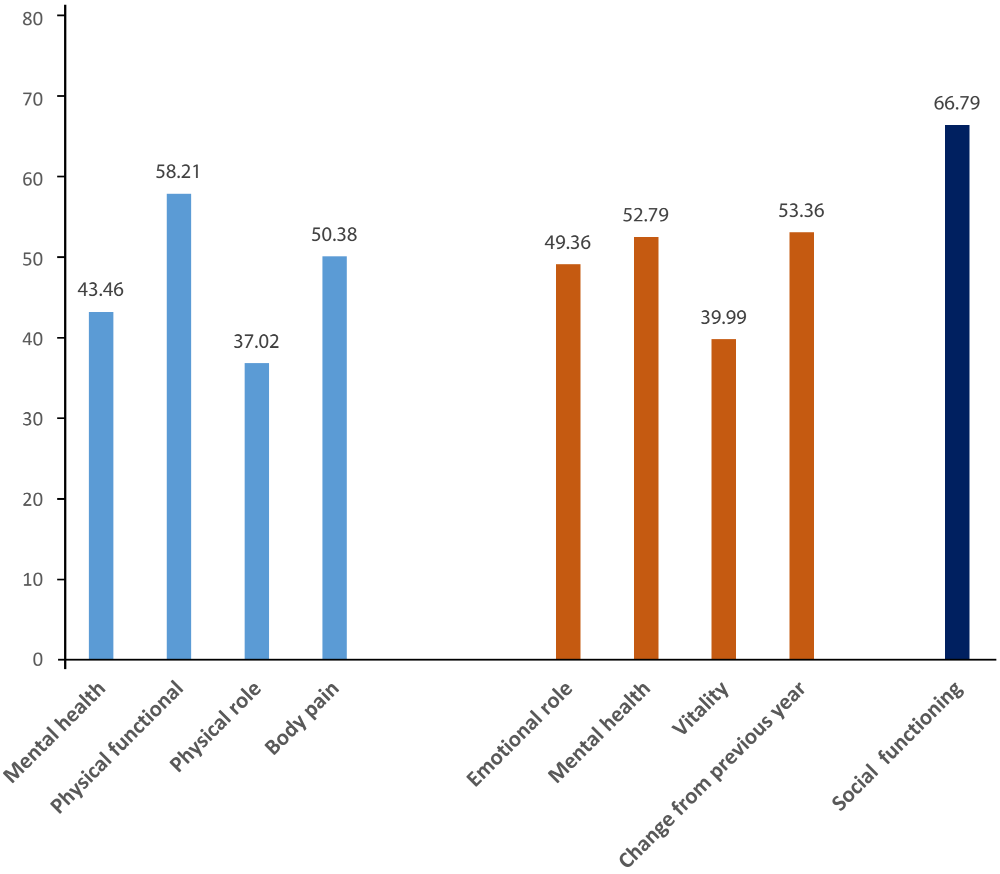

Table 3 shows the positive correlation between characteristics of population and disease and domains of QOL and also shows the alteration of QOL. Specifically, the influence of disease activity on the quality of life is observed in Table 4. The other characteristics analyzed and which did not show an association with the deterioration of the quality of life were: gender, professional status, socioeconomic level and renal, neuropsychiatric, respiratory and cardiovascular manifestations.

Table 3: Correlations between characteristics of patients and domains of QOL

Characteristics of patients		Domains	P	r
Age	Mature adults	General health	0.028	0.08
		Physical functional	0.023	0.12
Marital status				
	Not married	General health	0.043	0.01
Education level		Body pain	0.004	0.09
	Secondary level	General health	0.015	0.11
		Physical role	0.003	0.16
		Physical functional	0.025	0.10
		Mental health	0.004	0.15
Type of manifestations	Mucocutaneous	Vitality	0.001	0.16
	Haematological	Social functioning	0.021	0.10
Disease activity	Very high	Social functioning	0.010	0.19
Treatment received	No treatment	Physical role	0.033	0.06
		Physical functional	0.021	0.13
		Mental health	0.011	0.11
		Vitality	0.009	0.12

Table 4: Influence of disease activity on the quality of life

	Disease activity (SLEDAI)					
Domains	Mild	Moderate	High	Very high	P	r
General health	51.25	42.00	36.00	35.00	0.3116	
Physical role	49.99	33.33	22.50	28.57	0.365	
Body pain	56.50	49.83	42.50	45.36	0.661	
Physical functional	64.10	58.67	52.00	49.30	0.546	
Emotional role	58.33	55.55	40.00	23.81	0.329	
Social functioning	**73.70**	**74.10**	**63.75**	**35.71**	**0.010**	
Mental health	59.65	54.40	46.80	38.30	0.136	
Vitality	45.00	40.33	36.50	30.00	0.556	
Change from previous year	61.84	63.33	37.40	31.14	0.092	**0.19**

Discussion

This was a descriptive and analytical cross-sectional prospective study which aimed to look at QoL of lupus patients attending Cocody University Teaching Hospital in Abidjan. The study found that the patients had poor QoL and they were mainly young women, not married, secondary-educated level, mucocutaneous and haematological manifestations, very high disease activity (SLEDAI) and patients who had not received any treatment.

It was noted in this study a predominance of young women as in almost all the studies on SLE[15-20]. The patients in our study were mostly not married (65.38%) as in the study by Gaballah *et al*[21] in Egypt (86.2%) and Nyambane *et al*[10] in Kenya (58.1%). The marital status impacted the QOL specifically the "not married" status which impaired the QOL by affecting the general health (P= 0.043; r = 0.01). The literature has revealed that "not married" status was associated with a poor quality of life and "married" status was linked to better QOL[4,8,22]. This could be explained by the lack of consistent family support among these "not married" groups. Indeed, in our context, the mystical interpretation of this unpredictable disease very often leads the husband to abandon his wife, justifying the impact of the general health in our study. Patients in this work mostly had a university level of education (59.62%) just like in the study of Kompaoré *et al*[9] but not Affane[8] in Morocco. However, the secondary education level in our study impacted the domain body pain, thus affecting the quality of life (P = 0.040; r = 0.09). It is obvious that patients understanding of SLE is necessary for better management of the disease. It has been shown by Alarcon *et al*[5] that there is a correlation between the level of education and the domains "physical and emotional role, general and mental health, social and physical functioning". According to Devilliers *et al*[4] and Benitha *et al*[23], high level of education was associated with better QOL in the "physical pain" domain. Referring to these latest studies, it seems that education is a key determinant of QOL because it affects the general perception of the world and can influence the patient's attitude towards health and illness. The SEL of our patients was low (82.69%) and almost 52% had no health insurance coverage. Our study could not demonstrate an association between SEL and QOL. Studies by other authors showed that the SEL influenced the QOL [5,6,24,25]. Conversely, two other studies by Freire *et al*[26] and Thumboo *et al*[27] showed the opposite of our study findings. We recognize that the management of SLE has a high cost in our context. Therefore, it is advantageous to have economic resources and/or health insurance.

The disease had an average duration of 76.79 ± 59.37 months in our study population. This was in agreement with Phuti *et al*[28] in South Africa. This delay seemed to be too long and was due to the ignorance of the disease and the insufficient number of rheumatologists in Black Africa although Kenya is an exception with a diagnostic delay of 18 months[11,29]. Different other studies revealed conflicting results where the authors had revealed a link between the duration of the disease and the QOL[4,5,8,30]. Other authors have argued to the contrary[31-33]. Our study did not identify an association between disease duration and altered QOL as in the study by Odiambo *et al*[11] in Kenya. On the other hand, this link was reported by Nyambane *et al*[10] (P = 0.01; r = 0.31). According to Fortin *et al*[34], a long duration of disease would increase the score in the "emotional role" domain, therefore would not affect the QOL. The main manifestations in our study were rheumatological, dermatological, and haematological. The same observation was made by Budhoo *et* al[15], Dzifa *et al*[17] and Hamdy *et al*[35]. Our study showed that specially skin manifestations were determinants of altered QOL by affecting the domains general health, physical role, physical functioning, mental health and vitality, and haematological manifestations affected the social functioning domain (P = 0.021; r = 0.10) according to Gaballah *et al*[21]. Mucocutaneous manifestations will lead to the development of an aesthetic complex with a negative physical-psychological impact[36]. On the other hand, joints and visceral manifestations were not associated with an impairment in QOL in our study although several other studies confirmed the functional prognosis of rheumatological involvement[4,10,11,32,37]. The average SLEDAI score was 9.92 in our study, indicating a moderate activity. Disease activity in our study was a factor associated with an impairment of QOL specially the very high activity that affected social functioning (P = 0.010; r = 0.19). Empirically, one would think that the more intense the activity of the disease is, the more QOL would deteriorate. This has been confirmed in the literature and it varied from one domain to another[38-41]. Indeed, in Affane *et al*[8] study, the "physical and social functioning", "general health", "vitality" and "physical pain" domains were the ones affected, whereas Devilliers *et al*[4] only reported "physical functioning" domain, and in the study of Hamdy *et al*[35], "general health", "social functionning" and "body pain" were affected. Many other authors have not found a correlation between the activity of the disease and the change in QOL [4,11,22,42,43]. The most common drug in lupus specific treatment was HCQ and the symptomatic drug in our population was prednisone (92.31%) as found in other studies[10,11,18,20]. It is important to mention that the activity of the disease will strongly depend on the quality of the treatment received. In fact, in our study the lack of treatment (due to low SEL) was a determining factor in the alteration of the QOL by affecting several domains: physical role, physical functioning, mental health and vitality. As we found in our study, treatment was not correlated with QOL in the literature[11].

Conclusion

In Abidjan, the use of the SF-36 questionnaire in SLE has shown that patients attending Cocody University Teaching Hospital have a lower QOL and the most affected domains were: "physical role" and "vitality" and their impairment affected the QOL of patients. Patients at risk of impaired QOL in SLE in Abidjan are: mature adults, not married, secondary-educated women whose disease manifestations are mucocutaneous and haematological with severe very high disease activity (SLEDAI) and patients who have not received any treatment.

Conflict of interest: None to declare.

Consent of the patients: This was received.

Ethical approval: The study was cleared by the relevant ethics committee.

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