

Correlates of Health-Related Quality of Life among Patients with Systemic Lupus Erythematosus

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Abstract

Background: Systemic Lupus Erythematosus (SLE) is an autoimmune disease that associated with high morbidity and mortality and causing a burden on the quality of life (QOL). **Aim of the study:** To explore the correlates of health-related quality of life among patients with systemic lupus erythematosus. **Design:** A descriptive correlational research design was used in this study. **Setting:** The study was conducted in Rheumatology and Rehabilitation outpatient clinics at Suez Canal University Hospitals in Ismailia City, Egypt. **Subjects:** A convenient sample of 60 patients with systemic lupus erythematosus. **Tool of data collection:** Data was collected by using three tools; tool I: Structured interviewing questionnaire to assess sociodemographic data and medical condition, tool II: Adherence of patient to therapeutic regimen questionnaire to assess patient's adherence to therapeutic regimen and tool III: Short Form Health Survey 36 (SF-36) to assess QOL. **Results:** The mean age of studied patients was 31.96±9.20 years. 75% of the studied patients had high QOL. There was a significant positive correlation between total QOL and total adherence of the studied patients to therapeutic regimen with p value 0.01. There was statistically significant relation between the studied patients' QOL level and duration of suffering of SLE with p value 0.022. **Conclusion:** There was a significant positive correlation between total QOL and total adherence of the studied patients to therapeutic regimen and there was significant positive relation between the studied patients' QOL level and duration of suffering of disease. **Recommendations:** Educational guidelines to improve good correlates of quality of life were recommended.

Keywords: Correlates, Health Related Quality of Life, Systemic Lupus Erythematosus.

1. Introduction

Systemic lupus erythematosus (SLE) is a chronic autoimmune disorder that is distinguished by immune dysregulation and systemic inflammation, which damages multiple organs including the heart, kidney, bones, brain, lungs, skin, and blood vessels

(Choi & Costenbader, 2022).

There are an estimated 5 million persons globally who have systemic lupus erythematosus (SLE), with 20 to 150 instances per 100,000 people in the US (Stojan & Petri, 2018). The prevalence of adult SLE in Egypt was estimated to be

6.1/100,000, with 1.2/100,000 males and 11.3/100,000 females (**Gheita et al.,2021**).

Systemic lupus erythematosus has no known cause, but there are a number of risk factors that include genetic predisposition, emotional or physical disability, and environmental factors like exposure to certain viruses, UV radiation, smoking, and specific medications like isoniazid and penicillamine (**Elgendi, 2021**).

SLE has a chronic or recurrent illness course and is nonhomogeneous in its clinical manifestations that affect one or more organs, including the skin, joints, heart, kidneys, neurological system, and lung lining (**Elkaraly et al., 2020**).

Persons' quality of life (QOL) can be described as how they view their place in life, their aspirations, expectations, and concerns, as well as how they relate to the values and culture of the community in which they reside (**Rodrigues et al., 2022**). Health-related quality of life (HRQoL) is a phrase that is broken down into many domains in normal clinical practice and gives patients a viewpoint on sickness and its impact on everyday living in terms of physical, social, and mental health (**Shi et al., 2021**).

The fatigue and pain were the two most reported symptoms that affecting the patients' quality of life. Constant fatigue has a devastating

effect on many aspects of patients' life and undoubtedly constitutes a factor that worsens the quality of life. Over 90% of patients suffer from joint pain that it is one of more frequent reasons why patients visit a physician. Pain significantly influences everyday functioning of patients, limits their abilities to discharge professional duties as well as household responsibilities, perform physical exercise and even personal activities (**Olesińska & Saletra, 2018**).

The disease has negative impact on social life that the patients do not fulfil their household and family responsibilities due to constant fatigue and bad mood. Women often report that they do not have the necessary strength to take care of children and neglect their duties as a mother and a wife. The disease has also negative impact on the partnership as the patients spend less quality time with their partners, who, in turn, have additional responsibilities. patients with low HRQOL have less chance to build a relationship with others (**Farinha et al., 2017**).

Depression in SLE patients has been shown to adversely affect health-related quality of life (HRQoL) and increase work disability that it is a significant negative predictor so understanding depression and its determinants may provide potential targets for intervention to improve HRQoL and health outcomes in SLE patients also, sleep disorders are common in patients with SLE with

prevalence ranging from 55% to 85% so poor sleepers had impaired HRQoL in almost all domains of the lupus quality of life than good sleeper(Chalhoub & Luggen, 2022).

Patient demographics, illness statuses, and the health care system are just a few of the variables that might affect patients' quality of life in terms of their health. Other factors that have been reported to have an impact on many components of HRQoL in SLE include female sex, older age, low education, low socioeconomic position, and smoking (Drenkard et al., 2022).

Age, gender, marital status, educational level, occupation, place of residence, and income make up the framework of the correlates, which also include psychological state and health-related knowledge and medical condition (duration of illness, comorbidity, and adherence to therapeutic regimen) (Nesbitt et al., 2014).

A patient's age and clinical traits, such as a long-term impairment and an active disease, have been linked to poor HRQOL. The prognosis and effectiveness of treatment have been reported to be worsened by worse HRQOL-related illness misconceptions. SLE is more common in young women of childbearing age, and it lasts less time when the person has high socioeconomic position (Carrión-Nessi et al., 2022).

A person's capacity for receiving and applying knowledge and experience to maintain health in a way that is appropriate to their individual and organizational contexts is defined as health literacy so inadequate health literacy leads to poor health outcomes, inefficient use of health care services, such as more frequent hospitalizations, higher readmission rates, and increased use of emergency services. A high level of health literacy is also required for many of the duties individuals with SLE must perform to manage their illness, such as attending routine clinic visits and comprehending drugs and disease-related issues(Correa-Rodríguez et al., 2022).

It is important for individuals with chronic illnesses to take their prescriptions as prescribed; non-adherence has been reported to be more common among SLE patients, which can have a negative impact on treatment outcomes and increase the risk of irreversible organ damage. In general, intentional nonadherence involves issues with medication use (such as side effects and financial difficulties, which are more common in underdeveloped nations), which lowers quality of life (Emamikia et al., 2022).

Health care providers and society are becoming more and more concerned about how systemic lupus erythematosus affects

QOL. It has a variable course and outcome and is susceptible to periods of exacerbation and remission. Lupus frequently affects the musculoskeletal system and skin, but it can also cause inflammation in the kidneys, heart, lungs, and central nervous system. Patients with chronic illnesses expressed worry about their chances of survival and the quality of that survival (Yousef et al., 2018).

Significance of the study:

Systemic lupus erythematosus is a disease with a high global burden that impairs patients' quality of life and results in a wide range of problems that affect many body systems, making it challenging to detect and treat. Despite many studies on SLE, a limited number of studies identified the correlates of health-related quality of life among SLE patients. So, this study will explore correlates that affect patients' quality of life and therefore decrease disease development and conduct guidelines that improve good correlates of QOL.

The aim of the study:

This study aimed to explore the correlates of health-related quality of life among patients with systemic lupus erythematosus.

Objectives:

1. Assess health-related quality of life among patients with systemic lupus erythematosus.

2. Assess the correlates of health-related quality of life among patients with systemic lupus erythematosus.

2.Subjects and Methods

Study design: A descriptive correlational research design was used in this study ,it is a type of descriptive research design that was used to examine the relationship between variables.

Study setting: The study was conducted in Rheumatology and Rehabilitation outpatient clinics at Suez Canal University Hospitals in Ismailia city, Egypt for data collection. It is located at the ground floor and contains three clinics open every day of the week.

The sample of the study:

A convenient sample of SLE patients that actually 60 cases. who attended to the outpatient clinics according to- :

-Inclusion criteria: Male and female adult SLE patients and among 20-60 years.

-Exclusion criteria: Pregnant patients and end-stage renal disease.

Sample size: was determined according to the following equation:

$$n = (Z \alpha/2)^2 * P (1-P) / d^2 \text{ (Dawson, 2004)}$$

- n= sample size

- $Z_{\alpha/2} = Z$ is the statistic corresponding to level of confidence (1.96)
- d = is precision (corresponding to effect size) (0.1)
- P is expected prevalence (17%)
(Yousef et al., 2018).

$n = 60$ participants.

Tools of data collection:

Tool (I): A Structured interviewing questionnaire:

It was designed by the researcher based on related literatures (Elbqry et al., 2017, Taha et al., 2018 & Elmetwaly et al., 2021) and consists of two parts:

Part 1: It was used to assess the studied patients' sociodemographic characteristics, such as; age, gender, marital status, occupation, educational level and place of residence.

Part 2: It was used to assess the studied patients' medical condition such as patient history and comorbidity.

Tool (II): Adherence of patient to therapeutic regimen questionnaire:

This tool was adapted, and it included 39 items to assess systemic lupus erythematosus patients' adherence to the therapeutic

regimen regarding medication, diet, exercise, rest & sleep and follow-up regimen. Medication (13 items), diet (11 items), exercise (5 items), rest and sleep (5 items) and follow up (5 items) (Elbqry et al., 2017).

Scoring system:

The total score of adherence ranged from 0 to 78. Each item was answered through the patient using three options are Yes = 2, Sometimes = 1, No = 0.

- $\geq 60\%$ was considered a satisfactory level of adherence behavior when the total grades were ≥ 47 grades.
- $< 60\%$ was considered an unsatisfactory level of adherence behavior when the total grades were < 47 grades (Elbqry et al., 2017).

Tool (III): Short Form Health Survey 36 (SF-36) :(Ware Jr & Sherbourne, 1992)

was adopted and used to assess the quality of life for patients with SLE. This tool contains 36 items grouped into eight domains: physical functioning(10items), bodily pain(2items), role limitations due to physical health problems(4items), role limitations due to emotional problems(3items), emotional wellbeing(5items),social functioning(2items), energy/fatigue(4items), and general health

perceptions (6 items).

Scoring system:

Scores represent the percentage of total possible score achieved in which: questions with 5 responses options were coded as 0, 25, 50, 75 and 100, questions with 6 responses options were coded as 0 ,20 ,40 ,60 ,80 and 100, questions with 3 responses options were coded as 0,50 and 100 and questions with 2 responses options were coded as 0 and 100, it was considered as the following:

- $\geq 70\%$ was considered a high quality of life.
- $< 70\%$ was considered a low quality of life (**Wolide et al., 2020**).

Tools validity and reliability:

Five experts from various academic fields revised the study tools for clarity, relevance, applicability, comprehensiveness, simplicity, and small adjustments. Three experts from medical surgical nursing and two experts from rheumatologist medicine each contributed their experience to the revision. Cronbach's (Alpha) was used to evaluate the reliability of the assessing tools. Tool II reliability scores, which measure a patient's adherence to therapeutic regimen, were (0.853). Tool III (SF-36) has been standardized.

Pilot Study:

Prior to conducting the real study, a pilot study with six SLE patients (10% of the total study population), was done to assess the tools' clarity, applicability, practicality, and time requirements. It was launched, and the adjustments were made. Patients who took part in the pilot trial were not included in the study's main sample.

Field work:

From the first day of December 2021 to the first day of April 2022, data collection took place over a period of around four months. The researcher gathered the data by visiting the rheumatology and rehabilitation outpatient clinics at Suez Canal University Hospitals twice a week (on Saturday and Sunday) from 10 am to 1 pm. Each patient was interviewed by the researcher for roughly 20:30 minutes. The researcher uses the interview questionnaire instrument to collect information about patient knowledge, adherence to treatment plans, and evaluation of quality of life.

Administrative design:

By submitting a formal letter from the vice dean of the Faculty of Nursing, the hospital administration team (director of hospital, department head) was able to get a formal permit for data collecting in Suez

Canal University hospitals. The researcher and nursing administrative staff got together and talked about how to increase collaboration during the study's execution, as well as how to communicate the study's goals and purpose to patients and obtain their written consent before starting data collection.

Ethical considerations:

The ethical committee in Faculty of Nursing, Suez Canal University approved the research proposal with the approval code 120-9/2021. The patient was informed of their right to participate in the study or not and that they had the option to withdraw at any time. The researcher emphasized the significance of maintaining the confidentiality of the patients' private information.

Statistical design:

Statistical program for the Social Sciences version 23 was used to code, enter, and analyze the questionnaire's results. Descriptive statistics like frequency, distribution, mean, and standard deviation were employed to describe attributes. Pearson correlation (r test) was used to examine relationships between various variables. A chi-square test was applied to examine the association between category variables. The

confidence interval and proportion likelihood of error (p-value) were utilized. The p value was set at 0.05 to indicate significant results.

3. Results

Table (1) shows distribution of the studied patients according to sociodemographic characteristics that (53.3%) of the studied patients were aged from 20 years to less than 30 years with Mean \pm SD were 31.96 \pm 9.20, and all the studied patients were female (100%). About 50% of the studied patients were married and (45%) of them had secondary educational level. Also (58.3%) had urban residency and almost of them were not working (70%).

Table (2) shows distribution of the studied patients according to their health history that (60%) of the patients had the disease (SLE) from less than 1 year and (51.7%) of them suffered from comorbid disease.

Figure (1) shows level of the total adherence to therapeutic regimen of the studied patients regarding SLE that (61.7%) of the studied patients have satisfactory level of adherence to therapeutic regimen while (38.3%) of studied patients have unsatisfactory level of adherence to therapeutic regimen.

Figure (2) shows the level of quality of

life of the studied patients that (75%) of studied patients have high quality of life while (25%) of studied patients have low quality of life.

Table (3) shows the relation between the studied patients' health-related history and their quality-of-life level that there was statistically significant relation between the studied patients' quality of life level and duration of suffering of SLE with P value = (.022).

Table (4) shows the correlation between the studied patients' total adherence to therapeutic regimen and their quality-of-life domains that there was significant positive correlation between total patients' adherence and general health perception with P value = (.023), social functioning with P value = (.004), Physical functioning with P value = (.012), energy/ fatigue with P value = (.001) and emotional wellbeing with P value = (.001).

4. Discussion

The current study found that more than half of the studied patients were between the ages of 20 and less than 30, this finding was consistent with **(Hassan & Gomaa, 2018)**, who reported that half of the studied patients were between the ages of 20 and 30 in their study on the "effect of systemic lupus on patient's self-esteem and quality of life."

According to the researcher, this is because women in reproductive age have the highest quantities of estrogen, which increases the risk of SLE.

In contrast, this finding was refuted by **(Mohamady et al., 2022)** who reported that more than half of the investigated patients were older than 30 years old in their study about "effect of self-care management on health outcomes and symptoms for females with systemic lupus erythematosus."

The current study's findings regarding gender corroborated those of **(Elmetwaly et al., 2021)** who reported that all the studied patients were females in their study on "the effect of nurse-led lifestyle intervention protocol on associated symptoms and self-efficacy of patients with systematic lupus erythematosus."

The majority of the patients in the study were female, according to **(Ferreira et al., 2023)** on a study about the "creation and validation of the European Portuguese version of the systemic lupus erythematosus quality of life questionnaire." According to the researcher, this is caused by female hormones like estrogen that raise the likelihood of getting the disease, as well as the fact that women are more susceptible to stress, which

in turn increases the incidence of SLE.

But this finding disagreed with **(Sakr et al., 2022)** in a previous study about "relationship of adherence to treatment with disease activity, physical function, quality of life, treatment satisfaction and beliefs in axial spondylarthritis patients" ,who revealed that the most of studied patients were males.

The current study's findings regarding marital status were in agreement with **(Mohamad et al., 2020)**, who reported that more than half of the studied patients were married in their study on the "effect of nursing education on knowledge and self-care for patients with systemic lupus erythematosus." According to the researcher, this may be because marriage increases obligations, which in turn increases stress, which is one of the risk factors for SLE.

Contrary to **(Chalhoub & Luggen, 2022)**, who reported that half of the investigated patients were single in the research about "depression-, pain-, and health-related quality of life in patients with systemic lupus erythematosus."

Regarding educational level, this study showed that more than two fifths of the studied patients had a secondary education. This finding was consistent with **(Hassan et**

al., 2017), who reported that two fifths of the studied patients had a secondary education in their study on "quality of life and disease activity among patients with systemic lupus erythematosus." Additionally, this result was consistent with **(Gaballah & El-Najjar, 2019)**, who reported that nearly two fifths of the studied patients had average education in a study on "clinical characteristics and health related quality of life (HRQoL) in Egyptian patients with systemic lupus erythematosus."

According to the researcher, this is a result of the typical urban nature of dwelling as well as the educational traditions of urban households. In contrast with **(Broadway-Duren & Cesario, 2022)** who stated that more than half of the investigated patients had a college degree in their study on "the lived experiences of women seeking a diagnosis of systemic lupus erythematosus."

More than half of the patients in this study lived in urban areas, which is consistent with the findings of a subsequent study by **(Mohamed et al., 2019)** on "the quality of life of pregnant women with systemic lupus erythematosus", which found that two thirds of the patients in that study also resided in urban areas. According to the researcher, this is a result of harmful habits like eating fast

food and being exposed to pollution.

This finding conflicts with **(Elsayed & Mesbah, 2018)**, who claimed that the majority of the examined patients resided in rural areas in their study on "effect of health education-based intervention on self-care among systemic lupus erythematosus clients."

In terms of occupation, the results of the current study supported those reported by **(Mohammed, 2018)** in a study about "effect of self-management guidelines on health outcomes for patients with systemic lupus erythematosus," which found that more than two thirds of the studied patients did not hold a job. According to the researcher, this is because all the patients were women, making them all stay-at-home mothers, and since the illness could cause physical impairment.

This finding contrasts with **(Kusnanto et al., 2018)**, who reported that more than two thirds of the studied patients were employed in a study about "self-care model application to improve self-care agency, self-care activities and quality of life in patients with systemic lupus erythematosus."

In terms of medical history, the results of the current study revealed that more than half of the patients had SLE for less than a year, which was consistent with the findings

of **(Hassan et al., 2017)**, who also stated that more than half of the patients had SLE for less than a year. However, **(Mohamad et al., 2020)** revealed that the majority of the investigated patients had disease for one to five years or less, which was contrary to the finding of the current study.

The finding of the study was consistent with **(Elmetwaly et al., 2021)** who reported that more than half of the studied patients suffered from comorbid diseases, and it was also in agreement with **(Gamal et al., 2022)** in a study about "comorbidities among Egyptian systemic lupus erythematosus: the COMOSLE-EGYPT study," who reported that the majority of the studied patients suffered from comorbid diseases. This finding conflicts with the findings of **(Mohamad et al., 2020)**, who claimed that the majority of the investigated patients did not have comorbid conditions.

The current study's findings regarding medication adherence were consistent with those made by **(Mazur-Nicorici et al., 2018)** in their study on "therapeutic adherence in patients with systemic lupus erythematosus," which claimed that more than two fifths of the studied patients had high medication adherence. And concurred with **(Du et al., 2020)**, who stated that more than half of the

investigated patients adhered to drugs in their study on "medication adherence in Chinese patients with systemic lupus erythematosus."

In terms of overall quality of life, the current study found that three-quarters of the patients had high QOL, at the researcher's point of view; this was because the patients had received adequate education about their disease, adhered to their treatment plan, and had a sufficient level of knowledge about their condition. This result was consistent with **(Martinec et al., 2019)** who stated that there was no statistically significant difference in QoL between patients and the general population in their study about "quality of life in patients with rheumatoid arthritis-a preliminary study." This result contrasted with that of **(Yousef et al., 2018)**, who claimed that more than three-quarters of the patients under study had poor QOL.

The current study found a statistically significant relationship between the studied patients' quality of life level and the duration they had to suffer from SLE. This finding was consistent with that of **(Hassan et al., 2017)**, who discovered a statistical difference between patients' quality of life and length of illness.

From the researcher's perspective,

patients' quality of life was negatively impacted anytime they received a new disease diagnosis since they were anxious, unsure of how to cope, and unaware of any safety measures.

Patients who endured long-term illness were more likely to be knowledgeable about their condition and the factors that influence it, to have adapted to it and to follow the recommended treatment plan, all of which contributed to a great quality of life. This result contrasted with that of **(Gaballah & El-Najjar, 2019)**, who discovered that the quality of life of patients was unrelated to the length of the sickness. In order to improve quality of life, teaching programs about all aspects of disease are conducted for newly diagnosed patients.

The current study found that there was a significant positive correlation between total patient adherence, general health perception, social functioning, physical functioning, energy/fatigue, and emotional. This finding was consistent with that of **(Sakr et al., 2022)** who found that there was a significant correlation between patients' quality of life and their adherence to therapeutic regimen.

According to the researcher, when patients followed their therapy regimen,

which included medication, food, exercise, rest, and follow-up, this resulted in an improvement in their physical, psychological, and mental health as well as a higher quality of life.

Conclusion:

Based on the findings of the present study, it can be concluded that majority of the studied patients had high quality of life regarding systemic lupus erythematosus. There was a significant positive correlation between total patients' adherence, general health perception, social functioning, physical functioning, energy/ fatigue, and emotional wellbeing .

Additionally, there was a significant positive correlation between total quality of life (QOL) and total adherence of the studied patients. There was statistically significant positive relation between the studied patients'

quality of life level and duration of suffering of systemic lupus erythematosus.

5. Recommendations:

Based upon the findings of this study, the following recommendations can be suggested: -

1. Regular monitoring of quality of life of systemic lupus patients as a standard of care.
2. Educational guidelines about adherence to therapeutic regimen as a key for improving quality of life.
3. Replication of this study by using a large probability sample acquired from different geographical area.
4. Further researches should be conducted on studying correlates of quality of life on other immunological disorders.

Tables and Figures

Table (1): Distribution of sociodemographic characteristics for the studied patients (n=60).

Sociodemographic characteristics	N	%
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Age (Years)		
• 20:<30	32	53.3
• 30:<40	11	18.3
• 40:<50	11	18.3
• 50:60	6	10
Mean ±SD	31.96±9.20	
Gender		
• Female	60	100
Marital status		
• Single	28	46.7
• Married	30	50
• Divorced	1	1.7
• Widowed	1	1.7
Educational level		
• Illiterate	7	11.7
• Primary	24	40
• Secondary	27	45
• University	2	3.3
Residence		
• Urban	35	58.3
• Rural	25	41.7
Occupation		
• Yes	18	30
• No	42	70

Table (2): Distribution of the studied patients according to their health history (n=60).

Health history	N	%
Duration of suffering of SLE (years)		

<1	36	60
1:<5	15	25
5:<10	7	11.7
>10	2	3.3
Comorbidity (HTN, DM ,Liver and cardiac diseases)		
Yes	31	51.7
No	29	48.3

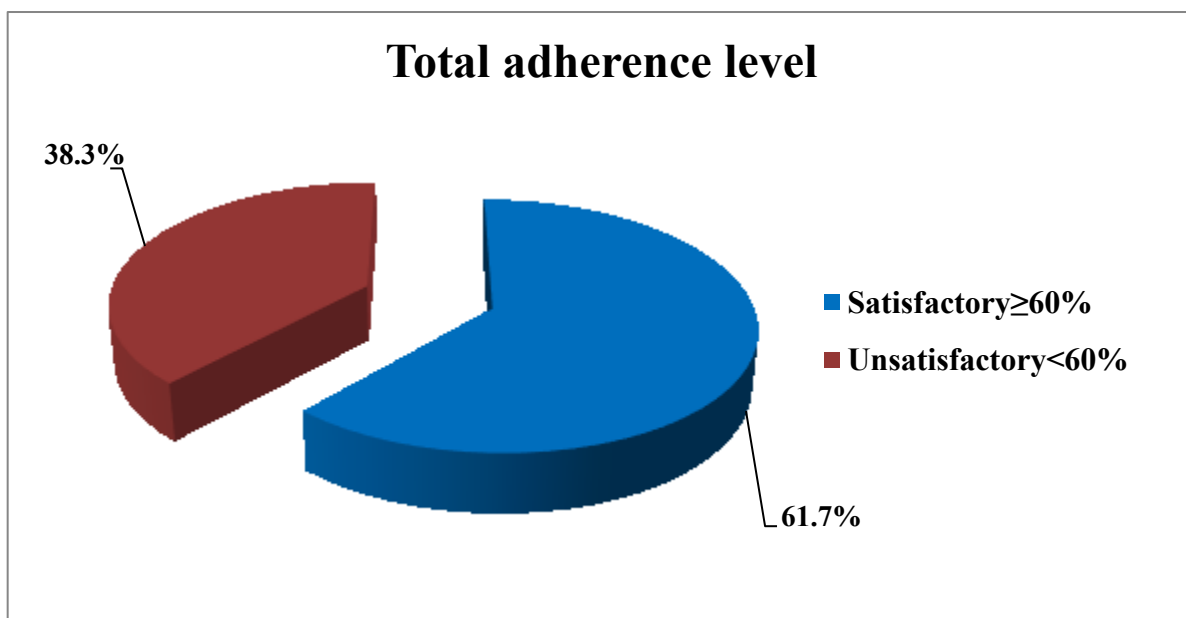


Figure (1): Level of the total adherence to therapeutic regimen of the studied patients regarding SLE (n=60).

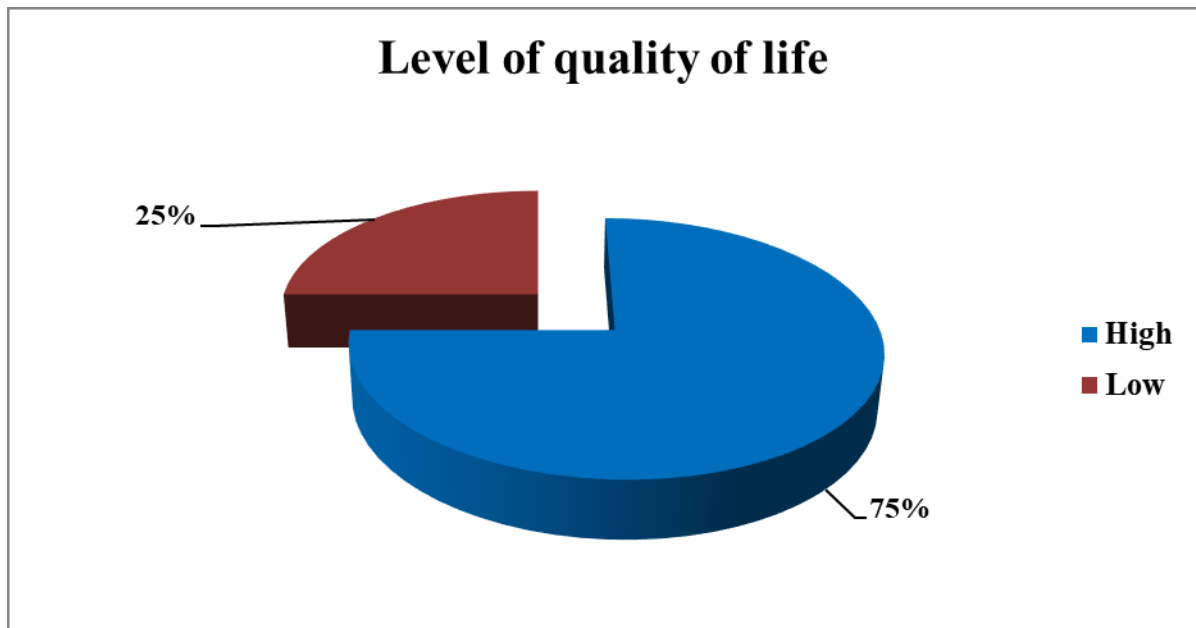


Figure (2): level of quality of life of studied patients (n=60).

Table (3): Relation between the studied patients' health-related history and their quality of life level (n=60).

Health history	Quality of life				X ² (P value)
	High		Low		
	N	%	N	%	
Duration of suffering of SLE (years)					
• <1	6	16.7	30	83.3	9.56(.022*) ^{MC}
• 1:<5	6	40	9	60	
• 5:<10	1	14.3	6	85.7	
• >10	2	100	0	0	
Suffer from comorbid disease					
• Yes	7	22.6	24	77.4	2.00(.655)
• No	8	27.6	21	72.4	

X² is chi-square test, ^{MC} is Monte Carlo for Chi square test P value is significant <.05.

Table (4): Correlation between the studied patients' total adherence to therapeutic regimen and their quality-of-life domains (n=60).

Quality of life domains	Adherence to therapeutic regimen	
	R	P value
General health perception	.294	.023*
Social functioning	.366	.004*
Physical functioning	.324	.012*
Role limitations due to Physical health problems	.207	.113
Role limitations due to emotional health problems	.027	.837
Bodily pain	.184	.159
Energy/ Fatigue	.405	.001*
Emotional wellbeing	.753	.001*

Rho is spearman rho & P value is significant (two tailed significance) $\leq .05$.

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