

Coping Styles among Patients with Systemic Lupus Erythematosus

Amr Salah Mostafa¹, Zeinab AbdElhalim Osman², Wafaa Osman Abd El-Fatah³, Nora Yousry Elsaid⁴

¹Demonstrator, Psychiatric and mental health nursing. Faculty of Nursing, Helwan University, Egypt

²Professor of Psychiatric and mental health Nursing faculty of nursing, Cairo-University, Egypt

³Assistant Professor of Psychiatric and mental health Nursing faculty of nursing, Helwan University, Egypt

⁴Assistant Professor of Rheumatology, Faculty of medicine, Cairo University, Egypt

Corresponding author email: Amr.salah@nursing.helwan.edu.eg

Abstract

Background: Coping with systemic lupus erythematosus (SLE) can be challenging due to chronic pain, life style change and psychological problems associated with the disease.

Aim: to assess coping styles among patients with systemic lupus erythematosus and find out the relation between coping styles and systemic lupus erythematosus. **Design:** descriptive correlational research design was used to conduct the study. **Setting:** the current study was conducted in the rheumatology clinic in Cairo university hospitals (Kasr Elainy). **Sample:** convenient sample (96) of SLE patients

Tools: 2 tools were used for data collection.; 1st tool - sociodemographic and medical history sheet. The 2nd tool - brief COPE scale.

Results: the mean age of the studied patients was 32.19±9.20. majority of studied patients were female (91.7%). Furthermore 70.8% of the studied patients had moderate level of approach coping styles while, 59.4% of them had low level of avoidant coping strategies. Also (75%) of the studied patients had moderate levels of total coping styles and (14.6%) of them had low levels of total coping styles. while only 10.4% of them had high levels of total coping styles.

Conclusion: there is a significant statistical relationship between total coping levels of the studied patients and their marital status and educational level, in addition there is a significant statistical relationship between total coping styles of the studied patients and their skin rash.

Recommendations. Studying the relation between disease activity and coping styles among patients with SL. Conducting psychoeducational program for enhancing coping styles among patients with SLE.

Introduction

Systemic lupus erythematosus (SLE) is a chronic autoimmune disease with heterogeneous clinical manifestations ranging from mild cutaneous disease to catastrophic organ failure and obstetrical complications. Young women are disproportionately affected by SLE, with a greater prevalence and incidence of this disease in certain ethnic populations such as Black, Asian and Hispanic populations (*Barber et al., 2021*). Although people of any age and gender can be involved, females of childbearing age are the most affected, with a female-to-male ratio of about 9:1 (*Mohammed et al., 2021*).

SLE can have a wide range of manifestations, involving virtually every organ or apparatus, and its severity can vary from very mild disease without major organ involvement, to severe life-threatening conditions. Clinical manifestations may include cytopenia, fever, malar and other skin rashes, oral ulcers, polyarthralgia/non erosive arthritis, vasculitis, renal, neurological, cardiac, and pleuro-pulmonary involvement (*Signorini et al., 2020*).

People who facing stressful life situations or uncertainties regarding their life or future, usually use many coping strategies, from these strategies., positive coping strategies or “adaptive” which include seeking social support, being compassionate, engaging in exercise, cognitive acceptance, and avoidance of threatening thoughts to relief their stressors and cope adaptively (*Ogueji & Okoloba, 2020*).

On the other hand, maladaptive coping strategies such as alcohol consumption or taking illegal drugs, changing behaviour to avoid the situation and difficult feelings, overly rehearsing a future event, excessive worrying, and hyper-vigilance, self-blame, or suicidal thoughts have been found among people facing stressful life situations, but their strategies have a negative health sequence (*Liang et al., 2020*).

Keywords:

Coping styles, Approach coping styles, Avoidant coping styles, Systemic lupus Erythematosus.

DOI:

10.5455/jcmr.2023.14.05.26

Nursing intervention for ineffective coping includes the following: Using techniques such as active listening, reflecting, open-ended questions, and even silence. Nurses can foster trusting relationships with patients and further explore barriers to their ability to cope. Offering the patient thorough information regarding signs and symptoms of their illness, what to expect with a test or surgery, and expected outcomes allows them to feel more in control of their care without the unnecessary stress of the unknown. The nurse can offer available options such as books, music, distraction, and guided imagery. Offer positive responses without false reassurances (Meadus, 2023).

Significance of the study

The highest estimates of incidence and prevalence of SLE were in North America (23.2/100 000) person-years, the lowest incidences of SLE were reported in Africa and Ukraine (0.3/100 000) person-years), and the lowest prevalence was in Northern Australia (0 cases in a sample of 847 people) (Phuti, 2020). Women were more frequently affected than men for every age and ethnic group. Incidence peaked in middle adulthood and occurred later for men. People of Black ethnicity had the highest incidence and prevalence of SLE, whereas those with White ethnicity had the lowest incidence and prevalence (Koo, 2021).

In Egypt the overall estimated prevalence of adult SLE was (6.1/100,000) population (1.2/100,000) males and (11.3/100,000)

females) There were 316 (8.6%) juvenile-onset (Jo-SLE) and 3345 adult-onset (Ao-SLE). Age at onset was highest in South and lowest in Cairo (Gheita et al., 2021). Also, it was reported that; about (85) cases monthly are admitted to the rheumatology department in Cairo University Hospital with different signs and symptoms (Mohamad et al., 2020). In Assiut University Hospital the total number of patients admitted in (2018) was about (400) cases to medical and rheumatology department (Abdelall et al., 2022).

From the researcher's point of view assessing coping styles is crucial because coping styles play an important role in motivating patients to remain mentally healthy, to engage in behaviours that help them cope with psychological problems caused by their life-threatening chronic disease, and to eventually improve their quality of life. Thus, studying coping styles will guide health care providers (HCP) to identify maladaptive coping used by the patients which is linked to poor health outcomes. Identifying coping styles will enable (HCP) to reinforce adaptive coping and minimize maladaptive coping styles.

Aim of the study.

The aim of this study was two folds:

1. To assess coping styles among patients with systemic lupus erythematosus.
2. To examine the relationship between coping styles and systemic lupus erythematosus.

Research questions

- 1- What are the coping styles used by patients with systemic lupus erythematosus?
- 2 What is the relationship between coping styles and systemic lupus erythematosus?

Methodology

Design

Descriptive correlational research design was used to achieve the aim of the study.

Setting

The current study was carried out in the rheumatology outpatient clinic at Cairo university hospital. The clinic consists of 2 rooms for all rheumatology patients including systemic lupus erythematosus Patients (SLE); 1st room for newly diagnosed or acute cases, and the second is for chronic cases which is called (follow up) clinic. SLE Patients visit the clinic for examination and follow up on Sundays, Mondays, and Tuesdays per week.

Sample

A convenient sample was used to achieve the aim of this study. (96) patients who accepted to participate in the study.

Inclusion criteria.

- 1- Patient ages less than 18yrs.
- 2- A diagnosis confirmed to SLE classification criteria by American college of rheumatology (ACR) & systemic lupus international collaborating clinics (SLICC) and follow at an outpatient clinic.
- 3- Being able to communicate and comprehend the questionnaires.

Exclusion criteria

- 1- The presence of cognitive deficits such as mental retardation or acute state of confusion which prevent the patient from completing the questionnaires.
- 2- Having disorder of consciousness.
- 4- Using psychotropic drugs such as anti-depressants and tranquilizers ..etc.
- 5- Having neuropsychiatric SLE.
- 6- Having severe dyslexia caused by SLE.
- 7- Patients with comorbidities (e.g., Serious infections, or cardiac, respiratory, gastrointestinal, or endocrine disease) that could influence SLE activity.

Tools for data collection.

The data were collected through using the following two tools:

Tool (I): Sociodemographic and medical history sheet.

Designed by the investigator after reviewing recent relevant literature and includes Sociodemographic data of the patients as (Number, Age, Marital Status, place of residence level of education, compliance of patient in follow up, duration of diagnosis with SLE...etc.

Tool (II): Brief COPE scale (Carver et al., 1989).

The Brief-COPE is self-report questionnaire designed to measure effective and ineffective ways to cope with a stressful life events and often used in health-care setting to measure how someone is coping with a wide range of adversity, including a cancer diagnosis, heart failure, injuries, assaults, natural disasters, and financial stress. The questionnaire includes 28 questions for avoidant and approach coping styles, each question has a different response as follow (1= I haven't been doing this at all, 2= A little bit, 3= A medium amount, and 4= I've been doing this a lot).

Moreover, the whole questionnaire takes

about 10 minutes to be completed. The scale can determine someone's primary coping styles as either Approach Coping, or Avoidant Coping. In addition, the following subscales are reported: Self-distraction, Brief COPE scoring system.

Active coping, Denial, Substance use, Use of emotional support, Use of instrumental support, Behavioral disengagement, Venting, Positive reframing, Planning, Humor, Acceptance, Religion, & Self-blame.

Low coping	35-47
Moderate coping	48- 68
High coping	69- 90

Tools validity

The tools used in this study are valid and standard tools, no modifications done for brief COPE scale. The Arabic version of brief COPE is a reliable and valid tool to assess coping styles among patients and it is useful in clinical practice and clinical research (Alghamdi, 2020). Content validity of sociodemographic and medical history sheet was reviewed by a panel of 3 experts from Helwan university and Cairo university (2 Expert in Psychiatric and mental health nursing and one expert in Rheumatology & immunology). Content validity by the experts was done to confirm tool clarity, relevance, comprehensiveness, understanding and applicability of tool.

Tool's reliability

Testing reliability of the used tools was done statistically by Cronbach's alpha test. The Cronbach's alpha for brief COPE subscales ranged from 0.50 to 0.90 (Kargari Padar et al., 2022). Cronbach's alpha for Arabic version of brief COPE scale was 0.8 (Alghamdi, 2020).

Ethical considerations.

An official permission to conduct the proposed study was obtained from the Scientific Research Ethics Committee in faculty of nursing Helwan university (Ethical committee No 30 -17 august 2022). Also, another permission to conduct the study was obtained from Faculty of medicine Cairo University (9-11-2022). Participation in the study was voluntary and subjects given a complete full information about the study and their role before accepting to participate in the study. The ethical considerations included explaining the purpose and nature of the study, stating the possibility to withdraw at any time, confidentiality of the information where it will not be accessed by any other party without taking permission of the participants. Ethics, values, culture, and beliefs of all participants were respected. **Pilot study**

A pilot study was carried out on 10% of the sample (9 patients) to test clarity and applicability of the data collection tools. The patients who participated in the pilot study were included in the study because no modifications were done for basic standard tools of data collection.

Fieldwork

The researcher introduced himself to all participants, explained the aim of the study to them, and informed all participants that their information would be treated confidentially and would be used

only for the purpose of research only. The researcher notified all participants that they had the right to accept or refuse to participate in the study and that they have the right to withdraw from the study at any time.

The study's beginning was from March 2023 to the end of June 2023. After acceptance and permission from the scientific research committee in the faculty of Nursing Helwan University, acceptance of the head of rheumatology department, OPD manager, Executive manager of Cairo university hospital and dean faculty of medicine - Cairo University

The patients attended the clinic for follow-up on days of (Sundays, Mondays, and Tuesdays every week) furthermore the researcher attended on these days once per week from 9:00 A.m. to 2:00 P.m. to collect data and meet patients who agreed to participate in the study, otherwise the questionnaires were translated into Arabic to help the patient in understanding the content of the questionnaire.

The required time to complete the questionnaire varied from person to person according to levels of education, environmental factors such as overcrowding around the clinic, and whether the patient completed the questionnaire by himself or was filled by the researcher after interviewing patients who couldn't read or write. Generally, the questionnaires were completed in about 15 - 20 minutes.

Additionally, the researcher helped patients who couldn't read or write in completing the questionnaire by asking them about the content of the questionnaire, especially unclear statements. On the other hand, the educated patients completed the questionnaire by themselves. Finally, the researcher performed a physical examination to confirm symptoms of SLE which were reported by the patients. **Statistical design.**

The collected data was coded, organized, analyzed, tabulated using a computer and presented into tables and graphs according to types of variables. Data were analyzed by using a statistical program for social sciences (SPSS) Version 20.0. Quantitative data were expressed as frequency and percentage. Quantitative data were presented as mean and standard deviation (SD) while qualitative data were expressed as frequency and percentage. Chi-square test (χ^2) was used as a test of significance to test relations between quantitative variables.

P less than 0.05 was considered non-significant (NS).

P more than 0.05 was considered significant (S).

Results

Table (1): Frequency distribution and percentage of the studied patients according to socio-demographic characteristics (n=96).

Items	N	%	Items	N	%
Age (in years)			Educational level		
20 - 35	52	54.2	Not read/write	40	41.7
36 - 50	42	43.7	Secondary level	36	37.5
≥ 50	2	2.1	University	20	20.8
Range	20-52		Residence		
Mean ± SD	32.19±9.20		Rural	28	29.2
Gender			Urban	68	70.8
Male	8	8.3			
Female	88	91.7			
Marital status					
Single	26	27.1			
Married	66	68.6			
Divorced	2	2.1			
Widow	2	2.1			

Table (1) reveals that,54.2% of the studied patients were in age group 20 - 35 years with mean age 32.19±9.20 while 91.7% of the studied patients were females. Moreover, 68.6% of the studied patients were married and 41.7% of them were not read/write. Additionally, 70.8% of the studied patients were from urban residences.

Table 2: Frequency distribution and percentage of the studied patients according to present history of SLE disease(n=96).

Items	N	%
Duration of the disease		
≤1 year	32	33.3
1- 5 year	22	22.9
6- 10 year	22	22.9
≥10 year	20	20.9
The major presenting symptoms *		
Alopecia	56	58.3
Oral ulcer	34	35.4
Skin rash	66	68.7
Arthralgia	56	58.3
Lower limb edema	20	20.8
Fatigue	62	64.5
Headache	22	22.9
Impaired vision	8	8.4
Renal impairment	40	41.6

Table (2) reveals that33.3% of the studied patients had SLE for less than one year.Skin rash and fatigue were the most common presenting symptoms among 68.7% and 64.5% of the studied patients respectively. While 35.4% of the studied patients had oral ulcer and 41.6% had renal impairment.

Table 3 : Frequency and percentage distribution of the studied patients according to total coping styles (n= 96).

Items	Low		Moderate		High		Mean ± SD.
	N	%	N	%	N	%	
Avoidant styles							
Self-distraction	33	34.4	49	51.1	14	14.5	4.54± 1.6
Denial	54	56.2	40	41.6	2	2.2	3.5± 1.64
Substance use	92	95.8	4	4.2	0	0	2.16±0.72
Behavioral disengagement	69	71.8	20	20.9	7	7.3	2.63±1.05
Venting	16	16.7	74	77.1	6	6.2	4.6±1.27
Self-blame	78	81.3	14	14.5	4	4.2	2.75±1.38
Approachstyles							

Active coping	30	31.3	52	54.2	14	14.5	4.64±1.58
Emotional support	16	16.7	64	66.6	16	16.7	5.1±1.67
Use of informational support	20	20.8	66	68.7	10	10.5	4.95±1.49
Positive reframing	14	14.5	72	75.1	10	10.4	4.65±1.33
Planning	12	12.5	76	79.1	8	8.4	4.65±1.29
Acceptance	2	2.2	82	85.3	12	12.5	5.65±1.11
Other styles							
Humor	60	62.5	30	31.3	6	6.2	3.27±1.83
Religion	6	6.2	64	66.6	26	27.2	5.81±1.47

Table (3) reveals that, regarding avoidant styles, 56.2% of the studied patients had low level of denial. While (95.8%) and (81.3%) of them had low levels of substance use and self-blame respectively. Moreover (77.1%) of the studied patients had moderate level of venting and (71.8%) had low level of behavioral disengagement.

Regarding approach coping styles, (85.3%) of the studied patients had moderate levels of “acceptance”. While (79.1%) of patients had moderate level of “planning” and (75.1%) had moderate level of “positive reframing”. Furthermore, (68.7%) and (66.6%) had a moderate level of “use of informational support, and emotional support” respectively. Also, (54.2%) had a moderate level of “active coping”.

Figure (2): Total levels of approach and avoidant coping styles among the studied patients (n=96).

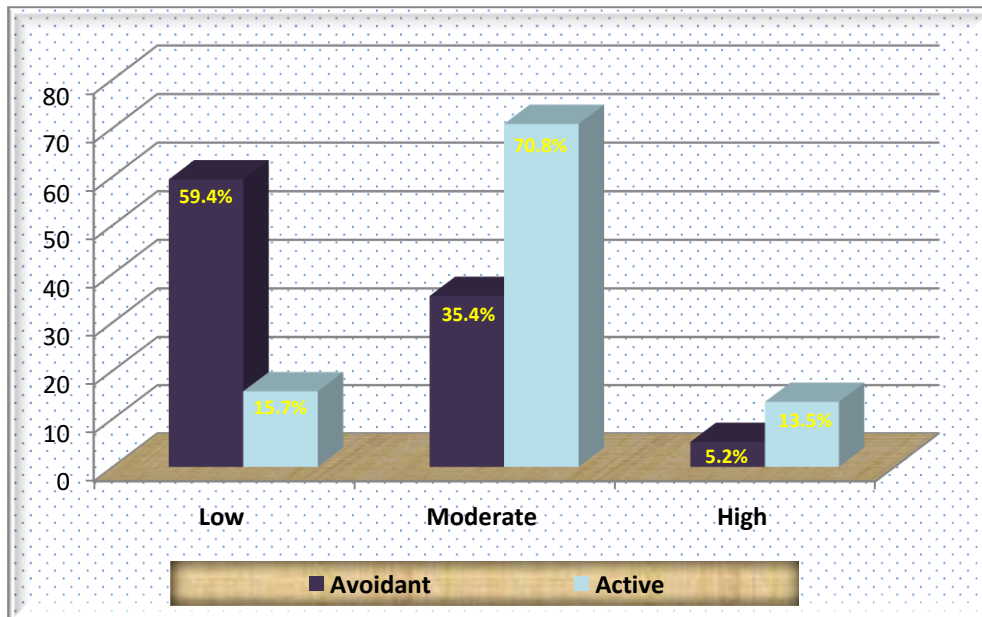


Figure (1) illustrates that, more than two thirds (70.8%) of the studied patients had moderate level of approach coping styles while, (59.4%) of them had low levels of avoidant coping styles.

Table 4: Frequency distribution and percentage of the studied patients in relation to total levels of coping styles (n=96).

Coping Styles Levels	N	%
Low	14	14.6%
Moderate	72	75%
High	10	10.4%
Total	96	100%
Mean &SD	58.91 + 10.36	

Table (4) illustrates that (75%) of the studied patients had moderate levels of coping styles and (14.6%) of them had low levels of coping styles. while only 10.4% of them had high levels of coping styles., mean & SD 58.91 + 10.36.

Table (5): Relation between socio-demographic characteristics of the Studied patients and total coping levels (n=96).

Socio-demographic characteristics	Total coping level						X ²	P-value		
	Low		Moderate		High					
	N	%	N	%	N	%				
Age (in years)	20 - < 35		16	16.7	28	29.2	8	8.3	4.725	0.317

	35 - < 50	16	16.7	22	22.9	4	4.2)NS)
	≥ 50	2	2.1	0	0.0	0	0.0		
Gender	Male	4	4.2	4	4.2	0	0.0	1.622	0.444)NS)
	Female	30	31.2	46	47.9	12	12.5		
Marital status	Single	6	6.2	16	16.7	4	4.2	7.973	0.001*) S)
	Married	28	29.2	31	32.3	7	7.3		
	Divorced	0	0.0	2	2.1	0	0.0		
	Widow	0	0.0	1	1.0	1	1.0		
Educational level	Not read/write	16	16.7	20	20.8	4	4.2	5.482	0.004*) S)
	Secondary	18	18.8	15	15.6	3	3.1		
	University	0	0.0	15	15.6	5	5.2		
Residence	Rural	6	6.2	18	18.8	4	4.2	3.415	0.181) NS)
	Urban	28	29.2	32	33.3	8	8.3		

Table (5) shows that there is a significant statistical relationship between coping level of the studied patients and their marital status and educational level at P value =0.010 and 0.004 respectively. Whilethere was no significant statistical relationship between copinglevel of the studied patients and their age, gender, residence, and duration of disease at p value =0.317, 0.444, 0.181 and 0.090 respectively.

Table (6): Relation between health history of the Studied patients and total coping levels (n=96).

Health history		Total coping level						X ²	P-value
		Low		Moderate		High			
		N	%	N	%	N	%		
Duration of disease	≤1 year	12	12.5	16	16.7	4	4.2	10.959	0.090) NS)
	>1- <5 year	4	4.2	12	12.5	6	6.2		
	5- <10 year	8	8.3	14	14.6	0	0.0		
	≥10 year	10	10.4	8	8.3	2	2.1		
Alopecia	Yes	12	12.5	23	24.0	5	5.2	0.954	0.621) NS)
	No	22	22.9	27	28.1	7	7.3		
Oral ulcer	Yes	24	25.0	29	30.2	9	9.4	2.053	0.358) NS)
	No	10	10.4	21	21.9	3	3.1		
Skin rash	Yes	18	18.8	11	11.5	1	1.0	2.371	0.002*
	No	16	16.7	39	40.6	11	11.5		

X²= Chi Square Test * P-value ≤ 0.05 Significant (S). P-value > 0.05= Non-Significant (NS).

Table (20) shows that there is a significant statistical relationship between coping styles of the studied patients and their skin rash at P value =0.002. Whilethere was no significant statistical relationship between coping styles of the studied patients and duration of the disease, Alopecia, oral ulcer, at p value =0.090, 0.621, and 0.358respectively.

Discussion

The current study results revealed that the vast majority of patients aged between 20- 50 year with mean ± SD 32.19 ± 9.20 and slightly more than half of the studied patients were in age group 20 - 35 years. This result was congruent with **AbdElzaher et al., (2023)**, who studied "Biopsychosocial needs" among patients withSLE and mentioned that more than third of the studied patients' age ranged from 21-30 years. Additionally, the current study results were in the same line with **Shaaban et al., (2022)**,who found that theage of the studied patients range between 20-55 with mean ± SD32.56± 11.51.

The present study results represented that most of the studied patients were females. This finding is supported by **Rider et al., (2018)**,who reported that SLE is linked to genetic susceptibilityand diverse environmental factors, however, the strongest risk factor for developing SLE is being female

(9:1 female to male ratio).

The current study results reported that one third of the studied patients have SLE duration less thanone year and less than one quarter of them had SLE from one to five years. This result wasn't in the same line with(**Liao et al., (2022)**),who stated thatmore than half of the study patients had SLE for more than 5 years. Additionally, this result was incongruent with **Cho et al., (2021)**, who reported that more than two thirds of the participants had a duration since diagnosis of more than 5 years.

Regarding symptoms of SLE The current study results illustrated that skin rash was common among more than two thirds of the studied patients, whereas fatigue was the second most common presenting symptom among two thirds of the studied patients respectively. Furthermore, Alopecia and arthralgia were common among more than half of the studied patients. Also, more than one third of patients have an oral ulcer.

This result was congruent with **Elefante et al., (2022)**, who mentioned that the most frequent active disease manifestations were cutaneous (skin rash, oral ulcers, and Alopecia), hematologic, and articular manifestations (arthralgia, arthritis). Additionally, this result was consistent with **Monahan et al., (2021)**,

who found that physical fatigue had the highest mean score among the patients. As well, this result agreed with Khedr et al., (2021), who found that alopecia and arthritis were common clinical symptoms among two thirds of the studied patients.

The current study results revealed that more than two fifths of the studied patients have a renal impairment. This result was in the same line with Elefante et al., (2022), who found that two fifths of the studied patients had renal involvement. Moreover, this result was inconsistent with Park et al., (2018), who found that one third of the studied patients had renal involvement.

Concerning avoidant coping styles, the current study results revealed that, the vast majority of the studied patients have low level of "substance use", most of them have low level of "self-blame", nearly three quarters of them have low level of "behavioral disengagement", more than three quarters have a moderate level of "venting". And more than half of them have a moderate level of "self-distraction".

With regard to approach coping styles, most of the studied patients had moderate level of "acceptance", "planning" while three quarters of them have a moderate level of "positive reframing". Regarding other coping styles- two thirds have a moderate level of "religion". While nearly two thirds of the studied patients have a low level of "humor". These findings are supported by (Zhou et al., 2021), who stated that short-term avoidance protects patients' spiritual world, facilitates psychological adjustment, and increases the likelihood of promoting positive change. This result was congruent with Mizukami et al., (2023), who mentioned that avoidance strategies had high mean score among patients with SLE.

The present study results showed that the majority of the studied patients had moderate levels of approach coping styles, while, more than half of them had low levels of avoidant coping styles. This finding agreed with Du et al., (2020), who stated that approach coping strategies can relieve stress, promote communication, and have a significant effect by improving mental status and healthy behaviors.

The present study results illustrated that more than half of the studied patients had moderate levels of coping and more than one third of them had low levels of coping, while only, minority of them had high levels of coping. This result disagreed with Fahmy et al., (2023), who showed that half of studied women had low coping levels, one third of them had moderate coping level, and only minority of them had high coping level.

the current study findings showed that there was a significant statistical relationship between coping levels of the studied patients and their marital status and educational level. While there was no significant statistical relationship between coping level and their age, gender, residence, and duration of disease. This result disagreed with Cornet et al., (2022), who found an association between some coping patterns with some patient characteristics as age, duration, and severity of the disease.

The current study results illustrated that there was a significant statistical relationship between total coping styles of the studied patients and their skin rash. While there was no significant statistical relationship between coping styles and disease duration, alopecia, oral ulcer.

This result agreed with Cornet et al., (2020), who studied (Coping with systemic lupus erythematosus in patients' words) and reported that there is a significant statistical relationship between coping styles and skin rash. On the other hand, this study reported also that there is no significant statistical relationship between coping styles and renal impairment and disease duration.

Conclusion

Based on results of the current study, it can be concluded that nearly three quarters (70.8%) of the studied patients had moderate levels of approach coping styles while, (59.4%) of them had low levels of avoidant coping styles. Also, three quarters (75%) of the studied patients had moderate levels of total coping styles and (14.6%) of them had low levels of total coping styles. while only (10.4%) of them had high levels of total coping styles., furthermore there is a significant statistical relationship between total coping levels of the studied patients and their marital status and educational level at P value =0.010* and 0.04 respectively, in addition there is a significant statistical relationship between total coping styles of the studied patients and their skin rash at P value =0.002*.

Recommendations

Based on findings of this study, the following recommendations are suggested:

1. Future studies should be conducted to Assess the relation between socio economic status and coping styles among patients with SLE.
2. Studying quality of life among patients with SLE disease.
3. Studying the relation between disease activity and coping styles among patients with SL.

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