Effect of Non-Pharmacological Nursing Interventions on Fatigue, Pain and Quality of Life for Patients with Systemic Lupus Erythematosus

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Abstract:

Background: Systemic lupus erythematosus (SLE) is a persistent multiple system autoimmune disease with eventual organ damage and pauper quality of life (QOL). Non-pharmacological management is the activities directed towards raising the general health of SLE patients. Aim of the study: Was to evaluate the effect of non-pharmacological nursing interventions on fatigue, pain and quality of life for patients with systemic lupus erythematosus. Subjects and Methods; Research design: A quasi-experimental design was used in this study. Setting: The study was conducted in the inpatient and outpatient clinics of rheumatology and rehabilitation at Zagazig University Hospitals, Egypt. Subjects: A purposive sample of eighty patients with SLE was recruited for this study. Tools of data collection: A structured interview questionnaire, brief pain inventory questionnaire, fatigue severity scale, and Rand 36 quality of life questionnaire. Results: The mean scores of knowledge at one month and at three months later of the studied patient were significantly higher than those of the pretest (p < 0.001). Also, during post and follow-up phases of the intervention, there were a highly statistically significant difference as regards level of fatigue, severity of pain, and QOL for SLE patients. Conclusion: The SLE patients' non-pharmacological nursing interventions had positive effects on improving in patients' knowledge, fatigue, pain and QOL level in post implementation and follow-up phases. Recommendations: Non-pharmacological intervention programs re-applied to patients with SLE in various settings to help in improving patients QOL and decrease the levels of patients reporting fatigue and pain

Keywords: Interventions, Non-pharmacological, Systemic lupus erythematosus.

Introduction:

Systemic lupus erythematosus everlasting multi-factorial autoimmune disease which causes organ damage. The most common age of diagnosis usually range from 15 to 45 years, with 20% of cases affect over 50 years. The illness affects women in their years of reproduction at a rate ten times higher than that of men (1). SLE patients now have a five year survival rate of more than 95% thanks to therapies for disease-related improved comorbidities over the last ten years (2).

In Egypt, the second most common admitted rheumatologic disease is SLE. The mortality rate among adult Egyptian patients is 2.5% and the most commonly involved organs are kidneys as an important cause of death among them (3). SLE leads to organ impairment including neuropsychiatric, pulmonary, cardiovascular. renal. hematologic. musculoskeletal. reproductive integumentary. It features a wide variety of clinical symptoms, an unpredictable prognosis, and a changing course that is marked by activation and remission phases (4).

There are multiple phenotypes for the disease, and its clinical manifestations can vary from mild signs on the mucosa to severe involvement of the central nervous system and several organs ⁽⁵⁾.

Systemic lupus erythematosus as a chronic illness with its general and local manifestations affects a patient's QOL because it is a lifelong disease. QOL is defined as an individual's recognition of their position in life in the extent of the value and culture systems in which they live objectives. about their anticipated outcomes. benchmarks. and worries Physical, psychological, social, and occupational aspects of the patient's QOL can all be negatively impacted by the manifestations of SLE. Where, SLE affects activities of daily living, job performance, career building, and social activities that lead to social isolation and frustration. It influences human relationships, partnerships, and family life. So, SLE patients have a significantly lower QOL compared to others with other chronic diseases

Due to the possibility of involvement of essential organs, disease management and symptom control are crucial. SLE has no known cure, although problems can be avoided by reducing flare-ups and modifying lifestyle choices, receiving an early diagnosis, and receiving appropriate medical care tailored to illness (symptom management reduction). To lower risks, patients and their families must receive ongoing education about disease's management, monitoring, complications, and therapies (8). As of right now, there is no recognized standard treatment protocol for SLE and Long-term glucocorticoid therapy or a combination of several immune inhibitors is the recommended course of treatment (9).

Non-pharmacological and self-management strategies in the management of SLE are increasingly supported by growing evidence. The limited availability of appropriate guidelines impedes the extensive use of non-pharmacological therapies, hence resulting in a lost chance to optimize patient care ⁽¹⁰⁾.

The objectives of non-pharmacological treatment are to lessen the symptoms of the illness, enhance quality of life, and stop organ damage, comorbidities, adverse events, and disease progression. This helps to improve patient understanding of the illness through organized patient education. improved psychosocial functioning, improved coping skills, reduced fear of the disease progressing and illness perceptions. unhelpful improved treatment adherence, efficient use of care, and enhanced work capacity (11).

Nurses play an essential role in a holistic interdisciplinary SLE patients rehabilitation programs. Nursing interventions are actions used by nurses to help people or families get closer to a goal ⁽¹²⁾. As a practice specialty, rheumatology nursing makes a substantial contribution to the management of SLE patients by employing both non-pharmacological and pharmaceutical techniques. The evolution of the role of rheumatology nurses is in line with a global trend among medical professionals to deliver more proactive, patient-centered, and evidence-based treatment ⁽¹³⁾.

Significance of the study:

Systemic lupus erythematosus is a chronic progressive autoimmune disease characterized by recurrent attacks and inflammation affecting several body systems. Fatigue and pain are

common symptoms for SLE ⁽¹⁴⁾. However, evidence-based interventions for fatigue and pain for SLE are lacking. Application of non-pharmacological management strategies is as integral components in determining requirements, carrying them out, and assessing the results of the holistic interventions for people living with SLE in a cost-effective manner ⁽¹⁵⁾. So this will help such group of patient to improve their fatigue, pain and QOL.

Operational definition:

Non-pharmacological nursing interventions:

It is a nursing intervention includes nutritional, behavior, cognitive interventions and psychological counseling to amelioration of disease symptoms, improvement of QOL, delaying the course of illness, and organ damage for patient with SLE.

Aim of the study:

The study aim was to evaluate the effect of non-pharmacological nursing interventions on fatigue, pain and quality of life for patients with systemic lupus erythematosus.

Objectives:

The following goals guided the conducting of the study:

- 1. Assess patient's knowledge regarding SLE.
- **2.** Assess level of fatigue, pain, and QOL for SLE patients.
- Design and implement non-pharmacological nursing interventions on fatigue, pain and quality of life for patients with systemic lupus erythematosus based on patients' actual needs.
- **4.** Evaluate the effect of non-pharmacological nursing interventions on fatigue, pain and QOL for patients with SLE.

Research hypotheses:

To accomplish the current study's aim, the following research hypotheses were developed.

H1: Patients' Knowledge regarding non-pharmacological nursing interventions for SLE will expect to be improved post and follow up phases of the implementation.

H2: Studied patients will exhibit positive effects regarding fatigue level; pain intensity and QOL post and follow up phases of non-pharmacological nursing interventions implementation.

Subjects and Methods: Research design:

A quasi-experimental design (pre-posttest and follow-up) was chosen to accomplish the study's aim.

Study Setting:

This research was conducted at the rheumatology outpatient clinic and inpatient unit both are affiliated to Zagazig University Hospitals. The rheumatology outpatient clinic is located on the ground floor of the outpatient clinic building at Zagazig University Hospitals divided into two clinics, the first one for clinical diagnosis and another is to following up for patients with SLE. The inpatient unit is situated on the floor five of the Sednaoui EL Salam Hospital, and its capacity is 22 beds. It attached to meeting room to instruct and teaching patients contain 30 chairs and data show projector.

Sample:

A purposive sample of eighty SLE patients was selected for this research. The sample was determined using sample size and power, using Epi Info (Epidemiological Information system) Software Version 6. The study's power was 80%, and there was a 95% confidence level in the acquired data.

The following formula was used:

$$n = [(Z_{\alpha 2} + Z_{\beta})^{2} x \{(p1(1-p1) + (p2(1-p2))\}]/(p1-p2)^{2}$$

Patients were selected according to inclusion criteria: Participation was voluntary and available at the time of data collection; age range between 18-60 years. Exclusion criteria included: Patient with other autoimmune or infectious disease, become severely ill health or complications, such as cerebrovascular stroke, paralysis, cognitive impairments, renal dysfunction, and cancer.

Tools of Data Collection:

Tool I: Structured Interview Questionnaire:

This tool was developed by the researcher after review of pertinent literatures (16, 17 & 18). Arabic was used to write it simply to avoid misunderstanding. It includes questions, within a multiple-choice format and in the form of short

open end questions it consisted of three parts to collect the following necessary data:

- Part 1: Demographic Characteristics: Which were made up of 7 closed ended questions including: age, sex, marital status, educational level, residence, occupation and monthly income.
- Part 2: Patient health History: Included duration of the disease, family history, Clinical manifestations and patient's medicine that received.
- Part 3: Patient's Knowledge questionnaire: To assess patient's knowledge regarding SLE. It consists of multiple-choice assessments as definition. causes. treatment, and follow-up, complications, non-pharmacological self-management management, and strategies.

Scoring system:

The scoring system assigned a "zero" score for an incorrect or absent response, while a "one" value was assigned for a correct response. These scores were then totaled for every patient. The total score given as a percentage. 60% or more of the patient's knowledge was considered satisfactory, while less than 60% was considered unsatisfactory (19)

Tool II: The Fatigue Severity Scale:

It was adopted from **Penson et al.** ⁽²⁰⁾ to measures severity of fatigue in individuals with SLE. It involves 9 questions and is simple to administer. Likert scales with seven points are used to score responses to the nine statements. With one representing severe disagreement and seven representing significant agreement. Scores of four or above indicating severe fatigue ⁽²¹⁾

Tool III: The Brief Pain Inventory:

This is a brief questionnaire was adopted from **Meseguer et al.** (22) to evaluate pain interference with the patient's daily functions. It determines how much pain has affected daily activities such as walking, work, general activity, mood, enjoyment of life, relationships with others, and sleeps over a seven-day period.

Scoring system:

The numerical rating scales for the items measuring how much pain interferes with a patient's function range from 0 (not interfere) to 10 (totally interfere). Pain interference is

scored as the mean of the seven interference items. The scores on the interference items are added to create function interference subscale (23)

Tool IV: Rand 36 item short form health survey (Rand-36):

It is a thirty six item scale constructed to survey health status and QOL adopted from Ware & Sherbourne (24) It is the most commonly used indicator of general health state. There are 36 questions total, with one transitional question and thirty five questions focusing on quality of life. The transition question asks patients to rate the amount of general health change they have experienced during the past year. The remaining 35 questions are organized into eight scales: Physical functioning: Ten questions (3 &12), role limitations due to physical health problems: Four questions (13&16), role limitations due to emotional problems: Three questions (17&19), energy/fatigue: Four questions (23, 27, 29 & 31), emotional well-being: Five items (24, 25, 26, 28 & 30), social functioning: Two questions (20 & 32), bodily pain: Two questions (21&22) and general health perceptions: Five items (1, 33, 34, 35 & 36).

The scoring system:

The RAND 36-Item Health Survey is scored in two steps. Prioritized numerical values are first recoded in accordance with the scoring key. Every object has a score, with a high number better condition of a Furthermore, every item is assigned a score between 0 and 100, meaning that the lowest and greatest potential ratings correspondingly set at 0 and 100. The proportion of the total possible score attained is represented by the scores. Step 2 involves averaging the items on the same scale to produce the eight scale scores. The scale scores are not computed with blank items (missing data) taken into account. Therefore, the average of all the scale items that the respondent answered is represented by the scale scores (25).

Content validity and reliability:

Validity was carried out by seven experts (five from the Medical Surgical Nursing staff and two Medical Rheumatology staff at Zagazig and South valley university), who checked the tools for comprehension, completeness, relevance, and clarity. Just a few adjustments were done, and then the tools were formulated in the last

format and tested for dependability. Cronbach's alpha coefficient was used to examine the reliability of the tools. Reliability of tool I, II, III and IV was (0.83, 0.86, 0.88 and 0.87 respectively).

Pilot study:

It was carried out on 10% (8 patients) of SLE patients in order to evaluate the suitability, accuracy, and amount of time needed for each tool. After making adjustments to the tools utilized, the final shape was produced. The patients in the pilot study were not included in the study population.

Field Work:

Data was gathered from March 2023 to November 2023, for nine months; the researchers attended to the study settings three days through a week between 9:00 am to 1:00 pm.

Both the director of the Rheumatology Department and the head of the hospital officially approved the study's conduct. Steps have been taken to protect patients' ethical rights. After being fully told about the purpose and design of the study, each patient was requested to sign a written consent form. There were four stages to the study: Planning, implementation, assessment, and evaluation.

1. Assessment Phase

During this phase, following participant confirmation of the study's criteria. researcher conducted one-on-one interviews with each patient at the inpatient departments and pre the non-pharmacological nursing interventions to explain the purpose of the study and obtained patients' written agreement to take part in this study. Then, the patients' initial base line data was assessed by the researchers by filling out the study tools for the pre-intervention evaluation usina а structured interview questionnaire (tool I) to collect information about the patients' socio-demographic characteristics (part one). The patients were then evaluated using Patient health History (part two), Patient's Knowledge questionnaire (part three), the Fatigue Severity Scale (tool II) and the Brief Pain Inventory (tool III). Then Rand 36-item short-form health survey (tool IV), they took 30-45 minutes.

2. Planning Phase

The non-pharmacological nursing intervention was developed after reviewing related literature (26 & 27) in accordance with the

needs of the patient assessment and their comprehension level. Patients were given basic PowerPoint presentations in Arabic as well as videos that covered every topic. related to non-pharmacological nursing interventions for SLE included: 1) self-management, 2) physical exercise such as stretching, strengthening exercises for joints, aerobic exercise such as walking mouth exercise therapy and yoga, [importance, duration, frequency], 3) lifestyle or behavior interventions [as, photo-protection or quitting smoking], 4) nutritional interventions, 5) hand and foot interventions, 6) assistive technology and devices, 7) methods like paraffin baths for oral health and hygiene.

The educational booklet includes contents covered the areas of SLE related to patient education as definition, etiology, clinical manifestations, follow up, treatment and complications.

3. Implementation Phase

In accordance to the assessment phase findings, goals and expected outcomes were established.

In this phase all patients received the contents of the non-pharmacological nursing interventions in the presence of his relative during face-to-face interview at inpatient departments within the morning shift. The researchers called each patient received telephone call from the research to make sure he was doing as instructed and to encourage and support him in adhering to the terms of his release.

Each patient received two sessions in order to gain clarification of non-pharmacological nursing interventions; sessions lasted 45-60 minutes on average in the meeting room.

Session 1: It took ten to twenty minutes. Using helpful clarification from the researcher, the patient responded to the tools, and then non-pharmacological nursing interventions were identified, in reference to the definition of lupus, brief facts about lupus, symptoms, and etiology, types, diagnosis, consequences, and therapy. Video viewing at home was permitted for the patient.

Session 2: It took thirty to forty minutes, and the goal was to review the information from the previous session and patient non-pharmacological nursing interventions about lupus were provided, which covered topics such as the effects of lupus on a person's life,

managing the disease at home, and counseling patients on how to prevent sun exposure-related issues, advice for patients on nutrition, physical activity, and overcoming lupus-related fatigue, and how to take care of the joints to reduce pain. Different teaching methods were used as demonstration, discussion. and demonstration. Also, videos were used to draw attention patient patients' and facilitate information. The researcher clarified their misunderstandings, asked for a response, and observed how they improved.

4. Evaluative phase

After one month following the implementation, Pre-test instruments were used to examine every study participant as they were filled out for post-intervention and three months later for the follow-up evaluation in the outpatient clinics.

Administration and Ethical considerations:

The research ethics committee of Zagazig University's Faculty of Nursing granted consent for the study before it began (code number: 90 & Date: 1st January 2023). The participants were informed of the purpose of the study. By initially getting their signed agreement, the patients' willingness to take part in the study was verified. The privacy and anonymity of the patient data were preserved. The researchers promised the participants they may leave the study at any moment and there would be no consequences.

Data analysis:

Using SPSS (Statistical Package for Social Sciences) version 20, all gathered data were arranged, classified, tabulated, inputted, and examined for frequency tables and statistical significance. The One-Sample Kolmogorov-Smirnov Test, ANOVA, the Monte Carlo and Fishers exact tests, and the Friedman test were used to evaluate associations. The associations between the variables were found using coefficient correlations (r), which were considered significant if $p \le 0.05$.

Results:

Table (1) demonstrates that greater than one quarter of the study sample (28.75%) their ages between thirty to forty years old with mean age \pm 32.3. The presently results regarding sex showed that most of the patients were married women. (96.25%, 72.5%, respectively). Concerning residence (75.0%) thee quarter of the studied patients were rural. Also, (90.0%) of

them were house wives and (72.5%) had insufficient income.

Table (2) illustrates that 10.0% of the patients had a history of SLE in her family. In relation to clinical manifestations the majority of 92.5% had patients musculoskeletal manifestations while (62.5%. 68.75%. respectively) had renal and hematological manifestations. Regarding the current medications all the patients had oral Prednisolone Hydroxychloroquine. and Concerning disease duration, (42.5%) of patients had 1-5 years duration.

Table (3) indicates that the degree of satisfactory knowledge increased from 10.0% in the initial evaluation to 91.25% and 88.75%, respectively, following program implementation and follow-up. A substantial statistical difference (p<0.01) was seen between the pre/post and pre/follow-up periods. Ultimately, it was noted that the patients' post-intervention knowledge scores were better overall than their pre-intervention scores. and there were statistically significant differences in patient knowledge linked to SLE between pre/post and pre/follow-up (P<0.001*).

Table (4) demonstrates that there is a highly statistically significant difference between the mean scores of fatigue severity scale for SLE patients throughout the study phases of the intervention (P< 0.01).

Table (5) indicates that there was a high statistical significant difference between mean scores of all items and the total scores of pain Interference scale among patients with SLE throughout the implementation of non-pharmacological nursing interventions (P < 0.01).

Table (6) reveals that with a p value of 0.000%, there was a highly significant difference between the mean QoL score and the total QoL before/after the follow-up.

Table (7) shows that there was a highly significant positive correlation between patients' knowledge and total quality of life pre, post and follow up phases of the intervention with p value 0.000 %. Conversely, there were very strong inverse relationships between patients' knowledge and QOL related to pain and fatigue scores throughout the study phases with p value 0.000 %.

Discussion:

Systemic lupus erythematosus is a condition characterized by extensive tissue damage and inflammation with various in clinical manifestations and disease activity. Fatigue is the most significant characteristic of SLE, along with widespread pain. It interrupts all aspects of patient's life develop different complications that require ongoing management and lifestyle modifications ⁽²⁸⁾. Therefore, this study aimed to evaluate the effect of non-pharmacological nursing interventions on patients with SLE.

Studied patients' demographic characteristics indicated that, regarding age, greater than one quarter of participants in the study their ages between thirty to forty years old with mean age ±32.3. In the same line **Elghareeb and Mahmoud** (29) reported that, aged between 25 and fewer than 45, almost half of the cases were identified. In addition, **Sedrak et al.** (30) showed that, the average age of SLE patients is between fifteen to forty five years. This is referred to as the bearing age, indicating that hormones during this time affect a person's susceptibility to this illness.

Concerning sex, the present study results illustrated that the majority of the patients were females. This was consistent with a study by **Elmetwaly et al.** ⁽³¹⁾, which found that women made up the majority of study participants. This demonstrates the factual truth of the illness, which is that women are more likely than men to be impacted in the majority of prior research. This difference in SLE between the sexes could be a result of female hormones, specifically estrogen. In men, androgen hormone serves as a barrier against lupus.

According to the study's findings, two thirds of the participants were married patients. These results corroborated those of **Youssef** (32), who said that married individuals made up the majority of the participants. Furthermore, the majority of individuals were married, according to **Mohamady et al.** (33). This might be because of the nature of the illness, which more frequently manifests itself in the third decade, which is also the era of marriage and childbearing in Egyptian culture.

Regarding place of residence, the study results showed that over two thirds of the study's patients lived in rural areas. This is consistent with the findings of **Abd El-Azeem et al.** ⁽²⁾, who said that most SLE subjects lived in cities.

The study's findings about the patients' employment status showed that housewives made up the majority of the patients. This finding was agreement with **Elsayed & Mesbah** (34) who reported that, the majority of the patient not working. This may be due to the fact that most of patients were females and development of disease complications which cause physical disability.

Health significantly influenced is by socioeconomic position. In regard to monthly income, most of studied subject had a monthly income that was insufficient. This data is consistent with **Ibrahim et al.** (35), who stated that nearly all patients have modest family incomes. This finding might due to that mostly SLE attacking females who have no economical source. As regards to the family history of SLE, the research findings revealed, that only ten percent of the patients had positive history. This result is consistent with Constance et al. (36), who reported that, the risk of autoimmune illnesses is higher among first degree relatives than in the general population, and around 10% of SLE patients have a family with an SLE diagnosis. SLE risk is unquestionably higher in families where there is a history of the condition.

The symptoms and course of systemic lupus erythematosus, a multisystem disease, might vary. Individual patients may present differently. and over time. different manifestations may appear in the same patient (37). In relation to clinical manifestations the majority of patients 92.5% had musculoskeletal symptoms while (62.5%, 68.75%, respectively) had renal and hematological symptoms. This finding is supported by Stöcker et al. (38) who indicate that, 68.75% of the people under study reported having arthralgia, 55.65% myalgia, and 48.31% arthritis, among other frequent musculoskeletal complaints. Whilst about 30% of SLE patients develop lupus nephritis at the outset of the disease, and up to 50-60% do so during the first ten years. Lupus nephritis is the most essential predictor of morbidity in SLE.

The majority of SLE patients had an illness duration that ranged from less than one year to less than five years, according to the analysis's findings. This aligns with **Fava and Petri** ⁽³⁹⁾, which reported that individuals' disease onset ranged from one to five years.

The results of the current study showed that knowledge items improved significantly and statistically following the execution of the intervention. The study's findings were corroborated by **Elghareeb and Mahmoud** ⁽²⁹⁾, who indicated that the intervention centered on health education significantly improved the understanding of SLE patients. This finding corroborates the study hypothesis, which proposed that following the implementation of a pharmaceutical nursing intervention, the study patients' level of knowledge improved relative to before the intervention.

As regards fatigue of the patients in the present study, it was showed that, there is a highly statistically significant difference between the mean scores of symptoms severity for fatigue severity scale for SLE patients during the entire study period. These results are consistent ⁽⁴⁰⁾, which with those of Kharawala et al. showed how patients' weariness may be reduced when they adhered to the guidelines. This is consistent with the findings of **O'Riordan** (41), who found that when SLE patients participated in an education program that included teaching and counseling, there was a significant improvement in their perceived levels of fatigue and total health ratings. This outcome may be the result of these individuals' needing to reduce their weariness in order to function well in their daily lives.

Throughout the use of non-pharmacological nursing interventions, patients with SLE showed a large statistically significant difference between the mean scores of all items and the total scores of the pain scale, according to the current study. These findings were consistent with the findings of **Ibrahim et al.** (35), who found that throughout the course of the trial, there were substantial statistically significant variations in the numeric pain rating scale's ability to measure pain before and after self-management education was given to SLE patients.

The quality of life of the patients in the current study revealed a highly significant difference between the pre/ post and pre/ follow-up mean scores for quality of life and total quality of life. This outcome is in line with the findings of **Brown et al.** (14), who found that using a mindfulness-based cognitive intervention helps SLE patients' symptoms and quality of life.

The finding of this study showed that there were highly significant inverse correlations between patients' knowledge and QOL related to pain and fatigue scores throughout the study

phases. This result is agreeing with **Elefante et al.** (42) who stated that, the biggest factor affecting lupus patients' quality of life has been found to be fatigue, particularly when it comes to their physical and mental well-being.

On the contrary, there was a highly significant positive correlation between patients' knowledge and total quality of life throughout phases of the intervention. This finding is supported by **Abd El-Azeem et al.** (2) outlined how self-management strategies involving health education and social support improved health outcomes for SLE patients by reducing pain, enhancing function, and delaying the onset of impairment.

A comparable outcome was observed in the research conducted by **EI said et al.** (43), which demonstrated a highly statistically significant improvement in SLE patients following intervention. This may indicate the significance of health education interventions and the improvement in health outcomes for SLE patients.

Finally, Non-pharmacological nursing interventions may increase a patient's vitality, primarily by helping them to overcome fatigue; furthermore, it can help patients maintain

emotional stability, increase adaptive coping and quality of life (44).

Conclusion:

The SLE patients' non-pharmacological nursing interventions had positive effects on improving in patients' knowledge, fatigue, pain and improving QOL in post or follow-up phases. In addition, there was high statistically significant difference in fatigue severity, pain severity and QOL in post implementation or follow-up phases.

Recommendations:

It is recommended that nonpharmacological intervention be applied to patients with SLE in distinct settings as the basis for routine nursing care to help in improving patients QOL and decrease the number of patients reporting pain and fatigue.

It is advised that the current study be repeated using a larger probability sample drawn from various geographic regions for the generalization of the findings.

Table (1): The frequency distributions of the SLE patients under study in relation to their demographic characteristics (n = 80)

Items	No.	%
Age per years	-	-
-<25 years	20	25.0
-25-	20	25.0
-30-	23	28.75
-≥40	17	21.25
	Mean ± SD	32,3±8.65
Sex		
-Males	3	3.75
-Females	77	96.25
Social status		
- Married	58	72.5
- Single	18	22.5
- Divorced	4	5.0
Residence		
-Rural	60	75.0
- Urban	20	25.0
Education		
- Illiterate	19	23.75
- Primary school	9	11.25
- Preparatory school	8	10.0
-secondary education	13	16.25
- Institute	14	17.5
- University	17	21.25
Occupation		
-Worked	8	10.0
- House wives	72	90.0
Income		
- Sufficient	22	27.5
- Insufficient	58	72.5

Table (2): The health history of the patients under study was distributed in terms of frequency and percentage (n=80)

Items	No.	%
Family history of SLE		
-Yes	8	10.0
-No	72	90.0
Smoking habit		
-Smokers	80	100.0
-Passive smoker	13	12.25
Clinical manifestations		
-Musculoskeletal	74	92.5
-Pulmonary	27	33.75
-Cardiac	6	7.5
-Neurological	8	10.0
-Psychiatric	3	3.75
-Renal	50	62.5
-Vascular	20	25.0
-Hematological	55	68.75
Current Medications		
-Oral prednisolone	80	100.0
-Hydroxychloroquine	80	100.0
-Azathioprine	38	47.5
-Cyclophosphamide	16	20.0
-Mycophenolate	30	37.5
-Rituximab	7	8.75
Disease duration		
-< one year	7	8.75
-1-5years	34	42.5
->5-10 years	28	35.0
->10 years	11	13.75

Table (3): patients' knowledge Frequency and percentage distributions related to SLE over the course of the study (n= 80)

Catiafaatama				Time			. χ²	χ^2	
Satisfactory		Pre		Post		FU		(P)	
Knowledge (60%+)	No.	%	No.	%	No.	%	Pre-post	Pre-FU	
General Knowledge abo	ut SLE:								
 Definition of SLE 	6	7.5	76	95.0	74	92.5	122.75(<0.001*)	115.60(<0.001*)	
- Risk factors of SLE		10.0	78	95.5	70	87.5	123.19 (<0.001*)	96.16(<0.001*)	
 Causes of SLE 	38	47.5	72	90.0	70	87.5	29.17(<0.001*)	32.044(<0.001*)	
 Sing and symptoms 	20	25.0	73	91.25	65	81.25	72.13(<0.001*)	50.82(<0.001*)	
- Diagnosis	18	22,5	68	85.0	68	85.0	62.85(<0.001*)	62.85(<0.001*)	
- Treatment	10	12.5	62	77.5	57	71.25	68.28(<0.001*)	56.72(<0.001*)	
 Complications 	12	15.0	60	75.0	58	72.5	58.18(<0.001*)	53.74(<0.001*)	
&prognosis									
Knowledge about Lifest	yle Modi	ification	:						
- Diet	24	30.0	76	95.08	74	92.5	72.10(<0.001 ¹	65.83(<0.001	
- Exercise, guided	0	0.0	71	88.75	68	85.0	127.64(<0.001)*	118.26(<0.001*)	
imagery & relaxation technique									
- follow-up	28	35.0	78	95.5	78	95.5	69.88(<0.001	69.88(<0.001	
Total knowledge score re			. 0		- 10		33.30(10.001	22.30(10.001	
- Unsatisfactory	72	90.0	7	8.75	9	11.25	105.64 (<0.001*)	99.24 (<0.001*)	
- Satisfactory	8	10.0	73	91.25	71	88.75	t: 98.65(<0.001*)	t: 212.07(<0.001*)	
Mean±SD	12.07			5±1.8	24.0			= :=::(3.33:)	

 $[\]chi^2$ chi square test t paired sample t test

Table (4): Difference between mean scores of Fatigue severity for SLE patients during phases of the study (n= 80)

		Time			
Fatigue severity scale	Pre	Post	Follow-up	t (p)	t(p)
	Mean ±SD	Mean ±SD	Mean ±SD	_	
FSS	58.3 ± 5.7	34.3 ± 8.5	38.2 ± 9.2	76.18 (<0.001)*	50.45(<0.001)*

^(*) Statistically significant at P < 0.05

Table (5): Means & standard deviations distribution of pain among patients with SLE across the study phases (n=80)

Dain laterference items		Time			_	
Pain Interference items	Pre	Post	Follow-up	t (p)	t(p)	
	Mean ±SD	Mean ±SD	Mean ±SD	•		
- General activity	6.3 ±2.5	4.3±1.2	3.7±1.1	13.76 (0.009)*	16.50 (<0.001)*	
- Mood	6.7±2.4	4.2±1.7	3.6±1.2	31.7(<0.001)*	22.69 (<0.001)*	
- Walking ability	5.4±1.9	3.1±0.93	3.2±0.7	20.44(<0.001)*	16.29(<0.001)*	
 Normal work (includes both work outside the home and housework) 	6.8±1.7	3.8±1.4	3.2±0.8	88.66(<0.001)*	35.55(<0.001)*	
- Relations with other people	5.4±2.2	3.4±2.6	2.9±0.9	44.44(<0.001)*	17.09(<0.001)*	
- Sleep	6.2±1.5	4.3±2.1	2.5±0.7	41.10(<0.001)*	27.19(<0.001)*	
- Enjoyment of life	5.6±1.7	2.8±2.4	2.8±2.1	35.55(<0.001)*	82.95(<0.001)*	
Total	42.40±13.98	24±10.76	23±9.05	50.55(<0.001)*	34.10(<0.001)*	

^(*) Statistically significant at P < 0.05

P: P value of Wilcoxon test * significant P value ≤0.05

^(**) highly significant at P < 0.01

^(**) highly significant at P < 0.01

Table (6): Quality of life mean scores for patients with Systemic Lupus Erythematous throughout the study phases (n= 80)

		Time		4 (n)	4(n)
SF-36 subscale	Pre	Post	Follow-up	t (p)	t(p)
	Mean ±SD	Mean ±SD	Mean ±SD	•	
Physical functioning	72.4±13.3	76.2±19.8	76.2±19.8	2.66 (0.009)*	5.27(<0.001)*
Role of limitations due to physical health	39.6±23.8	43.3±22.4	48.7±25.6	23.49(<0.001)*	46.47(<0.001)*
Role of limitations due to emotional problem	37.2±28.5	46.0±28.5	49.65±22.1	11.51(<0.001)*	17.42(<0.001)*
Energy/fatigue	41.9±27.6	53.2±18.5	56.4±19.7	9.72(<0.001)*	13.74(<0.001)*
Emotional well-being	47.7±15.6	51.3±17.7	53.3±17.6	15.99(<0.001)*	25.29(<0.001)*
Social functioning	55.8±22.2	67.1±17.5	68.2±18.1	21.69(<0.001)*	26.66(<0.001)*
Pain	60.8±22.5	65.7±18.3	68.1±17.7	10.37(<0.001)*	13.5(<0.001)*
General health	53.3±16.5	55.9±17.6	58.2±17.8	20.48(<0.001)*	35.19(<0.001)*
Total quality of life	51.06±23.4	57.33±21.9	59.54±19.6	37.15(<0.001)*	19.24(<0.001)*

^(*) Statistically significant at p< 0.05

^(**) highly significant at P < 0.01

Table (7): Correlation coefficient between knowledge, fatigue, pain, and QoL of patients with SLE all over the study phases (n=80)

items	knowle	dge			Fati	gue		Pai	in		QOL
	pre	post	FU	pre	post	FU	pre	post	FU	pre	post
Pre kno		.524**	-	-	058-	-					,
			.123-	.017-		.152-					
Pre		.107	-		.116	.390**					
Fatigue			.421- **								
Pre Pain	455-	-	-	.338**	.501**	.650			_	-	
		.402- **	.558- **								
Pre QOL	.801**	.611**	- *	-	016-	-	472-**	472-**	-		
			.286- [*]	.063-		.105-			.472- **		
Post kno			-		247- [*]	-		402-**			
			.086-			.050-		**	**		
Post Fatigue			- .421- **			.401		.501**	.501 ^		
Post	455-		-	.338**		.650**	1.000**		1.000		
Pain	**		.558- **						**		
Post	.718**	.462**	.099	-	243- [*]	-	744-**	744-**	-	.707**	
QOL				.119-		.385- **			.744- **		
FU		.	-	.	<u> </u>	.		.	.		
Fatigue			.558- **								
FU Pain	455-	-	-	.338**		.650**	_				
		.402- **	.558- **								
FU QOL	.696**	.421**	.282	-	291-**	-	727-**	727-**	-	.681**	.738
				.291- **		.376- **			.727- **		

^{*}Correlation not significant NS at less than 0.05, significant at more than 0.05, highly significant HS at less than 0.01)*

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