

Effect of nurse-led lifestyle intervention protocol on associated symptoms and self-efficacy among patients with systemic lupus erythematosus

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Abstract

Systemic Lupus Erythematosus (SLE) is a chronic autoimmune disease. In addition to various clinical manifestations, it has spiritual, psycho-social and economic consequences. **Aim:** this study aimed to assess the effect of nurse-led lifestyle intervention protocol on associated symptoms and self-efficacy of patients with systemic lupus erythematosus. **Design:** A quasi-experimental pre/post-test one-group design. **Setting:** This study was conducted at Rheumatology unit, affiliated to Ain Shams University Hospitals. **Subjects:** A purposive non-probability/nonrandomized sample of 100 patients diagnosed with systemic lupus erythematosus. **Tools:** data were collected using two tools: I. Structured interview questionnaire for patients with systemic lupus erythematosus, II. General Self Efficacy Scale-GSE.III. British Isles Lupus Assessment Group (BILAG) Index. **Results:** there was a highly statistically significant difference between associated signs and symptoms of SLE pre and post implementation of life-style intervention protocol regarding treatment and self-management of SLE at p value (0.0001), there was a statistically significant difference regarding studied patients' self-efficacy and patients' lupus awareness pre and post life-style intervention protocol implementation. **Conclusion:** the implementation of nurse-led lifestyle intervention protocol affected positively the lupus awareness, self-efficacy and improve the associated symptoms for patients with systematic lupus erythematosus. **Recommendations:** Continuous educational sessions to improve patients' awareness, self-efficacy and improve the associated symptoms.

Keywords: systemic lupus erythematosus, nurse-led, lifestyle intervention protocol, self-efficacy

Introduction

Systemic lupus erythematosus (lupus) is an autoimmune disease which the immune system aggression healthy cells, tissues, and organs, including the joints, skin, kidney, heart, lungs, brain, blood vessels, and associated with spread inflammation and tissue damage. The symptoms of lupus vary between patients (*Middletona et al., 2018*).

The common symptoms include swollen or painful joints, unexplained fever, skin rash, fatigue, and kidney problems. Lupus can be treated effectively, but there is no cure. People with lupus experience periods of exacerbation of symptoms, which are termed 'flares', as well as periods of remission. Nurses need to have a good understanding of the disease to provide patients with appropriate support and advice

about how to maintain wellbeing (*Koroma, 2012*).

Patients with active lupus experience mucocutaneous and musculoskeletal manifestations, including skin rash, joint pain and swelling, and fatigue. Frequently affected joints include wrists, fingers, hands, and knees, with some patients experience secondary osteoarthritis. In addition to joint inflammation, internal organ affection can be of greater concern when considering patients' prognosis, with SLE often affecting the heart, lungs, blood vessels, liver, kidneys, and nervous system. These symptoms and manifestations can contribute to reduced health-related quality of life (*Holloway et al., 2014*).

The development of SLE is a complex immune process that is brought about by dysregulation of B- and T-lymphocytes, the production of auto-antibodies, and the

formation of immune complexes. Cytokines are thought to play a key role in SLE; however, the extent to which they affect progression of lupus is not clear. Their involvement may help explain the variations seen in the clinical manifestations of patients (*Bernknopf, Rowley, & Bailey, 2011*).

Self-efficacy is defined as one's strength of confidence, and an important determinant of self-management behavior and in this case that one can do what is necessary to control a primary SLE-related symptom. It is shown to be important in relation to human functioning in various areas, e.g., mental and physical health, human development, or coping with environmental hazards or burglary. Self-management involves a constant process of making behavioral choices and decisions. Self-efficacy expectations strongly influence these choices and decisions. Interventions to enhance self-management behavior and health functioning should be aimed at strengthening self-efficacy expectations (*Wang & Osmond, 2010*).

Nursing can play an important role in the process of treatment of systemic lupus erythematosus especially during periods of exacerbation of the disease. Because the nurse helps patients to cope with the disease in their everyday lives, teaches how to deal with lupus symptoms, prevents periods of SLE exacerbations, and provide systematic health education concerning lifestyle changes. The nurse supports the patient and family by giving the necessary help, provides emotional support to the patient and family, undertaking educational actions connected with lifestyle and rehabilitation to improve their quality of life (*Ogórek-Tęcza & Pych, 2018*). lifestyle modifications, such as avoiding overexposure to sunlight, stress management, smoking cessation and a diet low in saturated and trans fats, are also very important (*Williams et al., 2017*).

Significance of the Study:

Systemic lupus erythematosus is a complex multi-system autoimmune disorder that requires both physical and psychological care from nurses. Both primary and secondary care nurses should have knowledge of this unfamiliar condition, so that they may support

the patient with SLE at whatever stage (*Lupus Foundation of America 2012*).

SLE has a negative effect on various aspects of a patient's life, such as mental health, quality of life, and daily functioning, which may lead to decrease employment rates and heavy economic burden. According to previous studies, patients with high level of self-care might achieve better health outcomes, so the patient needs to acquire self-care knowledge and skills and must find suitable ways to manage surrounding environments to maintain optimal health. As the leading causes of death from SLE are the complications of the disease, such as end stage renal disease and cardiovascular disease, rather than SLE itself (*Kusnanto, Sari, Harmayetty, Efendi, and Gunawan, 2018*).

In USA, the prevalence of SLE ranged from 5.8 to 130 per 100,000 population, whereas the prevalence in UK and Japan was approximately 40.7 and 19.1 per 100,000 population.2-4 In China, the prevalence of SLE ranged from 31 to 70 per 100,000 population(*Yang, Xie, Song, Nie, and Chen, 2018*). While in Egypt it was reported that; about 90 cases diagnosed with SLE monthly are admitted to the rheumatology department with different signs and symptoms. (*Information and Statistics Center of Ain Shams University Hospital, 2019*).

Operational definition:

Nurse-led lifestyle intervention protocol include interventions that was designed to enhance physical function, social support and delay disability and activity limitation among patients with lupus. Health education, aimed to reduce pain, improve health distress, global health, self-efficacy, and mental stress management.

Aim of the study:

This study aimed to assess the effect of nurse-led lifestyle intervention protocol on associated symptoms and self-efficacy of patients with systematic lupus erythematosus (SLE) through the following:

1. Develop and implement nurse-led lifestyle intervention protocol for patients with systematic lupus erythematosus

2. Assess the effect of nurse-led lifestyle intervention protocol on the self-efficacy of patients with systemic lupus erythematosus.
3. Assess the effect of nurse-led lifestyle intervention protocol on the associated symptoms of patients with systemic lupus erythematosus.
4. Assess awareness of patients with systemic lupus erythematosus regarding the disease.

Research hypothesis:

The current study was hypothesized that:

1. The implementation of nurse-led lifestyle intervention protocol will affect positively the self-efficacy of patients with systemic lupus erythematosus.
2. The implementation of nurse-led lifestyle intervention protocol will improve the associated symptoms for patients with systemic lupus erythematosus.

Subject and methods:

Research design:

A quasi experimental pre/post-test one-group design was utilized to meet the aim of the current study.

It is used to estimate the effect of an intervention in the absence of randomization. In the pre /post-test research design, the research involves measuring salient outcomes both before displaying the sample to a stimulant of some kind and after exposure to the stimulant. By constructing an experiment in this direction, a researcher can appraise alteration in targeted outcomes to be exposed to the stimulant (*Braddock, 2019*). The post-test permits the researchers to decide the immediate effects of the treatment on the outcome variable(s). In addition to the pre-test and immediate post-test, a delayed post-test or post-test is often included to examine the longer-term treatment effects (*Rogers & Révész, 2020*).

Research Setting:

The present study was conducted at Rheumatology unit, at the second floor of Ain

Shams hospital, affiliated to Ain Shams University Hospitals. The unit consisted of 10 rooms; that contains 28 beds. Added to that the day care room, that is used to give the non-hospitalized patient their treatment, which is in the same unit.

Subjects:

A purposive non-probability/ nonrandomized sample of 100 patients diagnosed with systemic lupus erythematosus. Admitted to the rheumatology unit, sample size was calculated according to power analysis equation calculating the flow rate of patients diagnosed as SLE and admitted to Ain Shams University hospital within the previous year (2018), it was 1000 patients (*Information and Statistics Center of Ain Shams University Hospital, 2018*).

- The sample size calculation done based on power analysis:
- Type I error with significant level (α) = 0.5
- Type II error by power test (1-B) = 90%

Inclusion criteria:

- Adult patients of both genders with different educational levels.
- The patients diagnosed as SLE less than 6 months.
- Had no mental disorders and able to participate in the study.
- All patients who did not attend any similar self-care guidelines

Tools of data collection:

I. Structured interview questionnaire for patients with systemic lupus erythematosus:

This tool was developed by the researcher, based on the relevant literatures (*Wang & Osmond (2010) and Smeltzer and Bare (2016)*) it included two parts as follows:

Part 1: Socio-demographic data: this part is concerned with assessment of Socio-demographic data of the studied patients as, age, gender, marital status, working condition, income adequacy.

Part 2: Clinical data: patient medical history, family history, smoking, associated illness, and History of previous hospitalization.

II. Lupus awareness's quiz: it was a self-administered quiz to the patients with SLE, it was used to assess the knowledge level of patients with SLE; it was adopted from *Belotti (2003)*. The quiz included 20 multiple choice questions related to Systemic Lupus Erythematosus, they were divided into 4 main categories with 5 questions for each one as follows: definition and incidence of SLE, signs & symptoms, complications, and treatment & self-management. The total score of lupus awareness quiz was 20 marks. Each correct answer was given one mark and the incorrect answer was given zero. It was categorized as follows: $\geq 60\%$ (12 marks) were considered satisfactory level of knowledge, and $< 60\%$ were considered unsatisfactory level of knowledge.

III. General Self Efficacy Scale-GSE: it was a psychometric scale for the patients with SLE. It was composed of 10-items that was designed to assess the perceived self-efficacy to predict coping with daily hassles as well as adaptation to stressful life events and disease difficulties. It was adopted from *Schwarzer & Jerusalem (2004)*, and revised by *Warner, et. al (2011)*. *Internal reliability for GSE = Cronbach's alphas between .76 and .90.*

Scoring system

The patient response for each statement was determined on a 4-point scale as follows; 1 = not at all true, 2 = hardly true, 3 = moderately true, and 4 = exactly true. The responses were Summed up for all 10 items to formulate the final score with a range from 10 to 40, and then categorized as follow: less than 20= low self-efficacy and more than 20 =high self-efficacy.

IV. British Isles Lupus Assessment Group (BILAG) Index. It was adapted from *Hay, et al. (1993)*. It is a reliable and valid instrument for measuring clinical disease activity in SLE. It included questions about SLE symptoms during the previous 4 weeks.

It is implicit in this scoring system that all features scored are thought to be due to active lupus. If a new feature has developed since the last assessment, it should be scored as new

(score 4), even if it has subsequently improved or resolved.

Scoring system:

The BILAG index is comprehensive, recording clinical disease activity in 8 different organ systems, which included General signs (5 items), Mucocutaneous (6 items), Neurological (4 items), Musculoskeletal (4 items), Cardiovascular & respiratory (5 items), Vasculitis (3 items), Renal (6 items) and Hematology and laboratory (7 items). Each item is measured qualitatively by clinical observation (yes/no, improving/ same/worse/ new) or quantitatively by measuring hematologic and renal lab values.

Nurse-led lifestyle intervention protocol for the patients with systemic lupus erythematosus:

It was a booklet developed by the researcher in Arabic-language based on related literature (*Smeltzer and Bare, 2016; Tucker, 2019 and Wallace, 2019*); and then reviewed by a jury of 7 experts in medical surgical nursing and consultants of Immunology and medical departments at Ain Shams University Hospitals.

The protocol was divided into four parts as follows:

Part one: general knowledge about SLE as definition, pathophysiology - causes - signs and symptoms of SLE.

Part two: complications and diagnostic measures and medical management of SLE.

Part three: lifestyle changes, and management of SLE associated symptoms.

The content of the lifestyle intervention protocol included knowledge about medicines and importance of consistent treatment, daily health care, infection prevention, proper diet, inducement avoidance, good sleep, hygiene, exercises stress management, and follow up appointment.

Preparatory phase:

- Preparing the data collection tools after reviewing the recent and relevant literatures in textbooks, periodicals, internet research and other resources.

- Assess the needed knowledge to be included in the health educational booklet through extensive review of the literature and other available resources.
 - Designing the lifestyle intervention protocol, preparation of its content and developing the educational booklet.
 - Testing the booklet's validity through experts' opinions.
- The purpose of the study was simply explained to the patients who agree to participate in the study prior to any data collection.
 - The study tools were filled in and completed by the patient with help of the researcher if needed, it was done on 2 stages (pre & post implementation of the lifestyle intervention protocol).

Validity and reliability:

Validity: assessing face and content validity of the tools, through a group of experts. It was tested by a jury of 7 experts (3 professors, 3 assistant professors, and 2 lecturers) from Medical Surgical Nursing department at faculty of Nursing, Ain Shams University for the content validity. The jury reviewed the tools for clarity, relevance, comprehensiveness, and simplicity; no radical modifications were done.

Reliability: Alpha Cronbach test was used to measure the internal consistency of the previously mentioned tools to indicate how well the items in an instrument fit together conceptually, Alpha Cronbach's test scores were 0.92 for the questionnaire, 0.88 for lupus awareness quiz, and 0.96 for BILAG Index.

Pilot study: A pilot study was conducted on 10% of the study subjects (10 patient with SLE) to test the applicability and clarity of the study tools, as well as estimating the average time needed to complete the tools. Accordingly, necessary modifications were done. Some questions and items were rephrased and then the final forms were developed. Patients included in the pilot study were excluded from the study subjects.

Field work: The study was started and finished through the following phases:

A) Assessment phase:

- The data collection tools preparation consumed about three months, starting from March 2019 to the end of May 2019. Data collection was started and completed within 7 months; from July 2019 to January 2020.

- The researcher was available at the Inpatient of Rheumatology unit, Ain Shams University Hospital, three days a week at morning and afternoon shifts to collect data from the studied patients.
- The patients who fulfilled the inclusion criteria were selected. The researcher obtained the patients' oral consent for participating in this study after explaining the aim of the study.
- Data collection was begun with the sociodemographic and clinical data, within about 15minutes for each patient.
- The lupus awareness quiz was completed by the patient in the presence of the researcher to answer any question or conduct any clarification within about 10 min. for each patient; then the General Self Efficacy Scale, took about 10 min. for each patient and (BILAG) Index was consumed about 20 min so, each patient needed about 55 minutes.
- Filling in the previously mentioned tools was done before implementation of the lifestyle intervention protocol according to the patients' understanding, tolerance and health condition.
- All gathered information through data collection tools was interpreted to identify the individualized learning needs.

B) Planning phase:

- The researcher plan teaching sessions based on the previously determined needs covering all objectives.
- The lifestyle intervention protocol resources and facilities were allocated (printed material and session location that best serve the learners).
- The researcher determined the teaching strategy (timetable of sessions, teaching

methods, media used and learners' activities).

- After pre-assessment data collection, the appointment for starting teaching sessions was determined.

C) Implementation phase:

- Sessions for each patient were established for explanation of the lifestyle intervention protocol, each session was completed at one day (60-90 min).
 1. **Session (1):** a general explanation for the lifestyle intervention protocol booklet was done. Each patient was given the booklet for reading at home. A general knowledge about SLE was discussed.
 2. **Session (2):** this session was concerned with explanation of the pathophysiology - causes - signs and symptoms of SLE.
 3. **Session (3):** this session dealt with complications and diagnostic measures and medical management of SLE.
 4. **Session (4):** the researcher discussed the last part which included information regarding lifestyle changes, and management of SLE associated symptoms in detail with the patient.
 5. **Follow up:** after finishing there was a follow up for the patient through phone calls communications.

D) Evaluation phase:

The second assessment one month after the final session, the same tools were distributed again for each patient to be answered to evaluate the effect of lifestyle intervention protocol implementation.

Administrative Design

An authoritative approval was obtained from the Rheumatology unit director at which the study was conducted, explaining the study purpose, and requesting the permission for data collection from the study group. An oral approval was received from the patients included in the study.

Statistical Design

The collected data were organized, categorized, tabulated, and statistically analyzed

using the Statistical Package for Social Science (SPSS) version (20.0) and Excel was used for data handling and graphical presentation to evaluate the studied subject's changes throughout the study phases (Pre & Post) and to evaluate the differences between the studied groups regarding the various parameters. Data were presented in tables and chart. The statistical analysis include percentage (%), the arithmetic mean (\bar{X}), standard deviation (SD), "t" test, Chi-Square (χ^2), P value, and alpha Cronbach test.

Significance of results was described as follow:

- Non-significant (NS) difference obtained at $p > 0.05$.
- Significant (S) difference obtained at $p < 0.05$.
- Highly significant (HS) difference obtained at $p < 0.001$.
- Very highly significant (VHS) difference obtained at $p < 0.0001$.

Ethical consideration:

- Purpose of the study was explained to the patients who agree to participate in the study.
- Prior to any data collection the patients were assured that any anonymity and confidentiality were guaranteed and the right to withdraw from the study at any time.
- Ethics, values, culture, and beliefs was respected.

Results

Table (1): shows that the mean age of patients under the study was 27.54 ± 11.02 . Regarding their gender, it was found that 100% of the patients were females. As regard to marital status 60% of the patients were married, and 40% of them were read and write. While 70% of the patients were not working and regarding to monthly income 50 % of them had enough monthly income.

Table (2): Regarding the percentage distribution of family and disease history showing that 90% of the patients had not family history of SLE or autoimmune disease. As regard to relation 6% of the patients who have the disease have relation from 2nd degree. Also, this table showed that 55% of the patients had the disease from less than 3 months and 100% of them does not smoke.

While 23% of the patients had diabetes and 15% of them had history of previous hospitalization.

Table (3): reveals that there was a highly statistically significant difference between pre and post lifestyle intervention protocol regarding lupus awareness in relation to treatment and self-management of SLE at p value (0.0001).

Figure (1): Reveals that, there was a significant difference between Lupus awareness pre and post lifestyle intervention protocol, the patients' satisfactory level was improved from 20% pre implementation to 50% post.

Table (4) reveals that, in relation to self-efficacy, there was apparent improvement post implementation of the intervention protocol regarding most self-efficacy items. For example, patient ability to be confident in dealing efficiently with unexpected events (0 pre & 15% post was exactly true), ability to find several solutions when confronted with a problem (10% pre & 20% post was exactly true) and can usually handle whatever comes his way there was (0 pre & 10% post was exactly true).

Figure (2): reveals percentage distribution of the patients regarding total self-efficacy scale pre and post-implementation of the intervention protocol, 30% of the patients has high self-efficacy pre and improved to 60% post.

Table (5): illustrates a statistically significant difference between pre and post protocol intervention regarding general signs, mucocutaneous, gastrointestinal and musculoskeletal, neurological, and Musculoskeletal signs at $P < 0.001$.

Table (6): shows improve in cardiovascular and respiratory (Dyspnea, Cardiac arrhythmias including tachycardia > 100 bpm in absence of fever, mild or intermittent chest pain). There were statistically significant differences between pre and post protocol intervention regarding

cardiovascular and respiratory signs and vasculitis signs at $P < 0.001$.

Table (7): presents means and standard deviations distribution of the patients regarding Disease activity (Renal & Hematology/laboratory) post-implementation of the intervention protocol, it shows the highest means and standard deviations among the patients under study which were in relation to renal (improved Systolic blood pressure, improved Diastolic blood pressure (110 ± 0.101 , 70 ± 1.310) respectively, and in relation to Hematology/laboratory (improved evidence of active hemolysis, improved Platelets, WBCS) (2.862 ± 1.048 , 214.3 ± 2.024 , 2.000 ± 2.100) respectively.

Table (8): shows that there was highly statistically significant relation between marital status, education, monthly income, and self-awareness at p-value < 0.001 . also, there was statistically significant relation between age, working and self-awareness at p-value 0.4 & 0.02, respectively.

Table (9): shows that there was highly statistically significant relation between marital status, education, monthly income, and self-efficacy at p-value < 0.001 . also, there was statistically significant relation between age, working and self-efficacy at p-value 0.4 & 0.02, respectively.

Table (10): reveals that there was highly statistical correlation between total levels of self-awareness and self-efficacy post-implementation of the intervention protocol at p value < 0.001 .

Table (1): Number and percentage distribution of the study subjects' demographic characteristics (n=100).

Items	No	%
Age (In years):		
18 - 25	40	40%
<25 - 45	55	55%
45+	5	5%
Range	18-48	
Mean±SD	27.54±11.02	
Gender:		
Female	100	100%
Marital status:		
Married	60	60%
Unmarried	40	40%
Education:		
Read/write	40	40%
Intermediate/basic	30	30%
High	30	30%
Working:		
Working	30	30%
Not working	70	70%
Monthly income		
Enough	50	50%
Not enough	50	50%

Table (2): Number and percentage distribution of the patients as regards to family & disease history (n. 100)

Items	No	%
Family history of SLE/ Autoimmune diseases		
Yes	10	10%
No	90	90%
Relation:		
1 st degree	4	4%
2nd degree	6	6%
Duration of disease:		
Less than 3months.	55	55%
3-6 months	45	45%
Associated diseases		
Diabetes	23	23%
Hypertension	18	18%
Renal	11	11%
Rheumatic	10	10%
History of previous hospitalization		
15		15%
- Smoking:		
- No	100	100%
- Negative smoking:		
- Yes	55	55%
- No	45	45%

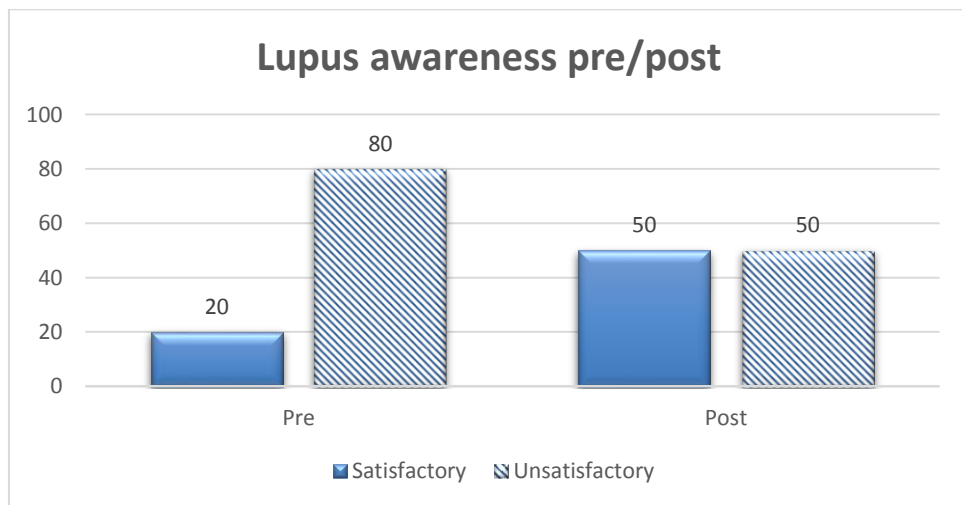


Figure (1): Percentage distribution of the patients regarding total level of awareness pre/post-implementation of the intervention protocol (n=100)

Table (3): Number and percentage distribution of the patients regarding to Lupus awareness pre/post-implementation of the intervention protocol (n. 100)

Lupus awareness items	Pre	Post	t-test	p-value	Sig.
	Mean \pm SD	Mean \pm SD			
Definition and incidence of SLE	63.4 \pm 0.3	92.0 \pm 0.4	1.7	0.05	NS
Signs & symptoms of SLE	65.0 \pm 0.6	78.2 \pm 0.9	0.03	0.8	NS
Complications of SLE	59.2 \pm 0.5	75.6 \pm 0.6	4.20	0.02*	S
Treatment & Self-management	52.1 \pm 0.7	69.5 \pm 0.7	3.50	0.0001**	HS

$P > 0.05$ Not significant * $p < 0.05$ Significant ** $P < 0.001$ Highly significant

Table (4): Number and percentage distribution of the patients regarding self-efficacy pre & post implementation of the intervention protocol (n=100).

Items	Not at all true		Hardly true		Moderately true		Exactly true	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post
	%	%	%	%	%	%	%	%
I can always manage to solve difficult problems if I try hard enough.	40%	20%	40%	40%	20%	35%	0	5%
If someone opposes me, I can find the means and ways to get what I want.	45%	25%	35%	35%	15%	30%	5%	10%
It is easy for me to stick to my aims and accomplish my goals.	45%	25%	35%	30%	15%	35%	5%	10%
I am confident that I could deal efficiently with unexpected events.	45%	15%	45%	30%	10%	40%	0	15%
I know how to handle unforeseen situations.	35%	15%	35%	30%	25%	45%	5%	10%
I can solve most problems if I invest the necessary effort.	35%	20%	30%	40%	25%	30%	10%	10%
I can remain calm when facing difficulties because I can rely on my coping abilities.	35%	10%	35%	50%	30%	35%	0	5%
When I am confronted with a problem, I can usually find several solutions.	45%	15%	35%	35%	10%	30%	10%	20%
If I am in trouble, I can usually think of a solution.	35%	10%	35%	45%	25%	35%	5%	10%
I can usually handle whatever comes my way.	40%	10%	40%	45%	20%	35%	0	10%

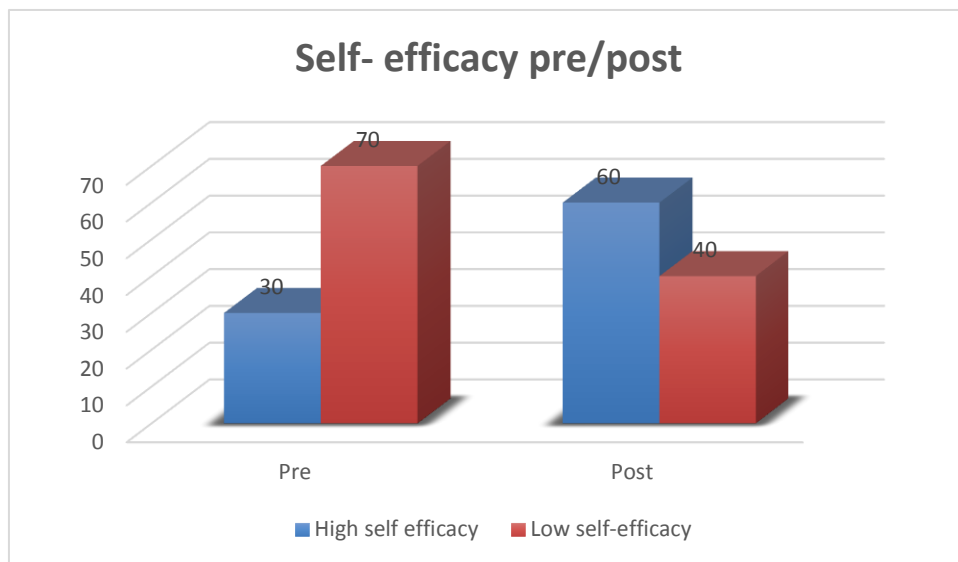


Figure (2): Number and percentage distribution of the patients regarding total self-efficacy scale pre & post-implementation of the intervention protocol (n=100).

Table (5): Number and percentage distribution of the patients regarding disease activity "general signs, Mucocutaneous & Musculoskeletal" pre- and post-implementation of the intervention protocol (n=100).

Items	Improving		Same		Worse		New		X ²	P-value
	pre	post	pre	post	pre	post	pre	post		
General signs										
• Pyrexia	40	60	10	5	20	10	30	25	21.1	<0.001**
• Weight loss, unintentional >5% in month	40	55	20	15	10	8	30	22	19.4	<0.001**
• Lymphadenopathy/splenomegaly	30	45	25	10	10	18	35	27	25.0	<0.001**
• Fatigue/malaise/ lethargy	30	50	25	20	10	7	35	23	19.3	<0.001**
• Anorexia/nausea/vomiting	35	47	15	13	20	16	30	24	9.7	0.05*
Mucocutaneous:									X²	P-value
• Alopecia-sever, active	40	42	25	22	20	19	30	17	22.1	<0.001**
• Alopecia- mild	35	52	20	15	15	13	25	20	1.4	0.15
• Extensive mucosal ulceration	30	43	20	18	20	14	30	25	22.1	<0.001**
• Small mucosal ulcers	45	58	20	18	15	11	20	13	1.6	0.14
• Malar erythema	35	41	20	17	30	26	20	16	23.3	<0.001**
• Swollen fingers	40	46	35	35	20	16	5	3	1.7	0.27
Neurological:									X²	P-value
• Impaired level of consciousness	40	58	15	12	30	14	15	16	22.1	<0.001**
• Psychosis/ delirium /confusional state	40	42	20	19	20	20	20	19	10.2	0.3*
• Seizures	45	46	30	31	10	8	15	15	22.1	<0.001**
• Headaches- sever, unremitting	35	61	30	25	20	10	15	4	1.8	0.25
Musculoskeletal:									X²	P-value
• Arthritis (definitive Synovitis)	40	43	20	18	10	10	30	29	19.1	<0.001**
• Arthralgia	40	41	20	17	10	9	30	33	17.5	<0.001**
• Myalgia	15	22	30	32	35	34	20	12	15.0	<0.001**
• Tendon contractures and fixed deformity	20	22	30	31	30	28	20	19	24.3	<0.001**

P>0.05 Not significant *p<0.05 Significant **P<0.001 Highly significant

Table (6): Number and percentage distribution of the patients regarding disease activity "Cardiovascular, respiratory & Vasculitis" pre- and post-implementation of the intervention protocol (n=100).

Items	Improved		Same		Worse		New		X ²	P-value
Cardiovascular & respiratory										
• Dyspnea	45	47	30	27	10	8	15	18	18.9	<0.001**
• Cardiac failure	30	33	20	18	20	18	30	31	19.6	<0.001**
• Effusion (pericardial or pleural)	15	16	30	32	35	33	20	19	25.2	<0.001**
• Mild or intermittent chest pain	35	45	20	19	30	27	20	9	9.4	0.03*
• Cardiac arrhythmias (tachycardia > 100 b/m in absence of fever)	40	45	20	17	10	7	30	31	24.1	<0.001**
Vasculitis:									X²	P-value
• Superficial phlebitis	45	49	30	34	10	10	15	7	16.9	<0.001**
• Minor cutaneous vasculitis (nail fold, digital, purpura, urticaria)	20	22	30	27	30	23	20	28	1.9	0.26
• Thromboembolism	40	41	20	22	10	12	30	25	17.9	<0.001**

*P>0.05 Not significant *p<0.05 Significant **P<0.001 Highly significant*

Table (7): Mean and standard deviation distribution among studied patients regarding disease activity " Renal, Hematology and laboratory" pre- and post-implementation of the intervention protocol (n=100).

Items	Improved	Same	Worse	New
Renal:				
	Mean ± SD	Mean ± SD	Mean ± SD	Mean ± SD
• Systolic blood pressure	110±0.101	100±0.358	98±1.254	98±1.452
• Diastolic blood pressure	70±1.310	65±0.000	50±0.420	75±0.201
• Accelerated hypertension	45±0.101	20±0.000	10±0.341	15±0.302
• 24 hour urine protein	10±0.105	13.5±0.001	18±0.210	14.5±0.605
• Creatinine (plasma / serum)	2.3±0.124	4.1±0.413	5.1±0.010	3.29±0.205
• Creatinine clearance	2.3±1.420	3.7±0.345	4.6±0.406	6.3±0.444
Hematology / laboratory				
• Hemoglobin	11.8±1.048	10.0±0.400	9.6±0.490	8.3±0.620
• WBCS	2.000±2.100	4.150±0.200	2.460±0.539	1.000±0.100
• Neutrophils	2.000±1.200	3.414±0.574	1.621±0.210	3.901±0.002
• Lymphocyte count	1.354±1.203	4.022±0.315	2.560±0.239	2.601±0.490
• Platelets	214.3±2.024	374.5±0.421	186.2±0.338	299.9±0.539
• Evidence of active hemolysis	2.862±1.048	3.000±0.400	2.631±0.490	2.347±0.620
• Coombs test positive	2.000±2.100	4.150±0.200	2.460±0.539	1.000±0.100

Table (8): Relations between socio-demographic characteristics and lupus awareness post implementation of the intervention protocol (n=100).

Items	Self-awareness (n=100)				X ²	P-value	Sig
	Satisfactory (n=50)		Unsatisfactory (n=50)				
	No.	%	No.	%			
Age (In years):							
18 - 25	20	40	20	40	9.2	0.4*	S.
<25 - 45	25	50	30	60			
45+	5	10	0	0			
Gender:							
Female	50	50	50	50	1.5	0.19	NS.
Male	0	0	0	0			
Marital status:							
Married	40	80	20	40	19.1	<0.001**	HS.
Unmarried	10	20	30	60			
Education:							
Read/write	10	20	30	60	24.1	<0.001**	HS.
Intermediate/basic	20	40	10	20			
High	20	40	10	20			
Working:							
Working	20	40	10	20	9.7	0.02*	S.
Not working	30	60	40	80			
Monthly income							
Enough	30	60	20	40	18.5	<0.001**	HS.
Not enough	20	40	30	60			

*P>0.05 Not significant *p<0.05 Significant **P<0.001 Highly significant*

Table (9): Relations between patients' levels of self-efficacy post implementation of intervention protocol and their socio-demographic characteristics (n=100).

Items	Self-efficacy (n=100)				X ²	P-value	Sig
	High (n=40)		Low (n=60)				
	No.	%	No.	%			
Age (In years):							
18 - 25	30	75	10	16.7	9.9	0.4*	S.
<25 - 45	10	25	45	75			
45+	0	0	5	8.3			
Gender:							
Female	40	100	60	100	1.3	0.19	NS.
Male	0	0	0	0			
Marital status:							
Married	40	100	20	33.3	18.2	<0.001**	HS.
Unmarried	0	0	40	66.7			
Education:							
Read/write	10	25	30	50	26.1	<0.001**	HS.
Intermediate/basic	10	25	20	33.3			
High	20	50	10	16.7			
Working:							
Working	30	75	0	0	9.5	0.02*	S.
Not working	10	25	60	100			
Monthly income							
Enough	30	75	20	33.3	18.9	<0.001**	HS.
Not enough	10	25	40	66.7			

*P>0.05 Not significant *p<0.05 Significant **P<0.001 Highly significant*

Table (10): Correlation between total levels of self-efficacy and self-awareness post-implementation of the intervention protocol (n= 100).

Self-efficacy		Self-awareness				Chi square	P- value
		Satisfactory (n=50)		Unsatisfactory(n=50)			
		No	%	No	%		
High self-efficacy (n=40)	No	35	70%	5	10%	11.33	<0.001**
	%	87.5%		12.5%			
Low self-efficacy (n=60)	No	15	30%	45	90%		
	%	25%		75%			

p>0.05 Not significant * P<0.05 Significant ** p<0.001 Highly significant

Discussion:

Systemic lupus erythematosus (SLE) is an autoimmune, systemic and a heterogeneous disease associated with widespread inflammation and tissue damage. It is associated with variations in signs, symptoms, and disease activity. Also, it is characterized by generalized body pain and most importantly, fatigue (*Pettersson, et. al 2017*).

The current study hypothesized that the implementation of nurse-led lifestyle intervention protocol will affect positively the self-efficacy of patients with systemic lupus erythematosus. The implementation of nurse-led lifestyle intervention protocol will improve the associated symptoms for patients with systemic lupus erythematosus. The finding of this study supports the research hypotheses.

In relation to socio-demographic characteristics, this study showed that the mean age of patients under the study was (27.54 ± 11.02). This finding is near of the finding of *Brinks et. al. (2016)* who found that the age was between 20-25 and at menopause and *Lemone et. al (2014)* who mentioned that SLE is very common in women in the childbearing age. This result is inconsistent with *Abd El-Azeem, et., al (2018)* in a study its title “Effect of Health Promotion Program on Quality of Life for Patients with Systemic Lupus Erythematosus” who stated that patients’ age was fifteen to forty five years.

Regarding to the studied subjects’ gender, it was found that all the patients were females. As regard to marital status less than two thirds of the patients were married and two fifth of them were read and write. The results revealed that the

subjects were all females could be due to sex hormones; this finding is in the same line with *Lemon et. al (2014)* who mentioned that SLE is most common in women rather than men and that more women with SLE have reduced levels of several active androgens that are known to inhibit antibody responses and that Oestrogens have been shown to enhance antibody responses and have an adverse effect in people with SLE.

In relation to work, it was found that more than two thirds of the patients not working this could be due to inability of some of them to work due to disease process also as females they might be housewives. Regarding to monthly income half of the studied patients have enough monthly income. This result is near to that of *El said et al. (2019)* who reported that half of the studied subjects were not working in a study titled “The Effect of Implementing A protocol of Nursing Care on SLE Patients’ Knowledge and Health Related Quality of Life.”

Regarding family and disease history the study found that most of the patients did not had family history of SLE or autoimmune disease. As regard to relation, minority of the patients who had family history of the disease the relation was from the second degree. This result is disagreeing with *Constance, et al., (2017)* in a study entitled “Family history of systemic lupus erythematosus and risk of autoimmune disease: Nationwide Cohort Study in Denmark 1977–2013” who stated that family history of SLE constitutes a major risk factor for development of SLE in a manner that depends on the degree of relatedness.

Also, this study result showed that more than half of the studied patients had the disease from less than three months and all of them did not smoke. This result was intended as research inclusion criteria, to involve patients diagnosed

with SLE maximally six months ago to avoid starting of the disease complications. More than one fifth of the studied patients had diabetes and less than one fifth of them had history of previous hospitalization. This result is consistent with *Kasemodel de Araújo (2015)* who reported that one tenth of the studied subject had history of diabetes mellitus.

Regarding lupus self-awareness, findings of the current study revealed that there was highly statistically significant difference between pre- and post-lifestyle intervention protocol implementation in relation to patient awareness about treatment and self-management of SLE, with obvious improvement post implementation. Results also found a significant difference regarding self-awareness pre and post lifestyle intervention protocol, the patients' satisfactory level was improved post compared to pre implementation. These results could be due to patients benefit from the protocol and had acquired knowledge that improved their awareness. These results were in the same line with *Abd El-Azeem, et., al (2018)* who reported improvement in patients' awareness post implementation of an educational intervention.

Concerning self-efficacy, the findings of this study revealed that there was evident improvement post implementation of the intervention protocol regarding be confident about how to deal efficiently with unexpected events, finding several solutions when confronted with a problem, and can usually handle whatever comes his way. Regarding total self-efficacy score, the current study found that the patients had high self-efficacy were markedly increased post-implementation of the intervention protocol when compared to pre implementation. This finding supports the first part of the hypothesis, that supposed a positive relation between improved self-efficacy and implementation of the intervention protocol.

The previous findings might be due to increasing patient's ability to manage their problems after increasing their awareness and acquiring healthy behaviors through educating them. On the same line with the previous findings, *Mohammed, (2018)* who identified that self-efficacy improved after the intervention, and a significant difference was found in self-efficacy score.

The current study findings illustrate a statistically significant difference between pre and post protocol intervention regarding general signs, mucocutaneous, gastrointestinal, musculoskeletal, neurological, and musculoskeletal signs. The study finding shows that there were statistically significant differences between pre and post protocol intervention regarding cardiovascular, respiratory and vasculitis signs, it seems to be improved. These study findings support the research hypothesis which supposed that the implementation of nurse-led lifestyle intervention protocol will improve the associated symptoms for patients with systematic lupus erythematosus.

It is apparent that there was an improvement in the associated SLE signs. This could be due to following the health care practices by the patients to prevent occurrence of the health problems and decrease the effect of the present problem through managing it appropriately. The previous results are congruent with *Breland & Kamen (2012)* who provide insight into the effectiveness of interdisciplinary treatment approaches including increasing self-efficacy and disease-related knowledge among patients facilitate improved outcomes.

Regarding patients' disease activity (Renal & Hematology/laboratory) post-implementation of the intervention protocol, the current study presents that the highest means and standard deviations among the patients under study were in relation to renal (improved systolic and diastolic blood pressure, and in relation to Hematology/laboratory (improved evidence of active hemolysis, improved Platelets, WBCS). These results could be due to following a healthy lifestyle that could be effective in improving health status parameters. Moreover, on the same line, *Zhang et al. (2019)* whose results suggested that improving patient education help them obtain sufficient information and improve the disease signs and symptoms.

Investigating the relation between demographic characteristics and self-awareness & self-efficacy, this study findings shows that there is highly statistically significant relation between marital status, education, monthly income, and self-awareness and self-efficacy. also, there is statistically significant relation between age, working and self-awareness and self-efficacy.

The study showed that the younger persons were more able to acquire self-awareness, and high self-efficacy rather than older people. This might be due to that younger people had more hope and desire for life and caring for their future life. Results also showed that the highest percent of the patients who had satisfactory awareness level and high self-efficacy were married. This might be explained as those patients caring about their own families and need to protect them.

According to this study findings that revealed a highly statistical correlation between total levels of self-awareness and self-efficacy post-implementation of the intervention protocol. This could be due to increasing self-awareness because of applying the intervention protocol, that consequently increased the self-efficacy, which plays essential role in acquiring a healthy lifestyle. This finding is supported by *Ibrahim et al., (2020)* and *Elsayed & Mesbah (2018)* who indicates that there was an improvement of self-efficacy after application of educational and lifestyle intervention program.

Conclusion

In the light of the current study, it can be concluded that the implementation of nurse-led lifestyle intervention protocol affected positively the lupus awareness, self-efficacy and improve the associated symptoms for patients with systematic lupus erythematosus.

Recommendations

The researchers recommended that:

- Continuous educational sessions to improve patients' awareness, self-efficacy and improve the associated symptoms.
- Provide care protocol for patients with SLE in the hospital departments to maximize their ability to manage themselves.
- Further research on a larger scale to validate these findings.

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