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Learning Instructional Package for Patients with Systemic Lupus Erythematosus and its Outcomes at Urology and Nephrology Center - Mansoura University

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Abstract: **Lupus is a chronic disease where health education is an integral part of which is to teach patients how to manage their daily lives. The research aimed to: develop and implement instructional learning package for patients with Systemic Lupus Erythematosus, as well as evaluating their outcomes at the study setting. Method: Quasi-experimental research design has been used to conduct this study. Sample: The purposive sample has been selected in this survey from all available adult patients with Systemic Lupus Erythematosus from both genders during a period of six months. Tools: Six tools were used in this study for data collection as follows: Tool I: Patient's Assessment Structure Interview: This tool contains two parts as follows: Part 1: Demographic characteristics, Part 2: Patient Medical History. Tool II: Lupus Knowledge Questionnaire. Tool III: (Lupus Patient Reported Outcome Tool) LupusPRO. Tool IV: Numeric Pain Rating Scale 0-10.Tool V: Fatigue Severity Score (FSS).Tool VI: Patient's Perception to Systemic Lupus Erythematosus Questionnaire. Results: Post implementing instructional learning package; there were high statistical significant differences in patients' knowledge, Lupus patient reported outcome, pain, fatigue and illness perception Conclusion: The learning Instructions package had a considerable consequence on the development of patient's knowledge, health status, pain, fatigue and illness perception post implementation of learning package. Recommendation: setting up patient educating program to enhance SLE patients care by written and illustrated guidelines need to be accessible in all lupus departments and clinics.**

Keywords: ***Instructional Learning Package, Outcomes, SLE Patients, Systemic Lupus Erythematosus(SLE).***

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1. INTRODUCTION

Systemic lupus erythematosus (SLE) is a multisystem autoimmune disease which fluctuates over time and is associated with a considerable level of morbidity and mortality **(1).** It is also considered a major public health trouble, wherein the immune system attacks regular body tissues as although they have been foreign substances, causing inflammation and tissue destruction in all parts of the body. It characterized through periodic flare-ups of intense signs and symptoms distressing any organ resulting in probably life-threatening complications. **(2)**

The prevalence of SLE is evaluated to be 0.1-1 for each thousand, and the rate is assessed to be 0.01-0.08 per thousand every year, across the sex, race and age groups. It is more commonly found in Native Americans, Hispanics, and people with an African or Asian origin than in white individuals, which may also suggest a genetic role in the pathogenesis. An overall standardized mortality proportion was accounted to be 2.4 for this disease, which implies that the mortality in SLE is 2.4 times as high as that in the all-inclusive community. **(3, 4)**

The cause of lupus isn't recognized, in which the individual who develops lupus possibly acquires it from one or both parents and after that builds up the disease whilst offered to a cause. Triggers can also take in being offered to daylight, becoming ill with an infection, having surgical treatment, or becoming pregnant **(5).** Signs and symptoms of lupus may be introduced approximately by inflammation that may have an effect on the entire or parts of the body. Varied lupus manifestations are harm to a specific organ system, joint ache and stiffness, skin alterations, variations in kidney function, the digestive system may be influenced through medications used to treat lupus. Moreover, Lupus be able to influence lung, heart, nervous system and eye **(6).** Lupus can affect many parts of body, producing various complications which include skin (necrosis), hematologic (thrombocytopenia, hemolytic anemia, neutropenia, catastrophic antiphospholipid syndrome, and thrombotic thrombocytopenic purpura), heart (pericardial tamponade, myocarditis), lung (alveolar hemorrhage, pulmonary hypertension), gastrointestinal (vasculitis, pancreatitis), adrenal insufficiency, and neurologic (myelitis) can been countered. **(7)**

Self-management is fundamental to overseeing lupus or SLE. It’s vital to teach patient the warning signs of a flare. Warning signs may include increased fatigue, joint pain, rash, or fever. When the patient notice any of these signs, should take steps to control his/her symptoms **(8).** It is essential for the patient to know about the symptoms of lupus in order to recognize when flares start. In the chronic phase of lupus, these symptoms may show up again and signal the beginning of another flare. The patient who notification these signs should report it to the doctor to take appropriate action and perform tests. **(9)**

A patient needs to get self-care information and aptitudes, and must find suitable approaches to manage surrounding environments to maintain ideal wellbeing. As the leading main sources of death from SLE are the complications of the illness, such as end stage renal disease and cardiovascular disease, rather than SLE itself. **(10)**

Self-care mediations were described as interventions that purpose to provide the patients with abilities to actively share and take duty within the care of their sickness so as to work ideally through acquiring information and a combination of at least two of the subsequent: symptoms checking, drugs adminstration, enhancing problem-solving and decision-making skills for scientific management, and changing their physical activity, nutritional, and smoking conduct. **(11)**

Despite the fact that there's no complete curative for lupus, medical interventions may decrease signs and symptoms, restrict damage to vital organs, and decrease the threat of recurrence. The diet is one of these interventions as a lot of people with lupus have to eat a well- balanced diet. But the individual can also make changes in eating regimen specially people with active lupus. **(12)**

As well exercise mediations can expand aerobic health and decreasing some SLE signs and symptoms. SLE patients may encourage in exercise and training with physician permission. **(13)** Moreover, lowering exposure to ultraviolet via keeping off the sunbeams, protecting arms and legs, wearing a hat, and applying broad-spectrum sun block to protect skin **(14)**. The lupus patient should learn how to minimize pain and keep it at an acceptable level by numerous methods like apply heat or cold compresses to the affected joints, help the affected joints with pillows, blankets, or splints (if ordered through doctor), relaxation the affected joints as lots as feasible to decrease swelling. **(15)**

So, nurses have an important role in assistant patients diagnosed with SLE, including nursing education, support and advice. Nursing education refers to the delivery of intended learning approaches for patients that allows persons to expand their health knowledge and effect their self-care behavior. **(16)**

1.1. Significance of the study

Systemic lupus erythematosus (SLE) is related to large mortality, morbidity rate and cost for the patient and society **(17).** Systemic Lupus Erythematosus is a complicated disease to diagnose, deal with and control. It is estimated that there are approximately 391,780 patients with Systemic Lupus Erythematosus in Egypt **(18).** Moreover, it was informed that; about eighty-five lupus patients are admitted to the rheumatology department in Cairo University Hospital monthly **(19).** Where it was found that many of the SLE patients at Mansoura University did not know information about the disease, its complications and therefore found lack of commitment to medication and follow-up and thus increase the complications of the disease. As it provides learning package for patients increases their knowledge of the disease, reduce symptoms and prevent the occurrence of complications.

1.2. Aim of the Study

This study aims to develop and implement instructional learning package for patients with Systemic Lupus Erythematosus, as well as evaluating their outcomes at the study setting.

1.3. Research Hypotheses

1. The Learning Instructions Package will have a positive effect on patient's knowledge, health status, pain, fatigue and illness perception.

2. The Learning Instructions Package will have no effect on the patient's knowledge, health status, pain, fatigue and illness perception.

2. PARTICIPANTS AND METHOD

2.1. Research design and setting: A quasi-experimental design was used to conduct this research at Urology and Nephrology Center –Mansoura University.

2.2. Study sample: The purposive sample was selected in this study from all available number of adult patients with Systemic Lupus Erythematosus from both sexes during a period of six months

Inclusion Criteria:

- Patients with Systemic Lupus Erythematosus and consented to participate the study.
- Patient's age ranged from (20: 60 years old).
- Patients who are able to communicate.

Exclusion Criteria:

Any patients with the following conditions were excluded from the study:

- Psychiatric patients.
- Cancer patient.
- End stage kidney disease on regular hemodialysis.

2.3. Tools of Data Collection

Six tools have been used in this research for data collection as follows:

Tool I: Patient's Assessment Structure Interview: This tool consists of two parts as follows:

Part 1: Demographic Characteristics: It was developed by the investigator in order to assess the demographic Characteristics; it comprised the patients' name, age, gender, level of education, marital status, place of residence and job.

Part 2: Patient Medical History: It was developed by the investigator including four questions about hospitalization, family history, smoking and the patient information about the lupus.

Tool II: Lupus Knowledge Questionnaire: This tool was modified by the investigator from (20). It was a questionnaire containing 28 items selected from 34 items to facilitate questions on the patient and remove repeated items. It was used to assess the patient level of knowledge about lupus. The items were all designed as True/False or Don't Know, the total lupus knowledge score was 28 classified as poor (<50%), fair (50-75%) and good (>75%) of the total knowledge score.

Tool III: (Lupus Patient Reported Outcome Tool) LupusPRO: This tool was modified by the investigator from (21-23) in order to be suitable and applicable to the patient. It was used to assess health status and how SLE disease and its treatment affected the patient health and QoL. In total, the LupusPRO comprises 18 items (13 for the health-related QoL, 5 for the non-health-related QoL) were selected from 43 items. The health-related QoL domains are lupus symptoms, cognition, lupus medications, procreation, and physical health. The nonhealth-related QoL domains are social support and coping. Each item is scored on a five-point Likert scale ranging from ‘‘none of the time’’ to ‘‘all of the time.’’ that relate to the past four weeks in the patient’s daily life. The score for each domain ranges from 0 to 90; higher scores indicate better QoL.

Tool IV: Numeric Pain Rating Scale 0-10: This standardized tool from **(24).** It was used to assess the severity of pain experienced by the patient. The patient is asked to make three pain ratings, corresponding to current, best and worst pain experienced over the past 24 hours. The intensity of the current, best and worst pain levels over the past 24 hours will measured on a scale of (0) no pain to (10) worst pain imaginable The total score was 10 classified as no pain (0), mild pain (1-3), moderate pain (4-6) and sever pain (7-10).

Tool V: Fatigue Severity Score (FSS): This standardized tool from **(25).** It was 9-item questionnaire with questions used to assess to how fatigue affects with certain activities and rating its severity. The items are scored on a seven-point scale with one (strongly disagree) and seven (strongly agree) and the total score =63

Tool VI: Patient's Perception to Systemic Lupus Erythematosus Questionnaire: This tool was modified by the investigator from **(26, 27)** to facilitate the questionnaire on the patient. It was a short questionnaire on the disease concept containing eight items out of nine because the excluded one was open ended question so as not to strain the patient in writing. This items scored on scale from 0 to 10.It was designed to assess the cognitive and representation of illness with total score 80**.**

Validity of the tools: Extensive review of the current national and international Literatures related to the study was done using textbooks, articles, magazine, internet and other related researchers. Tools were adopted and modified by the investigator then tested for content validity by a panel of five experts in the field of medical surgical nursing, Internal Medicine, and Statistics in Mansoura University reviewed the tools for clarity, relevance, comprehensiveness, understanding, applicability and simplicity for implementation and some modification were applied accordingly.

Reliability of the tools: Reliability test was made by using Cronbach's Alpha and was in Lupus Knowledge Questionnaire (alpha= 0.780) which is acceptable, it was in Lupus Patient Reported Outcome Questionnaire (alpha=0.827) which is good, it was in Fatigue Severity Questionnaire (alpha= 0.775) which is acceptable, it was in Patient's Perception to Systemic Lupus Erythematosus Questionnaire (alpha= 0.726) which is acceptable

2.4. Pilot study: carried out on ten patients who were selected randomly from patients under study those patients were then excluded from the study. The purpose of the pilot study was to ascertain the clarity and applicability of the tool and to estimate the time needed to answer the questionnaire. Based on the finding of the pilot study, modification was made to make the tool more applicable to patients.

2.5. Fieldwork: The study was implemented through the following four phases:

Phase 1: Preparatory Phase (Assessment):

The investigator introduced her to each patient sample and gave them a brief idea about the aim of the study. Then oral consent was obtained from each one. The interview sheets were filling by the investigator in the nephrology unit after interviewing each patient individually. The average time taken by the investigator to fill out the form for each patient was 20 to 30 minutes.

These pre-tests were done to assess the patient's knowledge, health status, pain, fatigue and illness perception before starting the learning package.

Phase II: Developing Instructional Learning Package:

The researcher assessed the educational needs of the patients with Systemic Lupus Erythematosus then went through literature review and internet searching for relevant information to construct the educational program under the guidance of the supervisors. A simple colored arabic booklet and CD contains PowerPoint and videos were developed and given to the patients as a gift covering all items related Systemic Lupus Erythematosus.

The Educational booklet includes definition of SLE and autoimmune diseases, fast Facts about SLE, categories of lupus symptoms of SLE, etiology, diagnosis, complication, treatment of SLE, diet, exercise, nutrition, immunizations, pregnancy and contraception, medications for SLE, Living with Lupus, Preventing Fatigue due to Lupus.

Phase (III): Implementation phase:

The learning package was introduced for each person individually, the researcher invited the patients in a room in the nephrology unit. Diverse teaching methods were used during the sessions including; interactive lectures, data show, videos, pictures, printed booklets. It took two session lasted for about 30-45 minutes each one. During each session the researcher answered questions and cleared up misconceptions when voiced. Moreover, the booklet was given to each patient to attract their attention, motivate them and to be as a reference. It took six months from the beginning of august 2017 to the end of January 2018.

Phase 4: Evaluation phase:

The evaluation phase focused on determining the effect of the learning package through patients with SLE interview sheet using the same tools in pre-program assessment directly after implementing the package (post-test) which performed after one month from (pre-test) and continued for six months. The results were compared to the pretest results to evaluate the impact of the package on patient's knowledge, health status, pain, fatigue and illness perception

2.6. Ethical Consideration:

All relevant ethical issues were taken into consideration including the following: The research approval was obtained before starting with the program, the aim of the study was explained to each patient and then an oral consent for participation in the study was obtained from each one of them, ensuring patients privacy and confidentiality of the collected data during the study. Voluntary participation as they were given an opportunity to refuse the participation, and they were assured that there information which would be used for research purposes only.

2.7. Statistical analysis

The composed statistics were implied, processed and examined using Statistical Package of Social Science (SPSS) program for windows (version 16). Qualitative information was presented as number (N) and percent (%). Pie and bar charts were used for graphical presentation of data. Quantitative parametric data were presented in mean and Standard Deviation (SD) while nonparametric data were presented in median, minimum and maximum.

Chi square was used for testing significance of categorical data. On comparing quantitative data within each phase (pre learning package and post learning package), independent t test and ANOVA were used for testing significance between parametric data while Mann-Whitny test and Kruskal-Wallis test were used if data were nonparametric. On comparing quantitative data between pre and post learning package phases, paired t test was used for parametric data and Wilcoxon rank test was used for nonparametric data. P value ≤ 0.05 was considered to be statistically significant.

3. RESULTS

Table (1): This table shows that, most of studied patients (95.8%) were female, two fifth of the participants age (40%) ranged from 20to30 years. Regarding level of education less half of studied sample (47.4%) were average education. The majority of the participants were married (82.1%).Concerning residence living in rural area prevailed among (77.9%) of the patients. Regarding occupation, the majority of studied sample (87.4%) was not working.

Table (1): Distribution of studied patients consistent with their demographic characteristics (n = 95).

Patient characteristics	Number (n)	Percent (%)
Gender		
Male	4	4.2
Female	91	95.8
Age		
20-	38	40.0
30-	37	38.9
40-50	20	21.1

Education		
Illiterate	13	13.7
Read and write	7	7.4
Average education University	45	47.4
education	30	31.6
Marital status		
Single	12	12.6
Married	78	82.1
Divorced	4	4.2
Widow	1	1.1
Residence		
Rural	74	77.9
Urban	21	22.1
Working status		
Work	12	12.6
Not work	83	87.4

Table (2): This table illustrates that the highest proportion of the study participants were nonsmokers (98.9%), had history of hospitalization (89.5%) and negative family history of SLE (91.6%).

Table (2): Distribution of studied patients according to their medical history (n = 95).

Medical history	Number (n)	Percent (%)
Present history of tobacco smoking		
Yes	1*	1.1
No	94	98.9
Past history of hospitalization related to SLE		
Yes	85	89.5
No	10	10.5
Family history of SLE		
Yes, 1st degree relative	5	5.3
Yes, 2nd degree relative	3	3.1
No(negative)	87	91.6

∗ Duration of smoking was more than three years

Figure (1): This figure shows that nearly half of the study participant did not know information about lupus (49%). According to source of their knowledge, (26%) of the patients know information from waiting in the outpatient clinics and only (1%) of the patients entered treatment program and read a book about lupus.

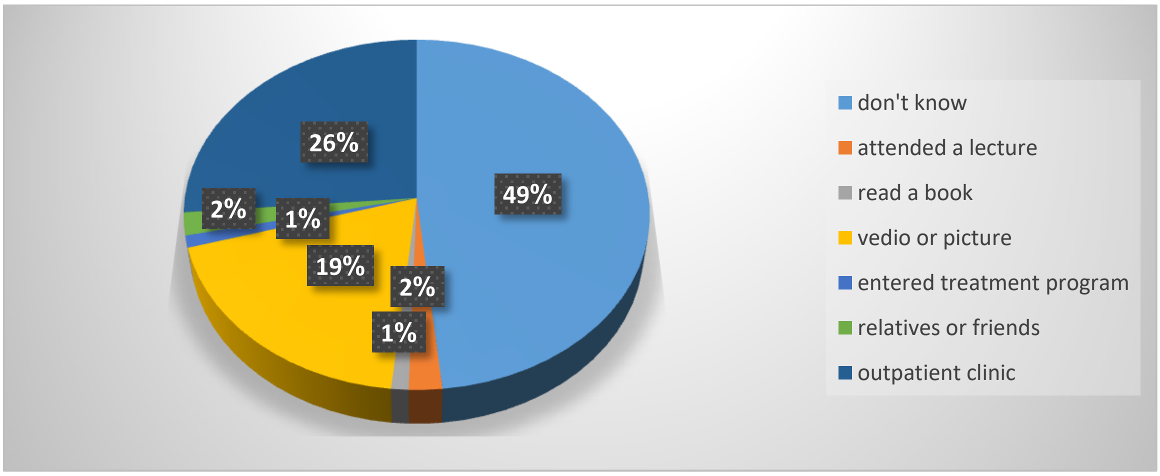

Figure (1): Percent distribution of studied patients according to their basic knowledge related the disease and source of this knowledge (n = 95).

Table (3): This table illustrates that, only (10.5%) of studied patients had a good score level related lupus pre implement of learning package while, this percent improved to (97.9%) at post implementation of learning package.

Table (3): comparison of studied patients regarding lupus knowledge score pre and post learning package implementation (n = 95).

Knowledge score (total = 28)	Pre learning package n = 95	Post learning package n = 95	P value*
	N (%)	N (%)	
Poor (<50%)	20 (21.1%)	0 (0.0%)	< 0.001**
Fair (50-75%)	65 (68.4%)	2 (2.1%0)	
Good (>75%)	10 (10.5%)	93 (97.9%)	
Mean (SD)	15.9 (3.5)	25.5 (1.7)	< 0.001**

∗ P ≤ 0.05

∗∗highly statistically significant result

Table (4): This table indicates that there was highly statistical significant difference (p< 0.001) between gender, age, education, marital status, residence, working status, past history of hospitalization, family history of SLE and lupus knowledge in post learning package when compared to pre learning package

Table (4): Relation between lupus knowledge score and demographic characteristics in pre and post learning package implementation.

Demographic characteristics	lupus knowledge score		P value*
	Pre learning package Mean (SD)	Post learning package Mean (SD)	
Gender			
Male	19.8 (2.6)	26.5 (1.0)	P= 0.007
Female	15.8 (3.5)	25.4 (1.7)	P<0.001
	P = 0.027	P = 0.223	
Age			
20-	16.0 (3.4)	25.6 (1.7)	P<0.001
30-	15.4 (3.6)	25.5 (1.4)	P<0.001
40-50	16.8 (3.6)	25.1 (2.3)	P<0.001
	P= 0.334	P= 0.528	
Education			
Illiterate	15.4 (3.0)	25.1 (1.3)	P<0.001
Read and write	17.7 (5.3)	26.3 (0.95)	P=0.004
Average education	15.9 (3.1)	25.3 (1.7)	P<0.001
University education	15.7 (3.9)	25.7 (2.0)	P<0.001
	P= 0.545	P= 0.326	
Marital status			
Single	15.4 (4.7)	26.3 (1.1)	P<0.001
Married	16.1 (3.4)	25.4 (1.8)	P<0.001
Divorced	15.0 (2.6)	24.0 (1.2)	P= 0.002
	P= 0.718	P= 0.064	
Residence			
Rural	16.0 (3.3)	25.4 (1.8)	P<0.001
Urban	15.8 (4.4)	25.9 (1.5)	P<0.001
	P= 0.865	P= 0.193	
Working status			
Work	16.8 (2.8)	25.3 (2.5)	P<0.001
Not work	15.8 (3.6)	25.5 (1.6)	P<0.001
	P = 0.393	P = 0.631	

Past history of hospitalization			
Yes	16.0 (3.6)	25.5 (1.7)	P<0.001
No	15.3 (2.8)	25.1 (1.4)	P<0.001
	P = 0.558	P = 0.469	
Family history of SLE			
Yes	14.5 (3.5)	26.8 (0.4)	P<0.001
No	16.1 (3.5)	25.4 (1.7)	P<0.001
	P = 0.237	P = 0.027	

∗statistically significant result if P ≤ 0.05, ∗∗Highly statistically significant result if P< 0.001

Table (5): This table shows that there was highly statistically significant difference (p< 0.001) in the post learning package phase compared to pre learning package phase regarding lupus reported outcome score.

Table (5): Comparison of studied patients in the pre and post learning package phase regarding their lupus reported outcome score (n = 95)

	Pre learning package n = 95	**Post learning package n = 95**	**P value***
	n (%)	**n (%)**	
Lupus patient reported symptoms (total = 40) Median (Min.-max.)	16 (2-29)	11 (1-19)	< 0.001**
Lupus patient reported physical health (total = 25) Median (Min.-max.)	7 (5-20)	3 (0-17)	< 0.001**
Lupus patient reported social support (total = 25) Mean (SD)	13.3 (2.8)	17.7 (2.4)	< 0.001**
Lupus patient reported outcome (total = 90) Mean (SD)	36.6 (8.3)	32.6 (6.8)	< 0.001**

∗statistically significant result if P ≤ 0.05

∗∗highly statistically significant result

Table (6): This table indicates that there was highly statistically difference between demographic characteristics and lupus reported outcome.

Table (6): Comparison of lupus reported outcome score (total = 90) in the pre and post implementation of learning package phases according to patients demographic characteristics

Demographic characteristics	**Lupus reported outcome**		**P value***
	Pre program Mean (SD)	Post program Mean (SD)	
Gender			
Male	41.7 (9.5)	40.5 (7.8)	P=0.743
Female	36.4 (8.3)	32.3 (6.6)	P<0.001
	P = .210	P = .018	
Age			
20-	38.7 (7.8)	35.5 (6.7)	P=0.002
30-	36.5 (8.3)	31.8 (5.6)	P<0.001
40-50	32.9 (8.6)	28.7 (6.9)	P=0.004
	P=.041	P=.001	
Education			
Illiterate	34.8 (7)	33.2 (6.5)	P=0.168
Read and write	32.7 (8.1)	27.4 (4.9)	P=0.030
Average education	35.5 (8.8)	31.8 (6.7)	P<0.001

University education	40.0 (7.5)	34.8 (6.9)	P<0.001
	P=.042	P=.045	
Marital status			
Single	41.2 (6.7)	40 (5.6)	P=0.526
Married	35.6 (8.5)	31.1 (6.1)	P<0.001
Divorced	42.0 (2.9)	39.3 (2.9)	P= 0.140
	P=.042	P<0.001	
Residence			
Rural	36.04 (8)	32.7 (6.7)	P<0.001
Urban	38.6 (9.4)	32.3 (7.4)	P=0.001
	P= .213	P= .788	
Working status			
Work	39.3 (7.5)	33.1 (8.2)	P=0.014
Not work	36.2 (8.4)	32.6 (6.7)	P<0.001
	P = .243	P = .812	
Past history of hospitalization			
Yes	36.2 (8.1)	32.3 (6.8)	P<0.001
No	39.7 (10.1)	35.4 (6.7)	P=0.069
	P = .218	P = .179	
Family history of SLE			
Yes	40 (7.5)	32.8 (6.9)	P= 0.008
No	36.3 (8.4)	32.6 (6.9)	P<0.001
	P = .232	P = .963	

∗statistically significant result if $P \le 0.05$.

∗∗Highly statistically significant result if $P < 0.001$

Table (7): Comparison of studied patients in pre and post implementation of learning package regarding their numeric pain rating score

Variable	Pre program n = 95	Post program n = 95	P value*
Median (Min.-max.)	5 (0-9)	4 (0-6)	< 0.001**

∗statistically significant result if $P \le 0.05$

∗∗highly statistically significant result

This table 7 illustrates that there were highly statistically significant differences between pre and post learning package implementation regarding pain assessment $p<0.001$ in numeric pain rating in post implementation of learning package when compared to pre implementation of learning package

Table (8): This table shows that there were statistically significant differences($P \le 0.05$) between patients demographic characteristics and numeric pain rating scale in pre and post learning package implementation regarding female sex, age, education categories(read and write, average education, university education), married, residence, not working, those with history of hospitalization and those without, those with no family history. Regarding the other demographic characteristics there were no statistically significant differences ($P>0.05$)

Table (8): Comparison of numeric pain rating scale (total = 10) of patients in the pre and post implementation of learning package phases according to their demographic characteristics

Demographic characteristics	Numeric pain rating scale		P value*
	Pre program Median (min. – max.)	Post program Median (min. – max.)	
Gender			
Male	3(0-7)	2(0-4)	P=0.593
Female	5(0-9)	4(0-6)	P<0.001
	P = 0.086	P = 0.204	

Age			
20-	5(0-9)	4(0-6)	P=0.027
30-	6(0-9)	4(0-6)	P<0.001
40-50	5(1-9)	3(0-5)	P=0.003
	P= 0.325	P= 0.167	
Education			
Illiterate	5(0-8)	4(1-6)	P=0.407
Read and write	7(5-9)	3(0-6)	P=0.027
Average education	5(0-9)	4(0-6)	P=0.002
University education	5(2-9)	3(0-6)	P<0.001
	P= .283	P= 0.160	
Marital status			
Single	5(0-9)	4(2-6)	P=0.788
Married	5(0-9)	4(0-6)	P<0.001
Divorced	7(3-8)	2(0-5)	P=0.144
	P= 0.189	P= 0.173	
Residence			
Rural	5(0-9)	4(0-6)	P<0.001
Urban	6(0-9)	3(0-5)	P=0.001
	P= 0.137	P= 0.076	
Working status			
Work	5(0-7)	4(0-6)	P=0.182
Not work	5(0-9)	4(0-6)	P<0.001
	P = 0.449	P = 0.674	
Past history of hospitalization			
Yes	5(0-9)	4(0-6)	P<0.001
No	6(4-9)	3(0-6)	P=0.011
	P = 0.505	P = 0.216	
Family history of SLE			
Yes	6(4-9)	4(0-6)	P=0.127
No	5(0-9)	3(0-6)	P<0.001
	P = 0.600	P = 0.544	

∗statistically significant result if P ≤ 0.05

∗∗Highly statistically significant result if P< 0.001

Table (9): This table shows that fatigue severity mean was 45.6 before implantation of learning package compared to 34.6 post implantation of learning package with significant positive relation at p-value was <0.001

Table (9): Comparison of studied patients in pre and post learning package regarding their Fatigue severity scale

Variable	Pre program n = 95	Post program n = 95	P value*
Fatigue severity scale (Total score = 63)			
Mean (SD)	45.6 (8.3)	34.6 (7.1)	< 0.001**

∗statistically significant result if P ≤ 0.05
∗∗highly statistically significant result

Table (10): This table demonstrates that there were highly statistically differences (P ≤ 0.05) between all demographic characteristics and fatigue severity score

Table (10): Comparison of fatigue severity score (total = 63) of patients in the pre and post program phases according to their demographic characteristics

Demographic characteristics	Fatigue severity scale		P value*
	Pre program Mean (SD)	Post program Mean (SD)	
Gender			
Male	46.8 (8.4)	32.3 (3.8)	P=0.015
Female	45.5 (8.4)	34.7 (7.2)	P<0.001
	P = 0.775	P = 0.503	
Age			
20-	45.0 (7.4)	34.3 (7.1)	P<0.001
30-	46.0 (8.4)	33.7 (6.2)	P<0.001
40-50	45.8 (10.1)	36.7 (8.3)	P=0.001
	P= 0.775	P= 0.503	
Education			
Illiterate	42.5 (6.8)	32.9 (7.8)	P=0.002
Read and write	45.9 (10.0)	38.1 (3.8)	P=0.083
Average education	45.1 (8.3)	34.2 (6.9)	P<0.001
University education	47.6 (8.5)	35.1 (7.5)	P<0.001
	P= 0.300	P= 0.431	
Marital status			
Single	46.0 (9.2)	34.9 (6.7)	P=0.001
Married	45.5 (8.4)	34.7 (7.1)	P<0.001
Divorced	47.8 (5.7)	33.5 (7.6)	P= 0.028
	P=0.859	P=0.938	
Residence			
Rural	45.9 (7.9)	35.2 (7.4)	P<0.001
Urban	44.4 (9.9)	32.3 (5.1)	P<0.001
	P= 0.476	P= 0.092	
Working status			
Work	48.8 (10.3)	38.3 (10.4)	P=0.002
Not work	45.1 (8.0)	34.0 (6.3)	P<0.001
	P = 0.148	P = 0.048	
Past history of hospitalization			
Yes	45.3 (7.9)	34.5 (7.1)	P<0.001
No	48.2 (11.7)	35.4 (7.1)	P=0.008
	P = 0.294	P = 0.700	
Family history of SLE			
Yes	47.1 (6.6)	32.9 (4.0)	P<0.001
No	45.4 (8.5)	34.7 (7.3)	P<0.001
	P = 0.585	P = 0.479	

∗statistically significant result if $P \leq 0.05$,
highly statistically significant result if $P < 0.001$

Table (11): This table indicates that Brief illness perception mean was 42.3before implantation of learning package compared to 46.8 post implantation of learning package with significant positive relation at p-value was <0.001

Table (11): comparison of patients illness perception score in pre and post learning package implementation

Variable	Pre program n = 95	Post program n = 95	P value*
Brief illness perception (Total score= 72)			
Mean (SD)	42.3 (8.1)	46.8 (5.9)	< 0.001**

∗statistically significant result if P ≤ 0.05

∗∗highly statistically significant result

Table (12): This table demonstrates that there were highly statistically differences between demographic characteristics and Brief illness perception score .

Indetails, this table shows that females, all age groups, illiterate, average education groups, married, rural residence, not working, those with history of hospitalization, those with no family history, showed significantly improved brief illness perception score in post learning package when compared to pre learning package.

Regarding, males, read and write, university educated, single, divorced, urban, working, those with no past history of hospitalization, those with positive family history showed improvement brief illness perception score in post learning package when compared to pre learning package, although did not reach significant level.

Table (12): Relation between illness perception score (total = 72) for studied patients and demographic characteristics during the pre and post learning phase

Demographic characteristics	Brief illness perception		P value*
	Pre program Mean (SD)	Post program Mean (SD)	
Gender			
Male	45.3 (3.0)	46.5 (7.1)	P= 0.758
Female	42.2 (8.2)	46.8 (5.9)	P<0.001
	P = 0.459	P = 0.924	
Age			
20-	41.3 (8.1)	46.3 (5.2)	P=0.001
30-	44.4 (8.9)	47.2 (5.9)	P=0.044
40-50	40.2 (5.5)	46.9 (7.2)	P=0.002
	P= 0.105	P= 0.785	
Illiterate	41.0 (3.0)	46.8 (7.5)	P=0.006
Read and write	41.7 (5.2)	47.9 (5.0)	P=0.111
Average education	40.9 (7.4)	46.5 (6.2)	P<0.001
University education	45.1 (10.5)	46.9 (5.0)	P= 0.245
	P= 0.159	P= 0.958	
Marital status			
Single	44.3 (7.4)	46.0 (6.7)	P= 0.465
Married	41.9 (8.4)	47.1 (5.8)	P<0.001
Divorced	43.3 (3.4)	41.5 (3.5)	P= 0.595
	P= 0.618	P= 0.164	
Residence			
Rural	42.0 (8.0)	47.1 (5.8)	P<0.001
Urban	43.2 (8.7)	45.7 (6.3)	P= 0.241
	P= 0.569	P= 0.352	
Working status			
Work	44.1 (9.3)	44.6 (6.1)	P= 0.801
Not work	42.0 (7.9)	47.1 (5.9)	P<0.001
	P = 0.417	P = 0.169	

Past history of hospitalization			
Yes	42.2 (8.4)	46.7 (6.0)	P<0.001
No	43.5 (5.1)	47.1 (5.4)	P= 0.085
	P = 0.622	P = 0.857	
Family history of SLE			
Yes	44.8 (10.5)	46.1 (4.2)	P= 0.739
No	42.1 (7.9)	46.8 (6.1)	P<0.001
	P = 0.374	P = 0.745	

∗statistically significant result if $P \leq 0.05$,

highly statistically significant result if $P < 0$

4. DISCUSSION

Systemic Lupus Erythematosus affects all aspects of a person's life and may require ongoing treatment and lifestyle changes for the person to continue functioning at a desirable level, the problems that experienced by someone with lupus are different. Thus medical treatment and self-management are important ways to intervene and stop the occurring of such problems, which interferes with the lives or even survival of patients suffering from SLE (28, 29). Moreover, the illness-induced disruption to lifestyle and daily activity continues to compromise health status in some patients. With adequate support and patient education from the nurse, patients can be more actively involved in improving their clinical outcomes and quality of life (15). This study was carried out to develop and implement instructional learning package for patients with Systemic Lupus Erythematosus, as well as evaluating its outcome.

The findings of this study revealed that, most of studied patients were females. This was in agreement with **Furr et al.** (30) who stated that, most participants in his study were females. Also, **Dhanhani** (31) found that most of his participants were females.

In the current study, two fifth of patients age in the second decade. This finding is in accordance with the study of **Ismail et al.** (32) who reported that mean age of their patients was 26.7. This finding was in contrast with **Harding** (33) who found that most of his participants were middle-aged population in the third decade. Also **Furr et al.** (30) found that the mean age of their participants was 45 years old. Moreover another study of **Fane et al.** (34) stated that the mean age of the women in their study was 52.6 years. It was mentions in many literatures that the illness exasperates youthful grown-ups and begins in the second and third decade of life.

In relation to the level of education, less half of studied sample was average education. This was in contrast with **Brittain** (35) who stated that, more than one fifth of his participants were bachelor's degree.

The majority of the patients in the present study were married. This was in the same line with **Furr et al.** (30) who reported that, the majority of his participants being married. Also **O'Riordan et al.** (36) reported that the majority of the participants were married in their study.

In this study, more than three fourth of the sample living in rural area. This is inconsistent with **Arnaud et al.** (37) who found that more than half of their participants were urban patients and more than one fourth of them were rural patients.

Regarding occupation, the majority of studied sample in the current study was not working**.** This finding was in contrast with **Harding** (33) who found that the majority of the participants in this study were working full time. Also, **O'Riordan et al.** (36) reported that more than half of the participants were employed.

The present study showed that, most of the studied patients hadn't present history of tobacco smoking. This is not agreed with **Montes et al.** (38) who told that more than half of his participants never smoked. Also, **Barbhaiya et al.** (39) reported in their study that no association were observed between smoking and SLE.

Concerning the past of systemic lupus erythematous, the present study showing that that the highest proportion of the study patients had negative family history of SLE. This result was congruent with a previous population based cohort study which stated that minimal of SLE cases occurred in patients with positive family history (40)**.** In the same line comes the study of **Kuo et al.** (41) who noticed that minimal of SLE patients had positive family history.

Durrani et al. (42) who reported in their study that the past of the family about SLE was significantly more common in adolescent-onset SLE than in adult-onset disease, about one third of the sample of adolescent-onset SLE patients have a +ve family history of SLE as in contrast to above one fifth of adult-onset disease patients.

According to patients basic knowledge related the disease and source of this knowledge, this study showed that nearly half of the study participants did not have information about lupus and only one patient entered treatment program and read a book about lupus. This result not agreed with **Sullivan** (20) who stated that more than one fifth of his participants know about SLE, more than two fifth of the sample read about SLE and four of them attended lecture on SLE. It can explain this diversity due to different race and society.

In the present study, there was statistically significant improvement post implementation of learning package in the most of studied patients. This finding is in the same line with **Yariz et al.** (43) who reported that; three quarters of patients with SLE are usually acquiring information about the nature of disease, pathology, treatment, prognosis and life style changes after implementation of health education. Also the study of **Mostafa et al.** (29) discovered that there was statistically significant development after implementation of guidelines whereas more than two thirds of patients had satisfactory awareness post implementation of self-management guidelines.

Moreover, this study in the same line with the study of **Maheswaranathan et al.** (44) who stated that, the improvements in scores suggests efficacy of the patient education event in increasing awareness and knowledge about lupus in those who attended educational program. This is consistent with **Sohng et al.** (45) who reported that the same results after implementing self-management course on Korean patients with SLE. They interpreted their findings by that it was probably because knowledge is usually accepted to be taught for patients with chronic illness to be aware of their own status.

Also, this study finding was supported by **Sahebalzamani et al.** (46) who referenced that, the constant ideal care significantly increase patients' knowledge level and understanding of their illness.

The present research showed that there was highly statistically major difference in the post learning package phase compared to pre learning package phase regarding lupus reported outcome score. Similar result was reported in the study of **Elsayed et al.** (19) who represented greatly statistical significant progress concerning all Lupus PRO(patient reported outcome) items post interference. This might reveal that the significance of health learning interferences and packages in improving health product for SLE patients. This result was in agreement with **Feldman et al.** (47), who found that the achievement of mediation can be estimated by upgrades in capacity to perform day by day living exercises, keep up a solid eating routine, and exercise consistently as result measures.

The present research illustrated that there was highly statistically considerable dissimilarities among pre and post learning package implementation regarding pain assessment in numeric pain rating scale after implementation of learning package. As well **Williams et al.** (17) explained that self-control interventions that contain each social assist and health education had a beneficial outcome in enhancing health outcome through diminished distress, improved function and delayed incapacity amongst patients with lupus.

The present study showed that fatigue severity mean decreased after implantation of learning package compared to pre implantation of learning package with significant positive relation. This is concordant with **Miljeteig et al.** (48) who reported in his study that, there was significant improvement in perceived fatigue levels and general health scores after participation in the education program by using teaching and counseling for patients with SLE.

This is inconsistent with **O'Riordan et al.** (36) who stated that there were no statistically significant differences in the FSS scores from the beginning to the end of the study although the proportion of participants with severe fatigue.

They interpreted their findings that it was probably because the lack of significant changes in the FSS scores may be that as fatigue is a constant symptom for up to most of people with SLE, it may not be possible to eliminate this symptom through a self-management program. Therefore perhaps the FSS was not the most suitable measure to use as it is a one-dimensional scale which measures severity of fatigue rather than the impact of fatigue on participants' daily occupations. Also, **Liang et al.** (49) reported on fatigue, that there was no statistically significant difference between patients receiving intervention or control treatment in level of fatigue.

The present study indicates which Brief illness perception increased after implantation of learning package compared to pre implantation of learning package with significant positive relation. Few studies have used a research method for assessing illness perceptions, One of them was **Daleboudt et al.** (50) who reported that , there was positive changes in the perceptions of identity, treatment control, and emotional representations after an intervention and SLE patients perceived their illness more negatively than patients with another chronic illness on most illness perception dimensions may indicate that SLE is a more severe illness.

For best of our knowledge, few studies have investigated the presence of this relation, the present study found that there was highly statistical significant difference between gender, age, education, marital status, residence, working status, past history of hospitalization, family history of SLE and lupus knowledge in post learning package when compared to pre learning package. This result on line with **Yosef et al.** (51) who stated that, there was a highly statistically significant improvement regarding patients' levels of awareness post implementation of SLE health promotion program. Moreover, there were highly statistically significant positive correlations between SLE patients' levels of awareness and QOL and their demographic Characteristics as regards their education level.

As regards lupus reported outcome score the present study results illustrated that there was highly statistically difference between demographic characteristics and lupus reported outcome, In agreement of our finding, the study of **Rodríguez-Rivera et al.** (52) who found thatsome demographic and clinical features differed between two study groups of Lupus patients and revealed significant differences in PROM between the study groups

Concerning numeric pain rating scale, this result showed that there were statistically significant differences between patients demographic characteristics and numeric pain rating scale in pre and post learning package implementation regarding being female sex, age, education level, married, residence, not working, those with history of hospitalization and those with no family history, regarding the other demographic characteristics there were no statistically significant differences. This is in the same line with **Grol-Prokopczyk** (53) who referred that chronic pain changes by age, sex, ethnic, socioeconomic status and education level.

According to fatigue severity score, this result demonstrated that there were highly statistically differences between all demographic characteristics and fatigue severity score. This results were inconsistent with study of **Razazian et al.** (54) who found which there was no significant relationship among fatigue and age in Multiple Sclerosis(MS) patients, higher ratings for fatigue on the FSS in male patients compared with female patients, there was no significant association among fatigue and marital status and the relationship between fatigue and educational level was also not significant .

In relation to illness perception score, this research demonstrated that there were highly statistically differences among demographic characteristics and brief illness perception score. This finding was in accordance with **Daleboudt et al.** (50) who found that several demographic and disease characteristics did show an association with illness perceptions. Patients' illness perceptions of emotion and identity showed a relationship with ethnicity and employment status, respectively. Patients who were unemployed or received sick benefit reported more symptoms than patients with a job or students. Patients with longer disease durations tended to be less concerned about their SLE

Another previous study on illness perceptions in SLE patients also found beneficial changes in illness perceptions over time. However, these changes were self-reported and no associations with socio-demographic or disease characteristics were investigated. (55)

5. CONCLUSION

As said by outcomes this study concluded that: The learning Instructions package had an important impact on the enhancement of patient's knowledge, patient health status, pain, fatigue and illness perception post implementation of learning package ,also there was highly statistical significant difference between demographic characteristics and other variables of study

6. RECOMMENDATIONS

1- Setting up an education program for patients to enhance SLE clients care with the aid of written instructions need to be in all SLE departments and clinics similarly to media including: newspapers, television, and radio to assist in enhancing the health status of those patients.

2- An Arabic guided photos booklet about SLE must be dispensed for every newly admitted affected person diagnosed with SLE.

3- Publishing this study for big number of clients and in various placing.

4- future research about self-control of patients with SLE are exceedingly recommended to discover the impact of self-care intervention on controlling SLE signs and symptoms and to attain the height degree of health satisfaction amongst those patients

5-An Egyptian Lupus organization ought to be advanced to keep in touch with the troubles of those patients.

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