

EFFECT OF SELF-CARE INSTRUCTIONAL GUIDE ON DISEASE ACTIVITY AMONG PATIENTS WITH SYSTEMIC LUPUS ERYTHEMATOSUS

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Abstract

Background: Systemic lupus erythematosus (SLE) is an episodic, chronic, multisystem, autoimmune disease characterized by a widespread inflammation of blood vessels and connective tissues. There is no cure for lupus, but medical interventions and lifestyle modifications can help control it. The seriousness of SLE can range from mild to life-threatening. Patients with SLE who get proper medical care and education can significantly lower disease activity and improve quality of life. **Aim of the study:** The aim is to evaluate the effect of self-care instructional guide on disease activity among patients with SLE. **Design:** Non-Equivalent pretest-posttest time series control group design was used in the study. **Setting:** The study was conducted at the rheumatology and rehabilitation department in one of Cairo University affiliated hospitals. **Sample:** A convenient sample of 120 male and female adult conscious patients with SLE who fulfilled the eligibility criteria was recruited. **Tools:** socio-demographic and medical data questionnaire; the adopted systemic lupus erythematosus disease activity index (SLEDAI) and lupus patient's self-care knowledge assessment test were used to collect data. **Results:** 45.0% of the study group and 46.7% of the control group are within age range between 20 < 30 years, 86.7% of the study group and 91.7 % of the control group were females. As for disease activity index scores; there was a significant statistical difference in SLEDAI between the study and control groups after implementing nursing instructional guide ($\chi^2 = 17.0$ $P = (0.001)$), also, there were highly statistically significant differences in self-care knowledge scores between the study and control groups at 3rd day and 3rd month after implementing nursing instructional guide ($\chi^2 = 91.7$ $P = 0.0001$), ($\chi^2 = 91.7$ $P = 0.0001$) respectively. Finally, there was a statistically significant negative relation between disease activity index and self-care knowledge ($r = -0.12$ $p = 0.17$). **Conclusion:** The self-care instructional guide had a significant effect on the improvement of patients with SLE self-care knowledge and lowering the disease activity state. **Recommendation:** regular implementation of instructional guidelines programs for patients with SLE to increase their knowledge and improve their quality of life.

Keywords: Systemic Lupus Erythematosus (Sle), Disease Activity, Self-Care Instructional Guide, Sledai, Autoimmune Disease.

INTRODUCTION

Systemic lupus erythematosus (SLE) is the most common form of a group of diverse, persistent autoimmune inflammatory diseases which is lupus erythematosus. It is characterized by autoantibodies production to nuclear and cytoplasmic antigens, multisystem inflammation, protean clinical manifestations, and a relapsing (flare-ups) and remitting course (Bartels, 2022). This disease may affect virtually any organ or structure of the body, especially the skin, kidneys, joints, heart, gastrointestinal tract, brain, and serous membranes (membranous linings of organs, joints, and cavities of the body). Also, it was observed that SLE has a global distribution affecting all races, gender and age groups (Center for Disease Control, 2022).

Systemic lupus erythematosus accounts for approximately seventy percent of all lupus patients. It frequently strikes women of childbearing ages 15 to 45 years, accounting for approximately more than ninety percent of SLE cases (Tennant, 2019). The exact cause of SLE is not known, but an extremely complicated and multifactorial interaction among various genetic, hormonal and environmental factors is probably involved (Spriggs & Herndon, 2020).

Systemic Lupus Erythematosus may also be precipitated or aggravated by certain triggers. It may include: being exposed to sunlight in peak time; being ill with an infection; having surgery; stopping the SLE medicines; stress; overwork; use of contraceptives that contain high dose of estrogen and being pregnant (Elsayed & Mesbah, 2018).

The presentations and course of SLE are highly variable, ranging from indolent to fulminant, depending on the organs affected, showing a wide spectrum of clinical manifestations. It has long been recognized that the majority of SLE patients experience alternative periods of active and inactive disease (Ogórek-Tęcza & Pych, 2018).

Disease activity refers to the manifestations of the underlying inflammatory process at a point in time in terms of magnitude and severity. Disease severity refers to the type and level of organ dysfunction and its consequences and is described as mild, moderate or severe, while, damage refers to the degree of irreversible organ dysfunction. Three patterns of disease activity have emerged: the flare (or “remitting relapsing pattern”), chronically active disease, or long quiescence. These patterns can be discerned using systematic clinical assessments, routine laboratory tests, and standardized measures of disease activity such as systemic lupus erythematosus disease activity index (SLEDAI) (Xie et al., 2018).

The nurse’s role will therefore be to undertake activities connected with the implementation of the physicians’s recommendations, especially during periods of SLE flare-ups, as well as to provide systematic health education concerning lifestyle changes that will condition better quality of life and reduce of the probability of subsequent relapses (Mary, Geetha, Sathiya & Rajeswari, 2021).

Self-care instructional guide is defined as written instructions on various aspects of SLE like definition, risk factors and signs and symptoms that aim to equip SLE patients with

practices to participate and take responsibility in their own care. To help patients to function optimally is through teaching the SLE patients how to deal with the disease symptoms, the warning signs of SLE flare-ups, and provide health education concerning lifestyle modifications, such as avoiding overexposure to sunlight, smoking cessation and eating a balanced diet, and undertaking physical activity adapted to the patient's fitness, as well as acquiring stress management skills (Mohamady, Srour & Saad, 2022). Therefore, this study aim is to evaluate the effect of self-care instructional guide on disease activity among patients with Systemic Lupus Erythematosus.

SIGNIFICANCE OF THE STUDY

Systemic Lupus Erythematosus is a devastating and life-changing disease associated with significant mortality, morbidity and cost for the individual patient and society. The Lupus Foundation of America (LFA) estimates that 1.5 million Americans, and at least five million people worldwide, have a form of lupus with an incidence of 16,000 new cases per year. It was also found that lupus was among the top 20 leading causes of death in females between the ages of 25 to 64 (Tennant, 2019). The Medical Reports and Statistical Data delineated that the average number of patient with SLE admitted to the Rheumatology and Rehabilitation Department at the study setting of Cairo University, affiliated hospital in Egypt were 396, 415, 431, 460 in the years 2015, 2016, 2017, 2018 respectively (Statistics & Medical Records Department, 2019).

A recent analysis revealed an estimated 400,000 new diagnoses of SLE worldwide annually, and an overall global incidence of 5.14 diagnoses per 100,000 person-years. In terms of prevalence, the overall estimated affected population was 3.41 million people, or 43.7 cases per 100,000 persons (Kaltwasser, 2022).

Center for Diseases Control and Prevention (CDC) (2019) work with national organizations to raise awareness, increase knowledge and enhance the skills of patients with SLE and their health care providers. It is the intent of this study to provide sets of instructions to enable patients with SLE for self-care management that may improve quality of life and disease outcomes. The findings of this study may contribute some evidence based data to help nurses to integrate it in the care of patients with Systemic Lupus Erythematosus. Data derived from this study may open scientific channels for further qualitative and quantitative studies in this field.

AIM OF THE STUDY

The aim of the study is to evaluate the effect of self-care instructional guide on disease activity among patients with systemic lupus erythematosus.

Research Hypotheses

To achieve the aim of the study, the following hypotheses were postulated to be tested:

- H₁:** There will be a difference in the mean scores of the Systemic Lupus Erythematosus Disease Activity Index (SLEDAI) in patients who received self-care instructional guide than the control group.
- H₂:** There will be a difference in the mean scores of the Lupus Patient's Self-Care Knowledge Assessment Test in patients who received self-care instructional guide than the control group.
- H₃:** There will be a correlation between the Systemic Lupus Erythematosus Disease Activity Index (SLEDAI) and the Lupus Patient's Self-Care Knowledge Assessment Test in patients who received self-care instructional guide than the control group.

SUBJECT AND METHODS

Research Design

Non-Equivalent pretest-posttest time series control group design was used to achieve the aim of the current study.

Schematic representation of research design

Group	Pre assessment	Intervention	Post assessment1	Post assessment 2
Group 1	O1	X1	O2	O3
Study group				
Group2	O1	-	O2	O3
Control group				

Key:

O1. Pre- intervention scores of patient's self-care knowledge assessment test, Lupus PRO and SLEDAI for both groups.
X1. Self-care instructional guide (Intervention) and routine hospital care.
O2. Post-intervention scores of Lupus Patient's Self-Care Knowledge Assessment Test for both groups.
O3. Post-intervention scores of Lupus Patient's Self-Care Knowledge Assessment Test, Lupus PRO and SLEDAI for both groups.

Setting

The study was conducted at the rheumatology and rehabilitation department in one of Cairo University affiliated hospitals, Egypt.

Sample

A convenient sample of 120 conscious adult male or female patients with a confirmed diagnosis of systemic lupus erythematosus since at least one year earlier were recruited as the study sample. The patients were selected in accordance with an inclusion criteria of being within the age range of 20 to 55 years, not in acute flare-ups, able to communicate and agree to participate in the study. The study sample was divided into two groups of 60 patients each; the first group constituted the study group who received the self-care instructional guide in addition to routine hospital care and the second group

constituted the control group who received only the routine hospital care. The patients who were not willing to participate in the study or those having cognitive impairment were excluded.

TOOLS FOR DATA COLLECTION

The data was collected through using three tools including:

1. Socio-Demographic and Medical Data Questionnaire. This tool was developed by the researcher which is divided into two parts as follows:

Part one (socio-demographic data). Covering the personal data related to age, gender, marital status, work status, level of education, place of residence, financial resource, income and number of family member's patient is living with.

Part two (Medical Data). This part includes patient's medical related data such as date of admission, duration of the disease, family history of SLE, number of SLE flare-ups per three months before and after implementing nursing instructional guide, hospital admission per three months before and after implementing nursing instructional guide, follow-up visits compliance, reasons for non-compliance and patient's information regarding medications.

2. Systemic Lupus Erythematosus Disease Activity Index (SLEDAI). This tool was adopted to be used in this study. It was originally developed by Bombardier, Gladman, Urowitz, Caron & Chang, (1992). It is a clinical index for the assessment of lupus disease activity in the preceding ten days that measures potentially reversible manifestations of the underlying inflammatory disease process by weighting the importance of each organ system involved. It was used as a part of regular medical assessment to follow-up all patients with SLE admitted to the study setting. Therefore, the data derived from this tool was integrated into the data of this study.

Scoring System. SLEDAI has 24 weighted clinical and laboratory variables of nine organ systems affected by SLE. The scores of the descriptors range from 1 to 8, and the total possible score for all 24 descriptors is 105. For every organ, score points were calculated. Points were based on a "weighted" index for lupus disease activity with 8 points for central nervous system and vascular system including (seizure, organic brain syndrome, psychosis, visual disturbance, cranial nerve disorder, lupus headache cerebrovascular stroke and vasculitis); 4 points for renal and musculoskeletal systems including (urinary casts, hematuria, proteinuria, pyuria, arthritis and myositis); 2 points for serosal, dermal and immunologic systems including (mucosal ulcers, pleurisy, pericarditis, new rashes, alopecia, low complement and increased DNA) and 1 point for constitutional and hematological including (fever, thrombocytopenia and leucopenia).

The points were assigned if the descriptor was present at the time of the patient visit or within the preceding 10 days, SLEDAI score = Sum of score points of 24 descriptors with minimum score = 0 and maximum score = 105. The score grading for SLEDAI include: 0

= no activity; 1-10 = mild; 11-20 = moderate; 21-45 = severe and more than 45 = very severe activity.

3. Lupus patient's self-care knowledge assessment test. This tool was developed by the researcher to assess general knowledge of patients with SLE and the influence of educational exposure on knowledge level. It is divided into three parts as follows:

Part One (warning signs of SLE flare-ups). This part inquires the patients about the warning signs of SLE flare-ups; which includes four signs: skin rashes, persistent fatigue or pain, weight loss and fever.

Part Two (precipitating factors of SLE flare-ups). It include 10 inquiries to the patients about the precipitating factors that must be avoided to decrease the activity of SLE disease (flare-ups): it includes ten questions which are; exposure to direct sunlight, wearing sunscreen, sudden discontinuation of medications ...etc.

Part Three (lifestyle modification). In this part the patients with SLE were asked about the life-style modifications that help them to cope with their disease. It includes fourteen questions related to adherence to the prescribed diet; deep breathing exercises as a mean of stress reduction; weight control; smoking cessation; importance of regular check-ups and adherence to prescribed medications.....etc.

Scoring System. The questionnaire include three parts divided to 28 agree/disagree questions, each question scores by (0 or 1), (0) means that; the patient disagree with the sentence while (1) meaning that; the patient agree with the sentence, the total scores are divided to two categories as follows, more than 80 – 100% (22.5 – 28 score) it means that; the patient's level of knowledge was satisfactory and 80% or less (less than 22.5 score) it means that; the patient's level of knowledge was unsatisfactory (Elaydi, Hassanin, Salama and Elwasif, 2019). The critical points on the questions related to the warning signs of lupus flare and its precipitating factors and medications adherence.

VALIDITY AND RELIABILITY

Face and content validity of the study tools were tested to identify the degree to which the developed tool measured what it is supposed to be measured, it reviewed by a panel of five expert faculty members in the field of Medical-Surgical Nursing faculty of nursing, Cairo University. The experts were asked to examine the instruments for content coverage, clarity, wording, length, format, and the overall appearance. Reliability of tools was tested statistically using test-retest reliability to measure the consistency of results when repeating the same tools on the same sample at a different point in time. Test-retest reliability for SLEDAI was 0.82, for Lupus PRO was 0.85 and for lupus patient's self-care Knowledge assessment test was 0.7.

Pilot Study

A pilot study was conducted on 10 percent of the study sample with the same inclusion criteria to ensure the feasibility and internal consistency of the study tools, and to

determine the time required to fill out the sheets. This is in addition to determine any possible problems in the methodological approach. Patients selected for the pilot study were excluded from the study sample.

Description of the Self-Care Instructional Guide

Self-care instructional guide was designed to meet patient's needs and to fit into their interest and levels of understanding. Its content was prepared based on the Lupus United Kingdom (Lupus UK) guidelines (2015); Brazeir (2018).

Content of Self-Care Instructional Guide. It consists of four parts. The instructional content was exclusively represented regarding: first part includes definition, causes and nature of SLE. Second part includes definition of SLE flare-ups and the warning signs of SLE flare-ups. Third part includes all the precipitating factors that need to be avoided to decrease the activity of SLE and the measures that help patient to deal with each problem. Finally, fourth part includes the life-style modifications such as: adherence to light range of motion exercises, deep breathing exercises as a means of stress reduction, prescribed diet and weight control, adherence to the prescribed medication, smoking cessation, emphasizing the importance of regular check-up and general tips for dealing with the physician treatment plan. The self-care instructional guide was developed in Arabic languages.

Methods of Instruction: All patients in study group received the same intervention using the same teaching methods, including: small teaching session followed by feedback from the patient and responding to their questions.

Media for Instruction: Using illustrated booklet.

ETHICAL CONSIDERATION

A written initial approval was obtained from the Research and Ethics Committee of the Faculty of Nursing - Cairo University (November, 2019). Also, an official permission was obtained from hospital/Rheumatology and Rehabilitation Department chief administrator to conduct the study. A written informed consent was obtained from each patient after explaining the nature and purpose of the study. The researcher emphasized to patients that, participation in the study was entirely voluntary and anonymity and confidentiality of the data would be assured. Patients were assured that no subsequent publication will be made without their permission. On completion of data collection, a written final approval was obtained from the Ethics and Research Committee of the Faculty of Nursing - Cairo University (October, 2022).

Procedure

Once permission to conduct the current study was obtained from appropriate authoritative personnel, the researcher initiated data collection. The data collection was conducted throughout four phases; assessment, planning, implementation, and evaluation.

- 1. Assessment or initial phase.** It involved preparing the tools for data collection after reviewing the literature dating back for at least 5 years using scientific data base. Besides ensuring the accessibility of patients, the setting as well as facilities needed to perform the proposed study. Also the researcher decided on the study design, sample size and select the appropriate tools to collect pertinent data of the study.
- 2. Planning phase.** Based on the outcome of the previous phase, the final format of the study tools as well as the patient's self-care instructional guide were developed based on the related recent review of literature and evidences.
- 3. Implementation phase.** It was carried out after obtaining the official permissions, the researcher contacted the patients in the selected setting 2-3 times/week. The researcher conducted an initial meeting with the patient for 10 minutes after the patient's condition was stabilized and was able to communicate (2-3 days after admission). The researcher introduced herself to each patient, to explain the nature of the study and obtained a written consent from the patients who met the inclusion criteria and were willing to participate in the study. Then; each patient was approached individually for 30-45 minutes by the researcher (in the same day of the initial agreement). The data was collected first from the control group and then from the study group.

Firstly, the data was collected from the patients of the control group by the researcher in the second day of hospital admission by using Socio-Demographic and Medical Data Questionnaire, and Lupus patient's self-care knowledge assessment test. In addition, the researcher obtained the scores of SLEDAI from patient's file or from the attending physician. After that, those patients were exposed to the hospital routine care. While, the first post assessment was done after three days, by using the Lupus patient's self-care knowledge assessment test only for knowledge retention.

Secondly, after finishing data collection from control group, the researcher started to select and assess subjects of study group and implemented the designed self-care instructional guide and collect related data by using all the study tools. The study group patients were approached individually for 30- 45 minutes in each session. Three instructional sessions were conducted on three consecutive days from the initial meeting during the hospital stay. The first session was conducted in the third day of hospital admission, while the second and third sessions were carried out in the fourth and fifth day respectively.

During the first instructional session the researcher instructed patients/caregivers regarding the SLE-definition, nature of SLE, causes, definition of SLE flare-ups, the warning signs of SLE flare-ups and its precipitating factors that need to be avoided. At the end of the first instructional session, each patient was given a copy of self-care instructional guide to be followed. The second instructional session included following lifestyle modification: adherence to the prescribed diet, weight control, smoking cessation and sleep.

Whereas, in the third session, the researcher instructed the patients about deep breathing exercises as a means of stress reduction and light range of motion exercises as well as emphasizing the importance of regular check-up and adherence to the prescribed medication. During each session, the researcher gave break time according to patients' needs and teaching media such as visual materials was used to facilitate the understanding of the information given for the patients/caregivers.

At the beginning of each instructional session the researcher revised the content of the previous session with the patient/caregiver to ensure patient's understanding and implementing nursing instructions. Patients and their caregivers were given the opportunity to ask questions which need to be answered or clarified. It is noteworthy to mention that the caregivers for the patients were intended to be facilitators for the patient learning of the instructional material.

The researcher followed patients by the telephone in the third day from the initial interview and after three months to reinforce implementation of nursing instructions. Data collection phase was conducted over a period of one and half year starting from February 2021 to August 2022 in the rheumatology and rehabilitation department. Finally control group was informed with the nursing instructions at the end of their assessment to maintain justice.

Evaluation phase. Pre assessment was carried out in the second day of hospital admission for the purpose of having baseline data for both control and study group. Two post-assessments were carried out; the first post assessment was carried out for the study and control group at the end of the third instructional session by using Lupus patient's self-care knowledge assessment test. While, the second post assessment was carried out for the study and control groups after three months from the baseline assessment data, using the SLEDAI, and Lupus patient's self-care knowledge assessment test.

The rationale behind making the post assessment after three months was that the medications the patients were receiving modulate the immune system (primarily corticosteroids and immunosuppressants) took at least three months to control the disease and prevent recurrence of symptoms known as SLE flares-ups (Gatto, Zen, Iaccarino & Doria, 2018). The collected post assessment scores were analyzed and compared statistically to evaluate the effect of self-care instructional guide on disease activity among patients. The pre assessment and the first post assessment were carried out during hospitalization, while the second post assessment was carried out during follow up visits at the Rheumatology and rehabilitation department.

Data Analysis

Collected data was tabulated, computed, and analyzed using statistical package for the social sciences (SPSS) program version 23 (Wagner III, 2019). Descriptive statistics including frequency distribution, percentage and means as well as inferential statistics as

Pearson's coefficient correlations, t-tests, were used to examine the relationships between variables. The alpha level of .05 was used for all tests of significance.

RESULTS

Table (1) presents that 45.0% of the study group and 46.7% of the control group are within age range between 20 < 30 years, with the mean age of 31.41± 7.65 and 31.1± 8.64 years respectively, 86.7% of the study group and 91.7 % of the control group were females, meanwhile 71.7 % of the study group and 56.7 % of the control group were single. There were no statistically significant differences between the two groups regarding age, gender and marital status.

Table 1: Frequency and Percentage Distribution of Demographic Characteristics among the patients in Study and Control Groups (N = 120)

Variables	Study group		Control group		X2	p
	(n= 60)		(n= 60)			
	No	%	No	%		
Age						
- 20 <30	27	45	28	46.7	1.8	0.39 NS
- 30<40	21	35	15	25		
- 40≤55	12	20	17	28.3		
Mean± SD	31.41± 7.65		31.1± 8.64			
Gender						
- Male	8	13.3	5	8.3	0.77	0.37 NS
- female	52	86.7	55	91.7		
Marital status						
- Married	12	20	14	23.3	4.2	0.24 NS
- Single	43	71.7	34	56.7		
- Divorced	3	5	6	10		
- Widow	2	3.3	6	10		

NS= Not Significant

*significant at p-value<0.05

Table (2) reveals that the majority of both patients in the study and control groups are housewives, 56.7% of the study group had post-secondary education and 41.7 % of the control group had secondary education. In relation to the residence equal percentage of 50% of the study group live in urban and rural areas while 65% of the control group live in urban areas. There were statistically significant differences between the two groups regarding work status

Table 2: Frequency and Percentage Distribution of Demographic Characteristics among the patients in Study and Control Groups (N= 120)

Variables	Study group (n= 60)		Control group (n= 60)		X2	p
	No	%	No	%		
	Work status					
- Working full-time	0	0	3	5	17.7	0.001*
- Working part-time	21	35	5	8.3		
- Unemployed	0	0	4	6.7		
- Housewife	35	58.3	43	71.7		
- Student	4	6.7	5	8.3		
Level of education						
- University	14	23.3	5	8.3	9.8	0.13
- Post secondary	34	56.7	3	5		NS
- Secondary	6	10	25	41.7		
- Primary education	6	10	5	8.3		
- Can read and write	0	0	12	20		
- Can't read and write	0	0	10	16.7		
Place of residence						
- Urban	30	50	39	65	2.7	0.09
- Rural	30	50	21	35		NS

NS= Not Significant *significant at p-value<0.05

Table (3) shows that 55% of the study group and 48.3% of the control group depend financially on their husbands. Both groups reported that their income is not enough to cover neither family needs nor covering the cost of their medications. In addition 50% of the study group have a family size of 4-6 members and 65% of the control group have a family size of 1-3 members. There were no statistically significant differences between the two groups regarding the financial status.

Table 3: Frequency and Percentage Distribution of Demographic Characteristics among the patients in Study and Control Groups (N = 120)

Variables	Study group (n= 60)		Control group (n= 60)		X2	p
	No	%	No	%		
	Financial source					
- Parents	13	21.7	18	30	9.6	0.2 NS
- Husband	33	55	29	48.3		
- Brother	2	3.3	1	1.7		
- Stepfather	3	5	0	0		
- Uncle	1	1.7	1	1.7		
- No financial source	0	0	1	1.7		
- one self	8	13.3	6	10		
- Pensions	0	0	4	6.7		
Income						

- Enough	3	5	1	1.7	0	1
- Not enough	57	95	59	98.3		
Number of family members living with						
-4	27	45	39	65	4.8	0.08
-10	30	50	19	31.7		
-17	3	5	2	3.3		

NS= Not Significant *significant at p-value<0.05

Figure (1) displays that more than one third of both patients in the study and control groups have SLE duration from 5<10 years. In addition, there was no statistically significant difference between both groups as ($\chi^2 = 9.0, P = 0.1$).

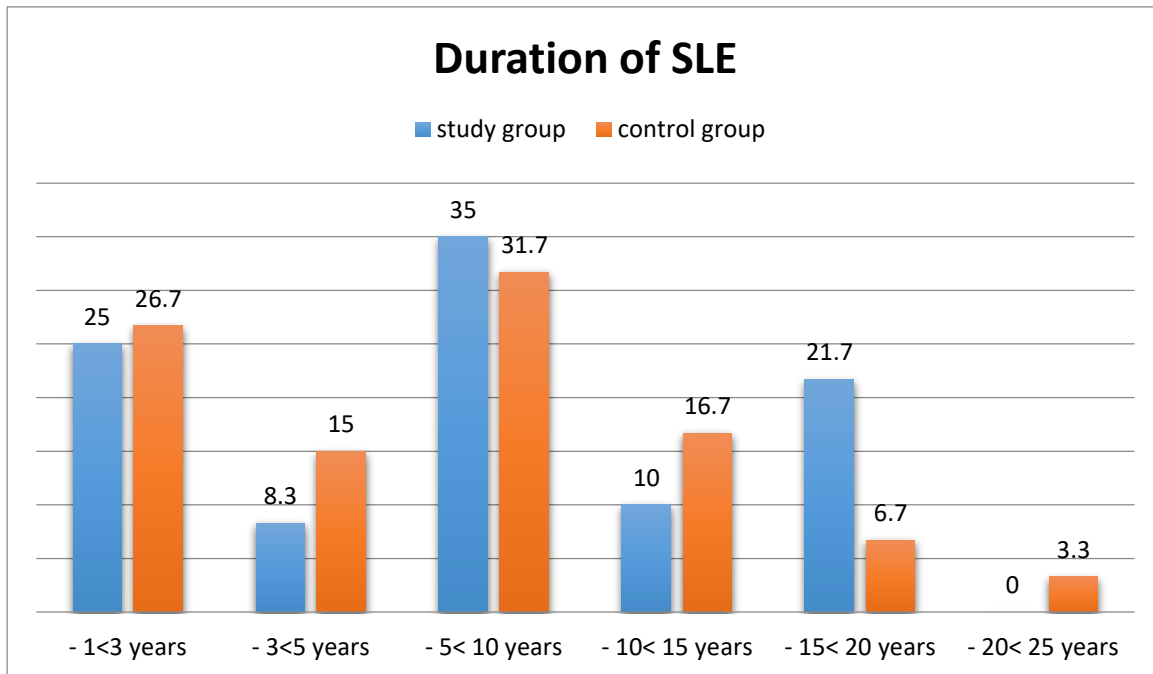


Figure1: Percentage distribution of systemic lupus erythematosus (SLE) duration among the study and control groups (N = 120)

Table (4) emphasizes that the majority of both patients in the study and control groups have no family history of SLE. While there was 13.3% of the study group have a family history of SLE in the second degree relative. However, 8.3% of the control group have a family history of SLE in the third degree relative. Finally, there were no statistically significant differences between the two groups regarding the family history.

Table 4: Frequency and Percentage Distribution of family history among the patients in Study and Control Groups (N = 120)

Variables	Study group		Control group		X2	p
	(n= 60)		(n= 60)			
	No	%	No	%		
Family history of SLE						
Yes	9	15	10	16.7	0.06	0.8
No	51	85	50	83.3		NS
Related family history						
- First degree	0	0	1	1.7	4	0.26
- Second degree	8	13.3	4	6.7		NS
- Third degree	1	1.7	5	8.3		

NS= Not Significant *significant at p-value<0.05

Table (5) illustrates that 63.3 % of the study group and 46.7% of the control group had suffered from SLE flare-ups once in the three months prior to implementing the instructional guide. While 45% of the study group and 18.3% of the control group did not suffer from SLE flare-ups in the three months after implementing the instructional guide. But 36.7% of the control group had suffered from SLE flare-ups once in the three months after being subjected to hospital routine care. There were a statistically significant differences between the two groups regarding frequency of SLE flare-ups after implementing the instructional guide.

Table 5: Frequency and Percentage Distribution of the frequency of SLE flare-ups among the patients in Study and Control Groups (N =120)

Variables	Study group		Control group		X2	p
	(n= 60)		(n= 60)			
	No	%	No	%		
Number of SLE flare-ups per three months prior the instructional guide						
- No flare-ups	3	5	3	5	5.8	0.44
- Once	38	63.3	28	46.7		
- Twice	2	3.3	4	6.7		
- Three times	0	0	1	1.7		
- Four times	4	6.7	3	5		
- All the time	13	21.7	21	35		
Number of SLE flare-ups per three months After the instructional guide						
- No flare-ups	27	45	11	18.3	21	0.001*
- Once	21	35	22	36.7		
- Twice	4	6.7	12	20		
- Three times	0	0	3	5		
- Four times	2	3.3	10	16.7		
- All the time	6	10	2	3.3		

NS= Not Significant *significant at p-value<0.05

Table (6) exhibits that 50 % of the study group and 38.3% of the control group were admitted to the hospital due to SLE flare-ups once in the three months prior to implementing the instructional guide. While, 86.7% of the study group and 65% of the control group were not admitted to the hospital due to SLE flare-ups in the three months after implementing the instructional guide. There were no statistically significant differences between the two groups regarding frequency of hospital admission respectively.

Table 6: Frequency and Percentage Distribution of the frequency of hospital admissions because of SLE flare-ups among the patients in Study and Control Groups (N=120)

Variables	Study group		Control group		X2	p
	(n= 60)		(n= 60)			
	No	%	No	%		
Hospital admission per three months prior implementing the instructional guide						
- No hospital admission	29	48.3	28	46.7	7.3	0.02
- Once	30	50	23	38.3		
- Twice	1	1.7	9	15		
Hospital admission per three months after implementing the instructional guide						
- No hospital admission	52	86.7	39	65	8.7	0.01
- Once	8	13.3	18	30		
- Twice	0	0	3	5		

NS= Not Significant *significant at p-value<0.05

Table (7) denotes that 65% of the study group and 76.7% of the control group were committed to the medical follow-up visits; however, 21.7% of the study group and 5% of the control group were not committed to the medical follow-up visits because of the long distance between the hospital and their homes. Concerning patient's information regarding medications 63.3% of the study group and 68.3% of the control group had adequate information regarding their medications. There were no statistically significant differences between the two groups regarding medical follow-up compliance and patient's information regarding medications.

Table 7: Frequency and Percentage Distribution of follow-up compliance and patient's information regarding medications prior the instructional guide among the patients in Study and Control Groups (N=120)

variables	Study group		Control group		X2	p
	(n= 60)		(n= 60)			
	No	%	No	%		
Medical follow up visits compliance						
- Yes	39	65	46	76.7	4.4	0.03
- no	26	35	14	25		
Reasons for non-compliance						
- Poor health status	0	0	1	1.7		
- Financial costs	6	10	6	10		
- Long distance between hospital and home	13	21.7	3	5		
- Poor psychological state	2	3.3	4	6.7		
Patient's information regarding medications						
- Adequate	38	63.3	41	68.3	0.33	0.56
- Inadequate	22	36.7	19	31.7		

NS= Not Significant *significant at p-value<0.05

Table (8) illustrates that there were a statistically significant differences in systemic lupus erythematosus disease activity index between the study and control groups after implementing nursing instructional guidelines.

Table 8: Comparisons between the Study and Control Groups Regarding Total Mean Scores of systemic lupus erythematosus Disease Activity Index Scores along the Study Period (N=120)

Disease activity index	Prior to the instructional guide/ Routine hospital care				At 3 rd month			
	Study		Control		Study		Control	
	(n= 60)		(n= 60)		(n= 60)		(n= 60)	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
mild	9	15	13	21.7	30	50	13	21.7
moderate	34	56.7	23	38.3	23	38.3	22	36.7
severe	15	25	22	36.7	7	11.7	24	40
Very severe	2	3.3	2	3.3	0	0	1	1.7
X2/P	4.1 (0.24)NS				17.0 (0.001*)			

NS= Not Significant *significant at p-value<0.05

Table (9) shows that the majority of both patients in the study and control groups had unsatisfactory level of self-care knowledge before implementing the instructional guide versus hospital routine care. After the 3rd day and 3rd month of the instructional guide 100 % of the study group and 13.3 % of the control group had satisfactory level of self-care

knowledge. After implementing the instructional guide there were a highly statistically significant differences in self-care knowledge between the study and control groups at 3rd day and 3rd month intervals.

Table 9: Comparisons between the Study and Control Groups Regarding Total Mean Scores of Lupus Patients Self-Care Knowledge Scores along the Study Period (N=120)

	Prior the instructional guide/ Hospital routine care				At 3 rd day				At 3 rd month			
	Study (n= 60)		Control (n= 60)		Study (n= 60)		Control (n= 60)		Study (n= 60)		Control (n= 60)	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Self-care knowledge	52	86.7	52	86.7	0	0	52	86.7	0	0	52	86.7
Unsatisfactory	8	13.3	8	13.3	60	100	8	13.3	60	100	8	13.3
Satisfactory	0.0 (1.0) NS				91.7 (0.0001*)				91.7 (0.0001*)			
X2/P												

NS= Not Significant

*significant at p-value<0.05

Table (10) shows that there were no statistically significant differences in self-care knowledge and disease activity index between the study and control groups prior to implementing the instructional guide versus hospital routine care. Meanwhile, there were statistically significant differences in self-care knowledge and disease activity index between the study and control groups at the 3rd month after implementing the instructional guide.

Table 10: Comparisons between the Study and Control Groups Regarding Total Mean Scores of lupus patient Self-Care Knowledge, and disease activity index Scores along the Study Period (N=120)

Items	Prior to the instructional guide/ Hospital routine care			At 3 rd day			At 3 rd month		
	Study (n= 60)	Control (n= 60)		Study (n= 60)	Control (n= 60)		Study (n= 60)	Control (n= 60)	
	Mean ± SD	Mean ± SD	t/p	Mean ± SD	Mean ± SD	t/p	Mean ± SD	Mean ± SD	t/p
	Self-care knowledge	17.93±4.13	18.70±3.84	0.74(0.45) NS	27.4±1.8	19.0±3.46	11.7(0.000*)	27.0±1.5	19.1±3.4
Disease activity index	16.87±9.50	19.85±1.08	1.13(0.26) NS	-	-	-	12.5±7.5	18.9±9.86	2.8(0.007*)

NS= Not Significant

*significant at p-value<0.05

Table (11) affirms that there was a statistically significant relation between disease activity index and self-care knowledge, which means that, when patients with SLE have satisfactory level of self-care knowledge will have low disease activity.

Table 11: Correlations Between the Study and Control Groups Regarding Total Mean Scores of Lupus Patients Self-Care Knowledge and disease activity index Scores along the Study Period (N=120)

Variables	Self-care knowledge	
	r	p
- Disease activity index	-0.12	0.17

NS= Not Significant *significant at p-value<0.05

Table (12) illustrates that there were statistically significant improvement between study and control group in self-care knowledge and disease activity index scores in relation to the frequency of SLE flare-ups.

Table 12: Comparisons Between the Study and Control Groups Regarding Total Mean Scores of Lupus Patients Self-Care Knowledge and disease activity index Scores in relation to the frequency of SLE flare-ups along the Study Period (N=120)

SLE flare-ups	Self-care knowledge		Disease activity index	
	Mean	SD	Mean	SD
- no flare-ups	18.71	4.2	15	6.33
- once	17.49	3.31	15.95	7.47
- twice	18.38	3.79	22.69	7.99
- three times	14.67	2.89	20	3.46
- four times	17.17	3.97	24.67	12.51
- all the time	23.88	2.3	28.5	23.02
ANOVA/p	4.9 (0.0001*)		5.0 (0.0001*)	

NS= Not Significant *significant at p-value<0.05

DISCUSSION

Systemic lupus erythematosus (SLE) is an episodic, chronic, multisystem, autoimmune disease characterized by widespread inflammation of blood vessels and connective tissue (Thanou et al, 2021). There is no cure for lupus, but medical interventions and lifestyle modifications can help control it. The seriousness of SLE can range from mild to life-threatening. Patients with SLE who get proper medical care and education can significantly lower disease activity and improve quality of life (CDC, 2022). So, this study is conducted to evaluate the effect of self-care instructional guide on disease activity among patients with systemic lupus erythematosus.

Section I: Demographic and Medical Data

Regarding to the studied patients' demographic characteristics, the results of the current study revealed that, less than fifty of the study and control group were within the age range between twenty to less than thirty years with mean age of 31.41 ± 7.65 and 31.1 ± 8.64 years respectively. As documented by various scientific references that the peak onset of SLE is between the ages of 20 and 30 years (Thomas & Jawad, 2022). The

current study findings is in the same line with the center of disease control (CDC) report (2022), which illustrated that SLE occurs most frequently between the ages of 15 and 45, with the average age of onset at 30 years.

Likewise, a study of Gheita, et al. (2021) about the epidemiology, clinical manifestations and treatment pattern of SLE in Egypt, found that the median age of studied patients was 30 years. Also, a study done by Elsaid, Niazy, Elgengehy & Mohamed (2021), pointed out that the mean age of the studied patients was 32.3 ± 9.1 years. However a study by Gaballah & El-Najjar (2019) reported a somehow higher age value that the mean age of the patients was 36.9 ± 14.1 years.

As regards to gender the current study showed that female represented the most predominant gender of the patients in study and control group. This finding was supported by the recent studies and literatures which suggested that the higher prevalence of SLE in female gender is due to the effect of estrogen on the immune system, leading to hormonal changes which are considered as the main risk factor of SLE [Thomas & Jawad, (2022); Vergnaud, (2021)]. In the same line, Zhang et al. (2019); Mahmoudi et al. (2021); Dadwal, Pathak, Subbiah and Dahiya (2023) stated that most of the studied patients were females.

As for marital status the current study found that less than three quarters of the study group and more than half of the control group were single, and one possible explanation for these findings might be that those patients experienced SLE before being married, besides the complexity of the disease in manifestation and side effects of medication make them difficult to be married. This finding is not consistent with Sedrak et al. (2020); Mohamady, Srour and Saad (2022) who denoted most of the studied patients were married.

As regard to working status and level of education; the current study found that most of study and control group were housewives. More than half of the study group had post-secondary education while less than half of the control group had secondary education these findings were partly supported with a study by El-Zayat, El-Kattan and Hassan (2022) in Egypt, which clarified that more than half of studied patients had secondary education and less than half of them were employed. Furthermore, the Canadian study conducted by Ugarte-Gil et al. (2023) reported that health related quality of life (HRQoL) in patients with SLE is influenced by the patient's educational level.

Concerning the place of residence, the study revealed that fifty percent of the study group were living in urban and rural areas, while two thirds of the control group were living in urban area. This finding is congruent with Mohamady, Srour and Saad (2022) who clarified that more than half of the studied patients were living in rural areas. In contrast, this finding is not supported by Yousef, Abd El-Azeez, Gomaa, & Ameen (2018); Mary, Geetha, Sathiya and Rajeswari (2021), who reported that the Majority the studied patients were living in rural area.

The current study showed that more than half of the study group and less than half of the control group depend financially on their husbands. Also, the majority of the study group and control group reported that not having enough income to cover family needs nor the financial ability to cover the cost of their medications. From the researcher's point of view these finding indicate the socio-economic state of those patients makes it somehow difficult to cover the life-long high expenses of medications which need to be continued for the proper disease management to avoid the untoward consequences of SLE such as flare-ups, which result in poor patients' outcomes. This finding was supported with Rizk, EL-Bastawesy and Hegy (2020) who revealed that two thirds of the studied patients were from rural areas and have not enough monthly income. This finding is not matched with a study by Ratanasiripong, Cahill, Crane and Ratanasiripong (2023) in Thailand which mentioned that the majority of studied patients reported that they had either sufficient income or savings, while one third of them did not have sufficient income. This difference might be due to the variations in the studied population society.

As regards to duration of disease, the current study findings exhibited that around one third of the study and control group had five to less than ten years duration. The researcher expected that increase duration of SLE, the patient is at risk for many complications in different body organ, besides the chronic nature of the disease. So, patients with SLE need long term follow-up to live better quality of life. This finding is partly in agreement with a study by Sedrak, Mohamad, Abo-EINoor and Abd-Elall (2020) which showed that the majority of patients with SLE had duration that ranged around one to five year. Moreover, the Egyptian study conducted by Behiry, Salem and Alnaggar (2019) stated that there was a weak positive significant correlation between disease duration and disease activity.

Regarding family history of systemic lupus erythematosus, the current study revealed that the majority of the study and control group have no family history of SLE. This finding is in the same line with Mary, Geetha, Sathiya and Rajeswari (2021); Mohamady, Srour and Saad (2022), who reported that almost all of the studied patients have no family history of SLE.

The current study denoted that more than half of the study group and less than half of the control group had suffered from SLE flare-ups once in the three months before implementing the instructional guide versus hospital routine care. While less than half of the study group and less than one third of the control group did not suffer from SLE flare-ups in the three months after implementing the instructional guide. The researcher might argue this point based on patients reports that the recurrence of SLE flare-ups was occur, because they have no financial assets to cover the cost of their prescribed medications and poor psychological condition that result from the large number of medications, which reach 16-24 pills per day leading to skipping the intake of medications suddenly till they manage to have access for money which was considered as one of the factors that triggers the SLE flare-ups. So, these patients need to nursing instructions to increase their awareness to cope with the unpredictability of SLE.

This finding is matched with Mohammed, Maaty, Shahin, Abo El-ata and Mohammed (2018) who conducted study entitled "Effect of Self-Management Guidelines on Health Outcomes for Patients with SLE" which indicated that SLE occurs in often unpredictable flares-ups, with alternating low and high disease activity. Good self-management is essential to managing SLE; as patients with SLE can improve their prognosis by learning about many aspects of the illness as well as closely monitoring their own health with their care providers.

In the current study more than half of the study group and more than two thirds of the control group reported their commitment to the medical follow-up visits. As well, patient's knowledge regarding medications was reported by more than half of the study and control group. This finding is in accordance with Sakr, Seif, Kamel and Eleishi (2022), who concluded that integration of a psycho-educational program in the management of patients with SLE was associated with improvement of quality of life, satisfaction with treatment, and medication adherence.

In the current study fifty percent of the study group and thirty eight percent of the control group were admitted to the hospital because of SLE flare-ups once in the three months before implementing the instructional guide versus hospital routine care. This percentage was markedly decreased after implementing the instructional guide. Based on the medical records of the study setting, most of patients with SLE suffer from repeated hospitalization because of the recurrence of SLE flare-ups (higher disease activity) and one hospital stay may range from one to three weeks in the study group, while the control group one hospital stay may range from one to six weeks, which reflect traumatic impact on patients (social, psychological, physiological, and economic aspects of their lives) as well as being a burden on the healthcare services. These findings were matched with the Egyptian study conducted by Kotb, Khalad and Moghazy (2023), which indicated that less than one third of patients with SLE were hospitalized, and concluded that SLE flare-ups was the most common cause of hospitalization among the studied patients with SLE.

Section II: Results Related to Study Hypotheses Covered total mean scores of SLE disease activity index (SLEDAI) and lupus patient self-care knowledge

As regards to mean scores of systemic lupus erythmatosus disease activity index (SLEDAI), the current study results illustrated that the mean scores of SLEDAI of the study and control group were (34±56.7, 23±38.3) respectively, which is evaluated as moderate disease activity before implementing the instructional guide. Also, the mean scores of SLEDAI of the study and control group were (30±50.0, 13±21.1) respectively, which is evaluated as mild disease activity after implementing the instructional guide. Moreover, there was a highly statistically significant improvement regarding all SLEDAI items after implementing the instructional guide.

Based on the above data, this finding supported the first research hypothesis which was stated as "There will be a difference in mean scores of the Systemic Lupus Erythematosus Disease Activity Index (SLEDAI) in patients who received self-care

instructional guide than the control group". This could reflect the importance of self-care instructional guide in lowering the disease activity state for patients with SLE. Also, the researcher viewed that the studied patients may be motivated to continue to follow the instructional guide.

This finding is in agreement with Maheswaranathan et al. (2021); Katz et al. (2021), who indicated that limited health literacy is relatively common in SLE and likely contributes to worse lupus-related outcomes, including disease activity and patient-reported outcomes. However, Fortin et al. (2022) who conducted study entitled "Challenges of perceived self-management in lupus" reflected a different view based on analyzing their study findings that when disease activity is low, people with SLE may be less motivated to continue to follow self-care strategies and increase their use when the disease is more active. Also, this study finding is not in accordance with Sakr, Seif, Kamel and Eleishi (2022), who concluded that integration of a psycho-educational program in the management of patients with SLE had no impact on disease activity.

Concerning self-care knowledge about SLE, the majority of the study and control group had deficient knowledge about their disease before implementing the instructional guide versus hospital routine care. This may be due to unavailability of educational programs to equip SLE patients with required information about the disease. After implementation of the instructional guide, there were improvement in the mean scores and standard deviation of studied patients' knowledge regarding SLE at third day and third month with statistically significant differences between pre and post intervention. Based on the above data, this finding supports the second research hypothesis which is stated as "There will be a difference in mean scores of the Lupus Patient's Self-Care Knowledge in patients who received self-care instructional guide than the control group".

The researcher might justify this result as most of the studied patients had unsatisfactory level of knowledge especially regarding the warning signs of SLE flare-ups, exposure to sunlight, performing deep breathing and light range of motion exercises. It could be due to some of those patients did not adhere to prescribed diet, laboratory investigation and dose of medications, because they had not the financial ability to buy the prescribed medications and seek the required laboratory investigation. This in turn will trigger the SLE flare-ups.

This finding was supported by Elsayed and Mesbah (2018); El said, Fathy and Mahmoud (2019) who reported that, the health education based intervention had a significant effect on the improvement of SLE patients' knowledge. Also, Mary, Geetha, Sathiya and Rajeswari (2021), who concluded that most of studied patients in pretest had inadequate knowledge whereas after the education-based self-management intervention, the majority of them had gained adequate knowledge, which is matched with the finding of the current study. In addition, the study conducted in Egypt by Mohamady, Srour and Saad (2022) denoted that there was a highly statistically significant difference between pre and one month after self-care management in all items of knowledge regarding SLE.

Section III: Correlational Findings between scores of disease activity and the self-care knowledge and Selected Variables

In the current study, it was proved that there was a statistically significant relation between disease activity index and self-care knowledge, which means that, when patients with SLE have satisfactory level of self-care knowledge will have low disease activity state. The above finding supports the third research hypothesis which is stated as "There will be a correlation between the Systemic Lupus Erythematosus Disease Activity Index (SLEDAI) and the Lupus Patient's Self-Care Knowledge Assessment Test in patients who received self-care instructional guide than the control group".

These findings were also consistent with Zhang et al (2019), who studied "lack of patient education as a risk factor of disease flare in patients with SLE " and proved that effective disease management, including educating patients about SLE and its drugs, is the key to ensure patients to execute the treatment plan strictly and remission of disease, which in turn means low disease activity. In contrast, the Egyptian study conducted by Elsayed & Mesbah, (2018) who studied the effect of health education based intervention on self-care among patients with SLE, which indicated that self-care practices were not correlated with health related quality of life and health outcomes in patients with SLE. The researcher might justify these controversial findings to some intervening factors among the patients in study.

The current study illustrated that there were statistically significant differences between study and control group in self-care knowledge and disease activity index scores in relation to the frequency of SLE flare-ups. These findings reflect that based on patients acquired knowledge about the disease, it helped them to continue to follow the instructional guide, which in turn would decrease the frequency of SLE flare-ups and hospital readmission, resulting in SLE, lower disease activity and improvement of their quality of life.

CONCLUSION

According to results this study concluded that: the self-care instructional guide had a significant effect on the improvement of patients with SLE self-care knowledge that will help patients in the management of their symptoms independently and lower the disease activity state. Also, there was a statistically significant negative relation between disease activity index and self-care knowledge after implementing the instructional guide.

RECOMMENDATIONS

- Patient education is an important part of standard care; establishing patient education program to improve the quality of care for patients with SLE through the use of written instructions and other available resources in all rheumatology clinics.
- Replication of this study on larger probability sample and other geographical areas is required.
- Future research is proposed to explore the effect of self-care instructions on controlling SLE disease activity.

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