Women's Awareness Regarding Systemic Lupus Erythematous: Impact of Self- Management Guidelines

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Abstract

Background: Systemic Lupus Erythematosus (SLE) is a common long-term autoimmune disease calls for self-care strategies tailored to enable women to actively manage their health and presume responsibility for disease control **Aim:** This study aimed to evaluate the impact of implementing self-management guidelines on the women's awareness regarding SLE. **Design:** A quasi-experimental designed study. **Settings:** the participants were recruited from the Rheumatology and antenatal outpatient clinics at Al-Azhar University Hospital in New Damietta. **Subjects:** A purposive sample was conducted on adult female women (18-45 years old), that suffer from different signs and symptoms of disease. **Four tools** were employed for gathering of data as follows: **Tool I** was a structured interview questionnaire divided into 2 parts to assess personal characteristics of the women and their medical and obstetric history. **Tool II** was women's awareness knowledge about SLE. **Tool III** was The Brief Pain Inventory (BPI) scale. **Tool IV** was disability index scale. **Results:** This study found that 67.7% of women had satisfactory knowledge about SLE disease, 72.3% were able to self-management post guidelines, statistically significant differences in improving knowledge, pain interference, and disability index post application of the self-management guidelines were found. Also, women acquired sufficient knowledge, and an increase in positive daily life practices was observed. **Conclusion:** The self-management guidelines reinforced the women's knowledge also improved daily life and reflected in decreased pain and increased disability index. **Recommendations:** Ongoing educational programs for females with SLE in order to enhancing their health status.

Keywords: Awareness, Disability index, Guidelines, Pain interference, Self-management & Systemic lupus erythematosus.

Introduction

Systemic lupus erythematosus (SLE) is a chronic autoimmune disorder affecting multiple systems of the body, characterized by periods of flare-ups and remissions **(Sedrak et al., 2020).** Lupus in females is about 10 times more prevalent than in males. It primarily affects women of working and reproductive age, with the highest incidence of SLE seen between the ages of 20 and 29, followed by those aged 30 to 39. The mortality rate in women with SLE is between two to five times higher in comparison to the general population as has been reported by **Elessawi et al., 2019**. The exact cause of this condition is still unclear, however, the research suggests that a combination of genetic and environmental elements participates in initiating this immune reaction. These genetic and environmental elements lead to the overproduction of autoantibodies by B cells and disturbance in cytokine regulation, in the end causing destruction to tissues and organs. SLE is defined by the existence of antibodies against the cytoplasmic and nuclear structures **(Karrar & Cunninghame 2018).**

The onset of SLE is influenced by multiple risk elements, including genetic tendency, often coupled with lifestyle and environmental factors. These include exposure to sunlight and radiation, a sedentary lifestyle, stress, and the intake of some medications that can trigger the disease (**Youssef 2019**).

The main cause of the symptoms of lupus is inflammation response that may alter either parts of or the whole body. Inflammation is also responsible for weight alteration and fatigue recognized with lupus. Other symptoms include destruction to a certain organ system, skin manifestations, and joint affection. Medications prescribed for lupus treatment can cause changes in the digestive system and renal functions. Also, lupus can affect the lungs, nervous system, eyes, and the heart (**Yariz, et al., 2014**). Generalized constitutional symptoms of SLE, which can be prominent in clinical presentation, include fever, weight loss, and fatigue (**Scherlinger, et al, 2022).**

Lupus-induced inflammation can impact various body regions with many complications as: hematologic (neutropenia, hemolytic anemia, thrombocytopenia, catastrophic and thrombotic thrombocytopenic purpura, and anti-phospholipid syndrome), dermal

(necrosis), cardiac (myocarditis, and pericardial tamponade), pulmonary (pulmonary hypertension and hemorrhage), adrenal insufficiency, gastrointestinal (pancreatitis, and vacuities), and central nervous system (myelitis) could be experienced (**Bruce & Burns, 2014**).

Timely identification, appropriate medical care tailored to the condition including symptom management and alleviation, and lifestyle adjustments diminish flare-ups, and complications (**Youssef, 2019**).

Treatment options for SLE do not provide a cure, and patients often undergo cycles of exacerbation and improvement (**Scherlinger, et al 2022**). Lifestyle adjustments as well as non-pharmacological interventions play a crucial role in managing the disease. These measures include educating females, ensuring adequate rest and fatigue reduction, protecting from sunlight, medication use, control of infection, maintaining a low-salt, low-fat, and low-cholesterol diet, vaccinations, avoiding stress, managing pregnancy and contraception, and minimizing psychosocial impacts. (**Kankaya & Karadakovan 2020**).

Managing SLE is crucial for enhancing female survival and preventing and addressing chronic complications, often taking precedence over direct treatment. Providing ongoing counseling and teaching to patients and families about the SLE, and its management has been shown to have a beneficial impact on female health outcomes. This approach also enhances self-care that is crucial in effectively managing the disease (**Petri 2018**).

Self-care management is an intervention designed to empower women with strategies to actively engage in and take responsible role for managing the disease to function in an optimum way by getting knowledge and utilizing a blend of self-monitoring signs and symptoms, managing medications, and improving problem-solving and decision-making abilities for medical care, while also adjusting diet, physical activity, and smoking habits **Petri 2018, et al.,**

Nurses play a crucial role in managing SLE, particularly during periods of disease flare-ups. They assist women in coping with the challenges of the disease in their daily lives, educate them on managing lupus symptoms, work to prevent exacerbations, and provide guidance on lifestyle adjustments through health education (**Ogórek-Tęcza & Pych, 2018**).

Making lifestyle adjustments, including minimizing sun exposure, managing stress, quitting smoking, and adopting a low-saturated diet, is also highly significant (**Williams et al., 2017**).

The community and obstetric nurse offers essential emotional support and assistance to the patient and her family, while also implementing educational initiatives related to rehabilitation and lifestyle aimed at enhancing their life quality.

Significance of the study

In general, the reported SLE- prevalence and incidence differ markedly by geography (**Rees et al., 2017**). Its prevalence is 24/100,000 population in the developed world (**El Saman et al., 2020**). SLE is multi-organ autoimmune rheumatic disorder that is potentially life-threatening (**Mohamed et al., 2020**). Age, ethnicity, and gender play a crucial role in the clinical presentation and disease management (**Rees et al., 2017**). SLE is more commonly found in women within the reproductive age bracket, typically between 15 to 44 years old (**Phuti, 2019**), Egyptian SLE patients may have a variable range of immunological and clinical presentations. The prevalence of SLE in Egyptian adults is approximately 6.1 cases/100,000 population (11.3/100,000 females and 1.2/100,000 males) (**Gheita et al., 2021**). Therefore, the study objective was to evaluate the impact of self-management guidelines on the awareness of women diagnosed with SLE.

Aim of the Study

The research aimed to evaluate the impact of implementing self-management guidelines on the awareness levels of women with SLE.

Research hypothesis:

The awareness of women with SLE would improve following the adoption of self-management guidelines.

Subjects and Methods

Technical Design:

This includes the study design, settings, subjects, and tools for data collection.

Research Design:

To achieve the aim of this study, a quasi-experimental design was employed.

Research Setting:

The study took place at the Rheumatology and antenatal outpatient clinics in Al-Azhar University Hospital, New Damietta. The hospital is composed of 5 buildings that separate from each other and the outpatient clinics in the first floor that contain Rheumatology clinic and obstetric clinics. The available days for rheumatology clinic were Saturday, Monday and Wednesday and the available day for antenatal clinics were all week days. This hospital was selected because it serves a large number of patients in the government.

Subjects:

A purposive sample of 65 adult female patients were selected for this study with inclusion criteria as follows: women that aged from 18 to 45 years, with manifestations of the disease and with different

educational levels admitted to rheumatology and antenatal outpatient clinics at Alazhar University hospital new Damietta and who didn't participate in any previous educational program regarding systemic lupus erythematosus and willing to participate in the study within 6 months.

The sample size was calculated using **Krejcie & Morgan (1970)** formula

$$n = \frac{NZ^2 P(1-P)}{d^2(N-1) + Z^2 P(1-P)}$$

Where: n = sample size, N = total population size
Z = the corresponding standard class of significance 95% =1.96
P = percentage of availability of the character and objectivity =0.1
d = error percentage = 0.05

$$n = \frac{42.180768}{0.6482244} = 65.071$$

Therefore, a sample size was 65 female.

Tools of data collection: Four instruments were employed:

Tool (1): Structured Interview Questionnaire
This questionnaire, developed based on a review of pertinent literature, was utilized by researchers to gather necessary data from study participants. It consisted of two parts:

Part I: Personnel characteristics. The assessment included variables such as age, phone number, and marital status, and occupation, level of education, residence, pregnancy status and source of information.

Part II: Medical history and Obstetrical history; medical history including family history, disease start, other chronic diseases, follow-up, diagnostic tests, health troubles in the past six months, and medications. Obstetric history including pregnancy, and parity before and with SLE.

Tool (2): Knowledge and awareness questionnaire for SLE Belotti (2003): It is a Self-administered questionnaire for women with SLE to assess their knowledge. It was translated from English to Arabic. It included 20 multiple-choice questions on SLE, covering areas such as its definition, causes, clinical manifestations, diagnostic tests, diseases complications, self-management and treatment.

Scoring system:
For knowledge-related questions, the total scores extended from 0 to 40. Each correct answer had two marks, and the incorrect answer was given zero.
According to the gained score, we identified two levels of knowledge as follows:
a. Insufficient = <24 marks (< 60% of total scores).
b. Sufficient = 24-40 marks (≥60% of total scores).

This tool was used twice; once before application of self-management guidelines and once one month later post application of self-management guideline.

Tool (3): The Brief Pain Inventory (BPI) – Pain Interference scale (Cleeland & Ryan, 1994). It was adopted to assess pain interference on daily function. The BPI sub-scale evaluates pain impact on seven day-to-day activities across seven domains as displayed in table 4.

Scoring system
The pain interference items on women's function were reported as numeric rating scales, from 0 (not interfering) to 10 (completely interfering). The BPI pain interference score is determined by averaging the values of the seven interference items. This tool was used pre self-management guidelines and post one month following self-management guidelines.

Tool (4): Disability index (Fries et al., 1980). It included 20 statements used to evaluate eight sections; arising, dressing & grooming, walking, eating, hygiene, grip, activities, and reach. dressing & grooming including dress herself and shampoo her hair; arising including get in and out of bed and eating including open a new milk carton, stand up from a chair; cut meat and lift a full cup to mouth; walking including climb up five steps and walk outdoors on flat ground, also it helped to assess any devices for assistance or from another person for doing those activities.; hygiene including take a tub bath, body wash and dry, using the toilet; reach as a 5-pound object reach and get down, clothing collect from the floor; grip as opening of previously-opened jars , open car doors and faucets turning on and off; daily activities including complete errands and shopping, enter and exit a car, and perform household tasks like vacuuming.

Scoring system
The women's response for each statement included four options: with no difficulty= 0, with some difficulty = 1, with much difficulty=2, can't do = 3. The maximum score for each item was four marks to yield the final composite score of only 60 grades.
According to the gained score, participants were divided into two levels as follows:
a. Able women: who had < less than (50%) 30 grads.
b. Disabled women; who had 30-60 grads (≥50%).
This tool was used pre self-management guidelines and post one month following self-management guidelines.

Operational Design
Preparatory phase:
This process implies reassessment of related literature and getting an abstractive vision into diverse features of the work through the internet, books, articles, magazines, and periodicals to tools for data collection.

Validity & Reliability:
Validity: evaluating the content validity of the proposed tools through a jury of 5 experts composed of one specialized in medical-surgical nursing, one in maternal and newborn health topics nursing, one in community health nursing, and two expert rheumatologists at the medical school. The recommended alterations were implemented, and reliability was evaluated by conducting a pilot test and calculating the Cronbach's Alpha value that indicate: The first tool internal consistency was 0.86, the second tool; lupus knowledge was 0.795, the third tool; the Brief Pain Inventory- Pain Interference Scale had an internal consistency of 0.78, disability index scale was 0.851.

Pilot Study:
A pilot study was conducted on one tenth of the women (6), who were subsequently omitted from the main sample. This pilot study took place in the rheumatology and antenatal outpatient clinics at Al-Azhar University Hospital in New Damietta. The purpose was to ensure the applicability, clarity, feasibility of the study tools, relevance, and to assess the time required to complete them.

Ethical considerations:
An official ethical approval was obtained from the scientific research ethics committee of the Faculty of Medicine, Fayoum University number 525. The women oral consent was taken before beginning of the study. Voluntary participation in the study and the study subjects were given complete information about study, rights to withdraw at any time and confidentiality of information.

Field Work:
Data collection commenced and concluded within a span of six months. Women who aged from 18 to 45, with manifestations of the disease and with different educational levels admitted to rheumatology and antenatal outpatient clinics at Alazhar University hospital new Damietta and who didn't participate in any previous educational program regarding systemic lupus erythematosus and willing to participate in the study were recruited for the study and provided with a questionnaire to complete, marking their responses on the datasheet. It took approximately 30-40 minutes for each woman to finish the questionnaire.

Phases of field-work
The study employed four phases to achieve its objectives: assessment, planning, implementation, and evaluation. Data collected from the mentioned settings underwent actual field analysis. one month post the self-management guideline were implemented, the post-questionnaires were completed.

Assessment phase
Women attending antenatal and rheumatology outpatient clinics were interviewed to gather baseline data. Researchers began by presenting themselves and explaining the design and aims of the study to the participants. Data were gathered from pre-program evaluation and a review of various aspects of current and previous, local, and international literature related to the topic.

Planning phase
Processing the self-management guideline as intended by the study objective was done and based on a literature review **Elessawi et al (2019)**. A structured booklet, written in clear and simple Arabic, was developed to serve as a guide for the women.
The guidelines underwent revision by a panel of five experts, consisting of one expert in medical-surgical nursing, one in maternal and newborn health nursing, one in community health nursing, and two expert rheumatologists at the medical school to ensure content validity. Following the expert panel's feedback, certain modifications were implemented, leading to the development of the final forms.

Implementing phase
A planned self-management guideline was implemented individually or in groups of women depending on their number in each clinic room. Each session was completed within 30-40 min and 45-60 minutes for theoretical sessions and practical sessions, respectively. Each session began with a recap of the previous session's content. Various teaching methods, including discussion, brainstorming, demonstration, and re-demonstration for women's physical activities; low-impact exercise as Squats, Alternating lunge, Incline pushup, Reverse crunch and Bridge, stress management techniques including lifestyle modification and relaxation techniques as deep breathing, meditation and yoga were employed throughout the sessions. Additionally, Arabic booklets containing relevant information about definition of systemic lupus erythematosus, causes, risk factors, symptoms, diagnosis, treatments, complications and using healthy diet measures as eating well balanced diet, take prescribed vitamins were distributed to all participants post the program. At the end of each session, women were briefed about the content and duration of the upcoming session.

It's carried out through four sessions as follows:
The first session covered basic knowledge about SLE definition, causes, risk factors, signs, and symptoms, general complications and complications during pregnancy as spontaneous abortion, intrauterine fetal death, pre-eclampsia, intrauterine growth retardation, premature rupture of membrane, preterm birth and neonatal lupus, diagnosis, and treatments.
During the **first session,** participants were provided with fundamental information about SLE, its definition, causes, risk factors, signs, and symptoms.

The session also covered general complications associated with SLE, as well as complications specific to pregnancy such as intrauterine fetal death, spontaneous abortion, pre-eclampsia, intrauterine growth retardation, preterm birth, premature rupture of membranes, and neonatal lupus. Diagnosis methods and available treatments for SLE were also discussed.

During **the second session,** participants received information about healthy dietary practices, emphasizing the importance of consuming a well-balanced diet and adhering to prescribed vitamin intake. Additionally, the session included practical demonstrations focused on women's physical activities (low-impact exercise) as Squats, Alternating lunge, Incline pushup, Reverse crunch and Bridge. This involved explaining and demonstrating instrumental activities of self-care activities performed at home, techniques for managing pain, and daily living.

In **the third session,** women were taught stress management techniques, including lifestyle adjustments, and relaxation methods. Additionally, measures to prevent relapses of trigger factors were demonstrated, emphasizing the importance of proactive strategies in managing stress and minimizing triggers.

During **the fourth session,** women were empowered to independently manage symptoms of SLE and prevent their recurrence. Researchers presented coping strategies, such as problem-solving techniques, to help women overcome challenges encountered in self-care. Additionally, participants were encouraged to express distressful emotions and maintain emotionally supportive relationships as part of their coping mechanisms. Compliance with medical regimens was also emphasized to ensure effective management of SLE symptoms.

Evaluation Phase

Evaluation was conducted one month post the implementation of self-care management guidelines by utilizing the same tools during monthly through follow-up visits of women to outpatient clinics, evaluation was done by divided study sample into 10 groups according to follow up visit, each group 6 women.

Statistical Design

The collected data were structured, categorized, tabulated, and statistically analyzed using SPSS (the Statistical Package for the Social Sciences) version 20.0 for Windows. The analysis includes the arithmetic mean (X), frequency, standard deviation (SD), percentage (%), Chi-Square (X^2), and paired sample t-test. It was recorded as not significant if $p > 0.05$, significant if $p \leq 0.05$ and highly significance if $p \leq 0.001$

Results

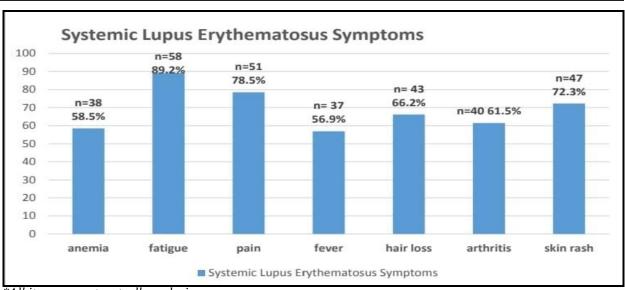**Table (1): Personnel Characteristics of the Studied Women's (N=65)**

Items	No.	%
Age (In years):		
19 - <25	26	40.0%
25 – <45	33	50.8%
≥ 45	6	9.2%
	Mean ± SD =26.72 ± 8.11	
Residence		
Rural	52	80%
Urban	13	20%
Marital status:		
Married	43	66.1%
Unmarried	22	33.8%
Education:		
Read/write	2	3.1%
Primary	12	18.5%
Secondary	32	49.2%
High	19	29.2%
Occupation:		
Working	20	30.7%
Housewife	45	67.7%
Pregnancy:		
Pregnant	28	43.0%
Non- pregnant	37	56.9%
Source of information		
Mass media	36	55.4%
Health care Staff	22	33.8%
Relatives & Friends	7	10.8%

Table (2): Distribution of the Studied Women's Regarding to Medical History (N=65)

Items	No.	%
Onset of the disease:		
< one year	6	9.2%
1 <5	26	40.0%
5-10	15	23.1%
> 10	18	27.7%
Other chronic disease:		
Yes	19	29.2%
No	46	70.8%
Family history of disease:		
Yes	21	32.3%
No	44	67.7%
Medical follow up		
Monthly	6	9.2
Every two month	23	35.4
Every three month	13	20
Every six month	12	18.5
Irregular follow up	11	16.9%
Taken medications during the past six months		
Yes	65	100%
Diagnostic tests performed during the past six months.		
Yes	65	100%
Health problems during the past six months.		
Yes	65	100%

Table (3): Distribution of the Studied Women's Regarding to Obstetric History for Married Women's (N=43)

Items	No.	%
Gravida:		
Null gravida	9	20.9%
Prim gravida	12	27.9%
2-3	14	32.6%
≥ 4	8	18.6%
Para:		
Nulliparous	21	48.9%
Primipara	9	20.9%
2-3	12	27.9%
≥ 4	1	2.3%
No of previous pregnancy with disease (N= 18):		
1	9	50.0%
2	7	38.9%
≥ 3	2	11.1%
Previous pregnancy complication with disease (N= 11)		
Abortion	8	72.7%
Preeclampsia	2	18.2%
Fetal congenital anomalous	1	9.1%
Mode of delivery with disease (N= 18)		
Normal	4	22.2%
Cesarean section	14	77.8%
Previous labor complication with disease (N= 9)		
Premature labor	2	22.2%
Premature rupture of membrane	7	77.8%

All items are not mutually exclusive

Figure (1): Distribution of the Studied Women's Regarding to Systemic Lupus Erythematosus Symptoms (N=65)

Table (4): Distribution of the Studied Women's Regarding to Pain Interference Level Pre and Post Implementation of Self-Management Guidelines (N=65)

Pain Interference items	Pre self-care management Mean ±SD	Post self-care management Mean ±SD	Paired t test	P value
General Activity	2.6154±49029	1.2615±.44289	15.718	.000**
Mood	1.4769± .50335	1.2769±.45096	3.007	.004**
Walking ability	2.2769± .62519	1.3231±.47129	10.420	.000**
Work	2.1846±.65889	1.6000±.49371	4.960	.000**
Relations with other people	1.5231±.66398	1.1385± .34807	4.428	.000**
Sleep	2.3385±.47687	1.4154±.49662	11.540	.000**
Enjoyment of life	2.2769± .62519	1.6000± .49371	6.566	.000**
Total	**1.8615±.34807**	**1.5692±.49904**	**3.474**	**0.001****

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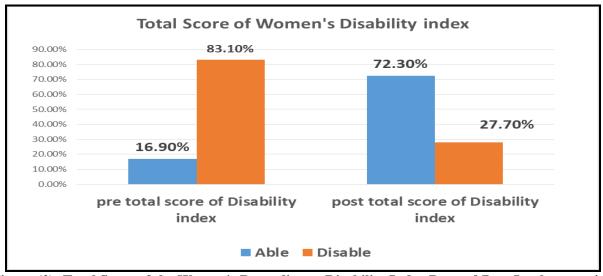

Figure (2): Total Score of the Women's Regarding to Disability Index Pre and Post-Implementation of Self-Management Guidelines (N=65)

Table (5): Distribution of the Studied Women's Regarding to Knowledge Pre and Post Implementation of Self-Management Guidelines (N=65)

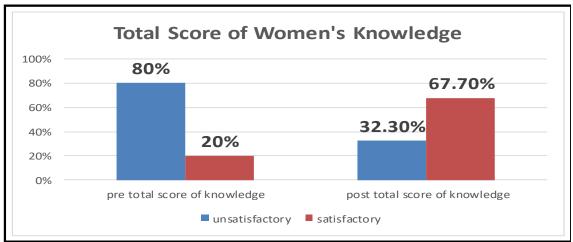| Knowledge Items	Pre				Post			
	correct		Incorrect		Correct		Incorrect	
	No	%	No	%	No	%	No	%
Definition	16	24.6%	49	75.4%	54	83.1%	11	16.9%
Causes	8	12.3%	57	87.7%	45	69.2%	20	30.8%
Types	7	10.8%	58	89.2%	53	81.5%	12	18.5%
Risk factors	4	6.2%	61	93.8%	60	92.3%	5	7.7%
Clinical manifestation	11	16.9%	54	83.1%	56	86.2%	9	13.8%
Diagnostic tests	10	15.4%	55	84.6%	48	73.8%	17	26.2%
Complication	12	18.5%	53	81.5%	48	73.8%	17	26.2%
Treatment	8	12.3%	57	87.7%	49	75.4%	16	24.6%

Figure (3): Total Score of the women's regarding to Knowledge pre and post-implementation of self-management guidelines (No=65)

Table (6): Relation between the Studied Women's Total Score of Knowledge and Disability index Pre and Post Implementation of Self-Management Guidelines (N=65)

Total Knowledge	Pre Disability Index				Post Disability Index			
	Disable		Able		Disable		Able	
	No	%	No	%	No	%	No	%
Pre Knowledge								
Un Satisfactory	52	80%	0	0.0%	18	27.7%	34	52.3%
Satisfactory	2	3.1%	11	16.9%	0	0.0%	13	20%
P-value	.000**				.009**			
Post Knowledge Satisfaction								
Un Satisfactory	21	32.3%	0	0.0%	18	27.7%	3	4.6%
Satisfactory	33	50.8%	11	16.9%	0	0.0%	44	67.7%
P-value	.009**				.000**			

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

Table (1): Denotes that 50.8% of studied women aged were >25 and <45 years old with a mean age were 26.72 ± 8.11. Furthermore, was found that 80.0% of the women had resided in rural regions. Also, it shows that (66.1%), were married, (56.8%) were non-pregnant, and housewives, respectively, 55.4% of participants had information about SLE from mass media. In the meantime, 33.8% of them had information from health-care staff.

Table (2): Reveals that 40.0% of participants were diseased from 1 to <5 years. 70.8% had no other chronic disorders. Also, 67.7% of them had no familial background of SLE, and 35.4 % of the patients had a bi-monthly follow-up 100% of studied women have taken medications and performed diagnostic tests during the past six months with SLE.

Table (3): This table summarizes the distribution of participants according to their gravidity; 32.6% of

study sample was pregnancy 2-3 times, mode of delivery; 77.8% of study sample was delivered by cesarean section), number of pregnancies with SLE, and complications during previous pregnancies and delivery.

Figure (1): Illustrates that the commonest SLE symptoms of studied women were fatigue (89.2%), pain (78.5%), skin rash (72.3%) as well, (66.2%) had hair loss, (61.5%) arthritis, 58.5% and 56.9% complaining of anemia and fever respectively.

Table (4): The findings suggest a statistically significant difference in the pain interference level among participating women pre and post self-care management. Furthermore, there was a noticeable decrease in the pain level among women following self-care management.

Figure (2): This clarifies that there was a highly statistically significant difference among the studied women between pre- and post-self-care management regarding the total disability index as well as a significant improvement with a reduction in the total disability index post-self-care management.

Table (5): Presents distribution of the participants regarding knowledge pre and post implementation of self-management guidelines. It was observed that only (6.2%), (16.9%), (24.6%), (and 10.8%) of studied women showed correct answers regarding risk factors, manifestation, definition, and types of systemic lupus erythematous pre-self-care management respectively compared to (92.3%), (86.2%), (83.1%), (81.5%) of studied women showed correct answer regarding the same previous items post-self-care management respectively.

Figure (3): Illustrates a notable improvement in the total knowledge score among studied women pre and post self-care management. Prior to self-care management, only 20% of participating women had adequate total knowledge score regarding SLE, which increased to 67.7% post-self-care management.

Table (6): Show a statistically highly significant variability between the participating women between before and after-implementation of self-management guidelines as regards to the total score of knowledge and disability index.

Discussion:
The hallmarks of systemic lupus erythematosus (SLE), a multisystem autoimmune disease, include immunological complex deposition, persistent inflammation in the traditional target organs—the skin, joints, and kidneys and autoantibodies directed against nuclear antigens. The burden of SLE remains high despite significant advancements in diagnosis and treatment. To enable early patient referral and diagnosis, it is critical to understand typical presentations and the diagnostic process **(Barber, et al 2021).**

Concerning personal features of the women included in the study, the present study reveals that slightly almost half of them were falls between 25 and < 45 years old and the mean age was 26.72 ± 8.11. The possible explanation is that the hormones influence vulnerability to this disease in the childbearing years when estrogen levels are highest. This emphasizes the need for targeted allocation of health resources for this specific population group. This observation aligns with **Mohammed et al. (2018)** who searched the impact of self-management guidelines on self-efficacy and awareness for patients with SLE. Who reported that 58.5% of the subjects under study fall between 25 and <45 with a mean age of 32.33±10.03. Also, **Mohamady et al. (2022),** noted that about half (51.5%) of the studied ones aged >30 years old with 30.07±7.57 years old as the mean age, in their study about the consequence of self-care management on symptoms and health consequences for those with SLE**. Chung et al. (2021),** in their nationwide population-based study about the incidence and prevalence of SLE among Korean women in childbearing years, concluded that the hazard and load of SLE are extensive among females through their childbearing years. As well**, Wageeh et al., (2020),** in their study of patients with SLE reported that most of the studied patients' age was between 35 and 45 years old. In contrast, these findings differ from those of **Yu et al. (2020),** who discovered that over half of the SLE patients in their study were 50 years or older. From the investigators' perspective, these data indicated that SLE is a chronic disability condition impacting young patients during their most productive years.

Moreover, our study revealed that two-thirds of the women surveyed were married. This finding agrees with those of **Mohamady, et al., 2022,** who concluded that (75.8%) of the studied sample was married. **Mohammed et al., 2018 and Ahmed et al., 2023**, reported that majority of the study sample was married. **These** findings were verified by those of other studies **(Sanz, 2010; O'Riordan, et al., 2017; Rizk et al., 2020).**   However, this finding was in contrast with **Hassan & Gomaa, (2018),** who studied about SLE patients' self-esteem and quality of life showed that slightly less than half of the sampled patients were single.

Also, our study illustrated that two-thirds of the women studied were not working. From the researchers' point of view, women with the disease had high levels of disability, absenteeism, and increased levels of retirement due to ill health, so most of them did not work. This result is following **Sedrak et al., (2020),** who demonstrated that

majority of their study participants are unemployed. This is similar to **El said et al., (2019), & Mostafa & Abd-Elrehem (2017),** who clarified that a high percentage of SLE patients had no job.

On the subject of residence, the present study reveals that four fifth of the women studied lived in rural areas. This was consistent with the findings of **Mohamady et al., 2022,** who reported that more than four fifth of the studied sample was living in rural areas, and **Abd El-Azeem et al (2018),** who found that more than half of the sampled SLE patients resided in rural areas. This goes in opposite with **Ahmed et al., 2023,** who showed that less than three quarter of his studied patients resided in towns or cities.

Concerning education, our study reported that slightly less than half of the studied subjects had secondary school education and less than one-third of them had a university degree. The results of these studies were similar to the findings of **Ahmed et al., 2023,** who illustrated that more than half had a technical institute of nursing, **Mohammed et al., 2018** reported that more than one third had moderate education. Also, this is in agreement with **Wageeh et al, (2020)**, who studied the impact of nursing education on self-care and knowledge of SLE patients, and reported that most of the patients were educated. **Zhang et al. (2019),** in a study of the education impact on disease flare in patients with SLE, found that about half of the studied group was highly educated.

Moreover, sources of information about SLE, slightly more than half of the women studied obtained knowledge regarding the disease from mass media and one third from health care staff. This result is in agreement with the findings of **Mohamady et al., 2022,** who come to an end that (57.60%) of the studied sample obtained information about the disease from mass media followed by healthcare staff (21.20%). These findings are in corporation by **Bin Haikel & Al Tulaihi (2018),** who found that over half of the participants were familiar with the term SLE and acknowledged it through the online websites. This study's findings contradicted those of **Macejova et al., (2020)**, who searched life of young females with SLE, and indicated that the primary sources of SLE-related knowledge were predominantly physicians.

As regards the medical history of the participants, this study reveals that two fifth of the studied women reported that the onset of the disease ranged from one to five years ago. Also, less than two-thirds of the studied women didn't have other chronic diseases. All of the studied women have taken medications and performed diagnostic tests during the past six months with SLE. These findings confirmed the results obtained by **Mohamady et al., 2022,** who found that

nearly two-fifths of SLE patients suffered the disease from one to < five years. These findings align with those of **El Fadeel & El-Deen (2020),** who reported that half of the study subjects and more one-third of the control subjects had been diagnosed with SLE within the past five years. Also, **Gheita et al., (2021)**, who studied adult Egyptians with SLE reported that the disease lasts for four years. This finding goes in opposite with **Ahmed et al., 2023,** who reported that less than three fifth of the studied patients suffered from a disease lasting ≤ 6 months. Additionally, less than half and more than one quarter of their patients had hypertension and had a history of previous hospitalization, respectively. **Rizk et al. (2020)** uncovered that over one-third of the patients had been afflicted by illness for a duration exceeding four years. Also, in a study by **El Fadeel, & El-Deen (2020),** on patients with SLE, who discovered that half of the study subjects and more than one-third of the control subjects had been living with SLE for < five years. Additionally, **Gheita et al. (2021),** in their study on adult Egyptians with SLE reported disease duration of four years.

As regards the previous medical records of the participants, reveals that about two-thirds of them no family history of SLE. This perspective aligned with previous reports **(Ahmed, 2023, Mohamady, et al., 2022)**

Regarding medical follow-up, the study findings indicated that every two months, more than one-third of participants attended medical follow-up appointments. These findings confirmed the results retrieved by **Mohamady et al., 2022,** who found that that every two months, about one-third of participants attended medical follow-up appointments.

Regarding previous obstetric history, it was clear that more than one quarter of the studied sample were prim- gravida, about one-third of the participating women had previous 2-3 pregnancies, and slightly less than half of the participating women were nulliparous. More than three quarter of them delivered by cesarean section. This could be attributed to its higher prevalence among women of the reproductive age.

These findings confirmed the results obtained by **Mohamady et al., 2022,** who disclosed that over one-fourth of the female subjects under study were primigravida, while greater than a third had previously experienced two or three pregnancies. Also, about half of the participating females were childless.

Likewise, **Abd El-Salam and his colleagues (2019)** investigated the life quality of pregnant females with SLE and found that approximately one-fifth of the them were primigravida, while greater than two-fifths had previous 2-3 pregnancies. Similarly, **Mohamady**

et al. (2022) elaborated that around two-fifths and one-third of the female participants had one or two pregnancies while suffering from SLE, respectively, and the about three fifth of the examined sample underwent cesarean section delivery.

Regarding previous obstetric history, this study also was clear that half of the studied women had one pregnancy with the disease, and about three quarter of associated delivery complications with the disease were abortion and premature rupture of membranes.

This perspective was consistent with **Mohamady et al., 2022,** who explained that the most commonly declared complications in preceding pregnancies were miscarriage, then pre-eclampsia. Additionally, delivery-associated drawback was premature rupture of membranes.[21] Similarly, this was corroborated by **Abdwani & colleagues (2018)**, who discovered that approximately one half of the studied sample had a previous abortion, nearly two-fifths experienced pre-eclampsia, and a few number suffered preterm labor

It was clear that the most common symptoms of the disease as reported by the studied women were pain, fatigue, and rash on the skin, loss of hair, arthritis, anemia, and fever. The findings of the our study are supported by **Mohamady & colleagues, 2022,** who illustrated that the most commonly reported disease symptoms were fatigue suffering (87.9%), pain sensation (74.2%), rash on the skin (71.2%), arthritis (60.6%), hair loss (69.7%) and anemia (59.1%). This is agreeable with **Cornet & colleagues, (2021)** who found that fatigue was identified as a highly prevalent and popular symptom, impacting over 75% of women with SLE in their study. Similarly, **Bin Haikel & Al Tulaihi (2018)** noted that general malaise and fatigue were the commonest symptoms of SLE. Furthermore, **Mahmoud & colleagues, (2018),** who examined the immunological and clinical patterns and outcomes of SLE patients in Egypt, observed that arthritis was one of the common presenting symptoms of SLE observed at the disease's onset. **Abdel Masieh et al., (2019)**, stated that over half of the study sample experienced arthritis. [43] Additionally, a recent study by **Elgendi (2021)** concluded that swelling of the joints, tenderness, and pain are common symptoms among females with SLE. The possible explanation is that all symptoms are similar in all studies conducted

Regarding the distribution of the participants regarding pain interference level, a significantly high difference among the studied women pre and post self-care management was observed. Also, a significant decrease in the level of total was observed among studied women's post-self-care management. This could be attributed to the positive impact of self-care management, along with the utilization of non-pharmacological control methods such as heat/cold

application, relaxation exercises, breathing exercises, and positioning. These findings support the hypothesis.

This finding follows **Mohamady et al., 2022**, who reflected a significantly high difference among the participants between pre- and one month post self-care management as regards the level of pain. Additionally, a notable decrease in the level of total pain among studied females was noted during one month of self-care practices, with a highly significant difference regarding pain. Similarly, these findings align with those of **Williams & colleagues, (2017)**, who deduced that self-management incorporating both health education and social support had a positive impact on improving outcomes in health by reducing pain and enhancing function of patients with lupus.

Regarding the total score of the women's disability index, there was a statistically highly significant difference in the participating women pre and post management of self-care as well as a marked improvement with a decrease in the total disability index after self-care management. Also, these findings support the hypothesis.

This result contradicted **Mohamed & colleagues, 2018,** reported that majority of the participants (93.8%) were able to post-implement regarding disability index and significant differences before and after (p=0.033). Also, **Koehler (2011), Giverson 2011 & Watson 2011**, reported similar results after applying self-management courses to participants with SLE arthritis. **Williams et al. (2017)** explained that self-management interventions that includes health education and social support had a positive effect on keeping disabilities back among lupus patients.[13] However, these findings contrast with those of **Koehler (2011),** who reported that most of the patients in after-education programs experienced disability in performing their routine daily acts.

It was clear that most of the patients included in our study showed correct answers and improved all items of knowledge awareness post-self-care management regarding risk factors, manifestation, definition, and types of SLE. From the researchers' perspective, the lack of knowledge pre initiating self-care management may stem from the absence of educational programs providing females with necessary information about the disease. However, enhancing females' awareness and promoting healthy behaviors through education can potentially increase their ability to manage their issues. This underscores the significance of self-care management in enhancing health outcomes for females with SLE. These results also confirmed the hypothesis.

This data is consistent with **Mohammed et al, 2018, & Ahmed et al., 2023**, who illustrated highly

statistical differences between pre and post-knowledge regarding definition, incidence, signs, complications, and treatment. **Wageeh et al, (2020)** demonstrated a significantly high difference in the knowledge of patients regarding SLE before and after the test for the participants, (p-value= 0.001)**.**

What is more, the study findings were backed by **Elsayed & Mesbah (2018)**, who reported that following the intervention implementation, there was an enhancement in both the mean and the standard deviation of the knowledge among the participants studied concerning SLE, showing statistically significant variances between the periods preceding and following the intervention. **Mostafa & Abd-Elrehem (2017)** observed that greater than two-thirds of the participants in their study exhibited a good level of awareness towards SLE following the carrying out of self-management guidelines, with a significantly high difference. This aligns with **Yariz & colleagues, 2012,** who reported high statistical differences in all components of knowledge before and after-implementation. **Nicol & Warier 2011** found the same result. This result confirms the impact of management of self-care in improvement of women's health outcomes with disease.

There was detectable improvement among participants' in knowledge total score post-self-care management and had satisfactory about SLE. These results also confirmed the hypothesis. These findings were similar to the results documented by **Ahmed & colleagues, 2023,** demonstrated a marked improvement the total knowledge scores of the participants before, after, and during follow-up following the implementation of self-care guidelines. A highly statistically significant difference was observed between the pre-, post-, and follow-up phases after the implementation of self-care guidelines.

Additionally, the study findings were supported by **Mohamed & Kamel (2018),** who reported that intervention based on health education remarkably improved the knowledge of patients with SLE. **Mohamady et al., 2022,** revealed that 17.9% of the patients had satisfactory total knowledge score before- and 84.30% had satisfactory total knowledge score after-self-care guidelines implementation, there were significant differences in the patients between the before and one month post-self-care management phases in respect to pain. [21] In same line, **Mohamed & Colleagues, 2018**, concluded that most of patients had adequate consciousness after self-management guidelines implementation. This is consistent with the findings of **Sohng et al. (2011),** who found similar results after implementation of self-management courses for patients from Korea

suffering from chronic illness, enabling them to become more aware of their health status.

Concerning the correlation between the total score of knowledge and disability index of the studied women, there was a significantly high difference among the studied women's total knowledge score and disability index pre and post implementation of self-management guidelines. From the researchers' point of view, the preceding findings might be attributed to patients' increased capacity to handle their difficulties as a result of increased knowledge and acquisition of good behaviors and practice through education, so lowered disability index which also confirms the hypothesis.

This is per **Feldman et al., (2013)** who examined developing a program to enhance care for women with SLE from medically underserved regions and determined that the effectiveness of the intervention can be assessed by some outcome measures as improvements in the ability to carry out daily living acts, adherence to a healthy diet, and engagement in regular exercises.

Limitation of the study

The women were very afraid to participate in the program despite explaining the aim, its importance and their rights to withdraw at any time.

Conclusion:

From the present study, concluded that the studied patients had low knowledge score levels prior self-management guidelines, Nevertheless, an improvement in total knowledge score was reported post self-management guidelines, and the self-management guidelines had positive effects for the studied women's and it reflects in decrease pain and increase disability index after implementing the self-management guidelines.

Recommendation:

The after-coming suggestions are recommended depending on the study findings

▪ Ongoing educational programs for females with SLE in order to enhancing their health status.
▪ An Arabic visual and written booklet about SLE that simple, overarching complete, with illustration should be provided all females newly diagnosed with SLE
▪ Repeat of this study with a larger patient sample across various settings.
▪ Ongoing campaign in different heath care settings to raise awareness of women.

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