Effect of Self- Care management on Health Outcomes and Symptoms for Females with Systemic Lupus Erythematosus

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Abstract

Background: Systemic lupus erythematosus is a common chronic autoimmune inflammatory disease and self-care management aimed to equip females with practices to participate and take responsibility in the care of disease. **Aim:** The study aimed to evaluate the effect of self- care management on health outcomes and symptoms for females with systemic lupus erythematosus. **Design:** A quasi-experimental design was utilized. **Setting:** The study was conducted at Rheumatology and Immunology and Antenatal outpatient clinics at El Mansoura University Hospitals. **Sample:** A purposive sample of 66 females was included in the study. **Tools:** Four tools were used for data collection; **Tool (I)** A structured interviewing questionnaire with three parts covering demographic data, clinical data and females' knowledge regarding systemic lupus erythematosus, **Tool (II)** Fatigue severity scale, **Tool (III)** Brief pain inventory & **Tool (IV)** Lupus patient reported outcomes. **Results:** There was a statistical significant difference between pre and one month after self-care management in all items of knowledge regarding systemic lupus erythematosus (P-value < 0.001) among females. There was a highly statistically significant reduction of fatigue and pain level between pre and one month after self-care management (P-value <0.001). There was a highly statistically significant difference in total Lupus PRO scores one month after self-care management as compared to pre interventions (P-value < 0.05). **Conclusion:** Implementation of self-care management had a positive and significant effect on females' knowledge level as well as reducing fatigue and pain severity, additionally a significant improvement in total Lupus PRO scores post self-care management were found. **Recommendations:** Design a continuous health promotion program for females with systemic lupus erythematosus in hospitals.

Keywords: Health Outcomes, Self-Care management, Systemic Lupus Erythematosus.

Introduction

Systemic lupus erythematous (SLE or lupus for short) is a chronic, multisystem disease involving complex pathogenic mechanisms characterized by widespread affections of different body organs as the kidney, cardiovascular system, and central nervous system in a progressive pattern with recurrent exacerbating attacks with a major contribution to the worldwide morbidity and mortality [1].

Lupus occurs ten times more often in females than males. It most commonly occurs in females in the reproductive and working age group with the peak SLE incidence occurs at age 20–29 years, followed by 30–39 years old for females.

The mortality risk in females with SLE has been ranged from twofold to fivefold relative to the total population [2].

Systemic lupus erythematous development has a different risk factors including genetic factors that is often associated with environmental factors and lifestyle factors, such as solar, radiation exposure, stress, sedentary behavior, and use of certain medications that tend to trigger disease manifestation. Early diagnosis, suitable medical management specific to the disease (management and reduction of symptoms) and lifestyle modifications reduce flares and thus prevent complications [3].

Also, pain, fatigue and side effects of medications impact negatively social

functioning, mental health, moreover; complex in the case of fertility and pregnancy [4].

Fatigue is a general and continued feeling of tiredness or difficulty performing physical and mental activities for days to weeks, which is not resolved by rest [5].

Fatigue is the most common and disabling symptom in SLE that may impair female patients' physical and mental health and reduce quality of life by impacting upon their emotions, work, and daily life activities[6].

Non-pharmacological interventions and lifestyle arrangements are very important in disease management, these include female education, protection from sunlight, rest and the reduction of fatigue, use of medication, infection control, vaccination, a diet low in salt, fat and cholesterol, avoidance of stress, pregnancy and contraception and reduction of psychosocial effects [7].

Disease management has an importance in SLE than treatment for increased female survival and for the prevention and managing chronic complications. Continuous education and counseling given to patients and their families on the disease, treatment and interventions in order to reduce flares positively affected female health outcomes and increased self-efficacy which is important in disease management[8].

Self-care management is defined as interventions aim to equip females with practices to participate and take responsibility in the care of disease in order to function optimally through acquiring knowledge and a combination of independent sign/symptom monitoring, medication management, enhancing problem-solving and decision-making skills for medical treatment , management and changing physical activity, dietary, and/or smoking behavior [8,9].

Nurses have a significant role in the SLE management process especially during periods of disease exacerbation. Because the nurse helps females to cope with the disease in their everyday lives, teaches how to deal with lupus symptoms, prevents periods of SLE exacerbations, and provide health education concerning lifestyle changes. The nurse provides the necessary help and emotional support to the female and family, undertaking educational actions connected with lifestyle and rehabilitation to improve their quality of life [10]. Lifestyle modifications, such as avoiding overexposure to sunlight, stress management, smoking cessation and a diet low in saturated and fats are also very important [11].

Significance of the study

Systemic lupus erythematosus (SLE) is a potentially life-threatening autoimmune rheumatic disease, which can affect most organ systems. SLE has an undesirable outcome on various features of female's life, for example mental health, pregnancy, labor, quality of life and daily functioning, which might result in low employment values and heavyweight economic load [9].

The prevalence of SLE in the developed world is 24/100,000 population. Furthermore, there was limited epidemiological studies from Egypt have been published limited by small sample sizes, and have not reported data from multiple geographic regions over the country [12].

In Egypt SLE had a wide variety of clinical and immunological manifestations, the overall estimated prevalence of adult SLE in Egypt was 6.1/100,000 population (1.2/100,000 males and 11.3/100,000 females) [13]. Therefore the aim of this study was to evaluate the effect of self- care management on health outcomes and symptoms for females with systemic lupus erythematosus.

Aim of the Study

The study aimed to evaluate the effect of self- care management on health outcomes and symptoms for females with systemic lupus erythematosus.

Research hypotheses

The following research hypotheses were formulated to fulfill the aim of the current study

H1: Knowledge scores of studied females regarding SLE will expect to be improved post implementation of self-care management**.**
H2: Studied females will exhibit improvement in their fatigue and pain post implementation of self-care management.
H3: Studied females will reveal improvement in their health outcomes post implementation of self-care management.
Subject and Methods
Research Design
A Quasi-experimental research design was utilized in this study.
Research Setting
This study was conducted at Rheumatology and Immunology and Antenatal outpatient clinics of El Mansoura University Hospitals, Egypt.
Subjects
A purposive sample of (66) females diagnosed with systemic lupus erythematosus was recruited in the study using a purposive technique based on inclusion criteria; adult conscious female aged above 18 years, who didn't participate in any previous educational program regarding systemic lupus erythematosus and willing to participate in the study. Based on the flow rate obtained from the statistical records of El Mansoura University Hospitals in the previous year (2020-2021) which was the year of the pandemic period of covid-19 the total population size (127 female) diagnosed with SLE [14] and the sample size was calculated using Krejcie & Morgan (1970) formula [15]

$$n = \frac{N\ Z2\ P\ (1-P)}{d2\ (N-1)\ +Z2\ P\ (1-P)}$$

Where: n= sample size, N=total population size ,   d=error percentage = 0.05,   P=percentage of availability of the character and objectivity =0.1

Z=the corresponding standard class of significance 95% =1.96

$$n = \frac{43.909488}{.660744} = 66.45$$

Accordingly, a sample size was 66 female.

Tools for Data Collection
For collecting the data, four tools were utilized
Tool (I): A structured interviewing questionnaire, this tool was developed by the researchers after reviewing relevant and recent related literature and research studies [13, 16, 17].It was divided into three parts:
Part (1) addressed the demographic data of the studied females including age, level of education, residence, occupation and marital status.
Part (2) was dealt with female clinical data; it included medical history as duration of disease, past medical and family history, medical follow up, signs and symptoms reported by females and aggravating factors of symptoms, also obstetric history including gravida, para, number of previous pregnancy with SLE, previous pregnancy complications with SLE, mode of delivery and previous labor complications with SLE.
 Part (3) was concerned with assessing knowledge of studied females about SLE; it was used as pre-post (one month after self-care management) using 8 items which contained 15 multiple-choice questions covering definition, causes, risk factors, signs and symptoms, SLE diagnosis, treatment and complications of systemic lupus.
Scoring system

Two levels of scoring for questions were as the following; complete and correct answer scored (2), incomplete and incorrect answer scored (1). The total score of knowledge was between 15 and 30, then distributed into two categories as unsatisfactory knowledge when the total score less than 75% (1< 23 degrees) and considered satisfactory knowledge when the total score equal and more than 75% (23 ≤ 30 degrees).

Tool (II): Fatigue Severity Scale (FSS)
It is a short and simple tool adopted from [18]. The FSS consisted of a form with nine items concerning fatigue symptoms.

Scoring system
Each statement is rated from one to seven. A higher score indicates a higher fatigue level. Options for answers: 1=strongly disagree, 2=disagree, 3=tend not to participate, 4=undecided, 5=tend to participate, 6=agree, 7=strongly agree.

Tool (III): The Brief Pain Inventory (BPI) – Pain Interference scale
It is a short questionnaire which was adopted from [19] to assess pain interference on daily function. The BPI measures how much pain has interfered with seven daily activities, including general activity, walking, work, mood, enjoyment of life, relations with others, and sleep.

Scoring system
The items of pain interference on females function are presented as numeric rating scales, with 0 not interfere to 10 completely interfere. BPI pain interference is scored as the mean of the seven interference items. A function interference subscale is calculated by adding the scores on the interference items.

Tool (IV): Lupus Patient Reported Outcomes (Lupus PRO)
It is SLE-specific tool that was adopted from [20]. The tool has a 43-item questionnaire that includes not only health related quality of life (HRQoL) domains such as lupus symptoms, cognition and body image but also non HRQoL domains including desires–goals, coping, social support and satisfaction with care. The Lupus PRO was

translated into Arabic and used to assess females reported outcome. The questionnaire was divided into 12 domains: lupus symptoms (Three items), cognition (two items), lupus medication (two items), procreation (two items), physical health (five items), pain-vitality (five items), emotional health (five items), body image (five items), desires-goals (four items), social support (two items), coping (three items) and satisfaction with care (four items).

Scoring system
The Lupus PRO has 5 point Likert response format, where 0=none of the time/not applicable, 1= a little of the time, 2= some of the time, 3=Most of the time, 4= All of the time, 5= not applicable (recode as 0 for scoring). Each item scored on Likert scale and each domain score was calculated by summing its items. A total score is calculated by summing the score of the 12 domains. Total Lupus PRO score presented in three categories as, low >75%, moderate 50 – 75%, and high <50%

Tools validity
The validity of the tools was checked by a panel of seven experts from the Medical Surgical & Maternity and Newborn Health Departments, modifications were done based on their opinions.

Test reliability
Testing reliability of the proposed tools was assessed using Cronbach's Alpha coefficient test; the first tool's internal consistency was 0.86. For the second tool (FSS) internal consistency was 0.95.The third tool (the Brief Pain Inventory (BPI) – Pain Interference scale) had an internal consistency of 0.78 and the fourth tool Lupus Patient Reported Outcomes (Lupus PRO) was 0.82.

Ethical Considerations
An informed oral consent was taken from females who agreed to participate in the research process after explaining all information related to the study (aim and activities, expected outcomes, and benefits

and risks associated) before data collection. Confidentiality and anonymity were also guaranteed. Participants were told the right to discontinue at any time without any consequences and without giving any reason. Values, culture, and beliefs would be respected. A code number was used instead of name.

Pilot Study

The simplicity, clarity, and applicability of the tools were evaluated in a pilot study involving 10% of the entire sample (7 female). The time required to fill the questionnaires was determined and any problems peculiar during data collection were identified. Females participated in the pilot study were excluded from the main study sample.

Field Work (Procedure)

An official letter from the dean of the Faculty of Nursing, Helwan University was taken and forwarded to the hospital director and nursing director of Mansoura University Hospitals seeking permission to perform the study after clarifying the aim of the study. The study was conducted in four phases namely assessment, planning, implementation, as well as evaluation. The phases lasted six months from beginning of January, 2021 to the end June 2021.

Researchers were available at Rheumatology and Immunology and Antenatal outpatient clinics at El Mansoura University Hospitals two days per week (Saturday & Tuesday) from 9.00 Am to 2.00 Pm. The clinics are suitable for direct contact with the females and applying the self-care management. The time consumed to fill the study tools was from 30 to 40 minutes for the pre-test; and about 20-30 minutes for posttest.

Phase I: Assessment phase

The researchers interviewed the females in the outpatient waiting place, introduced themselves, and explained to each female the objective, process, and expected outcomes and then informed consent from females was attained. The tools were filled by females or the researchers if the females were unable to read or write (pretest).

Phase II: Planning phase

According to the analysis of pretest findings gained during the assessment phase on detecting the actual educational needs of females and relevant literature, the researchers designed self-care management. The content of the self-care management was prepared by the researchers based on literature review [13, 21, 22]. Objectives of the study were determined based on the needs of the studied females. An illustrative structured booklet was prepared and written in simple Arabic language as a guide for the females. The study tools were filled in and completed in 2 phases (pre- self-care management and one month after the implementation of the self-care management).

Phase III: Implementation Phase

During this phase the self-care management was carried out through five sessions (two theoretical and three practical).

The first session focused on overview about systemic lupus erythematosus by providing information about definition, causes, risk factors, signs and symptoms.

The second session involved information about diagnosis, treatments, and measures related to healthy diet as eating well balanced diet, taking vitamins as prescribed .Also the session included complications such as 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.

The third session addressed the practice of females that involved demonstration to females physical activities by explaining and demonstrating instrumental activities of daily living, self-care activities performed at home and pain & fatigue management.

The fourth session involved demonstration to females the techniques used for stress management including relaxation techniques and lifestyle modification as well as

measures to prevent relapses of trigger factors.

The fifth session focused on empowering females to manage SLE symptoms independently and its recurrence, additionally compliance with medical regimen. The researchers presented ways of coping strategies such engage in problem solving to overcome and resolve the problems encountered in doing self-care , expressing distressing emotions and maintain emotionally supportive relationships. These educational sessions were done either individually or in groups (2-3) female based on the number of females in each room in the clinics.

Each session started by a summary about what had been given through the previous session then the objectives of the new topics, taking into consideration the use of simple language to suit the level of females. The duration of each session ranged from 30-45 minutes for theoretical sessions and (45-60) minutes for practical sessions and it was accompanied by feedbacks. Discussion, motivation and reinforcement during sessions were used to enhance learning. Teaching methods used were group discussion, questions and answers, demonstration and re-demonstration, PowerPoint presentations, brainstorming, and short educational videos.

Evaluation Phase

One month after implementation of the self-care management, post-test was applied to each female in the study using the same pretest tools (the first tool, the second , third and fourth tools) to evaluate effect of the self-care management , this evaluation was done during monthly follow up visit of females to outpatient clinics.

Statistical Design

The collected data were analyzed using (SPSS) version 24. The frequency and percentage of qualitative data, the mean and standard deviation of quantitative data were utilized. A Chi-square and paired sample t-test was used to detect the relation between the variables. Relations between different qualitative variables were tested using correlation coefficient (person correlation). Probability (p-value) $\leq$ 0.05 was significant < 0.001 was highly significant and > 0.05 was non-significant [23].

Results

Table (1): Denotes that 51.5% of studied females were more than 30 years old with a mean age 30.07±7.57. Regarding the level of education 53.0% had preparatory school. It was found that 83.3% of the females had living in rural areas. Regarding marital status, 75.8% of studied females were married and finally 71.2% were housewives.

Figure (1): Illustrates that, 57.6% of studied females had obtained information about systemic lupus Erythematosus from mass media. Meanwhile, 21.2% of the studied females obtained information from health care staff.

Table (2): Reflects that, 29.1% of studied females were primigravida, while the rest of them were multigravida with 36.4% having previous 2-3 pregnancies. Meanwhile, 34.5% of the studied females were nulliparous while, the rest had previous labor experience. The common mode of delivery was cesarean section (61.2%). According to number of pregnancies in the presence of SLE, 36.3%, 30.2% and 25.1% of the studied females had one, two and three or more pregnancies respectively. The reported complications during previous pregnancies were abortion (81.8%), pre-eclampsia (13.7%) and fetal congenital anomalies (4.5%). Also, 14 females of the study sample had associated complications with delivery, which included 71.4% premature rupture of membrane and 28.6% premature labor.

Table (3): Reveals that, 39.4% of studied females had the disease from 1 to <5 years. 72.7% didn't have other chronic diseases. Moreover 63.6% of them had no family history of systemic lupus erythematous and 30.3 % of them had follow up every two months. Regarding risk factors, 75.8% 66.7& 53% of studied females had physical,

emotional and hormonal risk factors respectively for SLE.

Figure (2): Illustrates that, the most common symptoms of studied females were fatigue (87.9%), pain (74.2%), skin rash (71.2%) as well, 69.7% had hair loss & 60.6% complaining of arthritis.

Table (4): Illustrates that, there was a highly statistically significant difference between pre and one month after self-care management in all items of knowledge regarding SLE (p-value < 0.001).

Figure (3): Displays that, there was noticeable progress among studied female's total score of knowledge pre and one month after self-care management. As well as the figure shows that , 17.9% of studied females had satisfactory total knowledge about SLE, which increased post self-care management to 84.3%.

Table (5): Clarifies that, there was a highly statistically significant difference among the studied females between pre and one month after self-care management regarding to all items of fatigue (p-value < 0.001). As well the same table showed a significant improvement with a reduction in total fatigue severity after one month of self-care management.

Table (6): Reflects that, there was highly statistical significant difference among the studied females between pre and one month after self-care management regarding to pain level (p-value < 0.001). As well a significant reduction in the total pain level among studied females was observed one month of self-care management**.**

Table (7): Displays that; mean total Lupus PRO score of studied females were improved significantly after one month of self-care management (97.1667 ±3.85340) compared to (83.2424±4.19912) pre self-care management. There were highly statistical significant differences regarding all Lupus PRO items between pre and one month after self-care management.

Table (8): Portrays a negative correlation between pain, fatigue and Lupus PRO score among studied females. In addition there was a highly positive correlation among studied females total knowledge, pain, fatigue and total Lupus PRO score at one month after self-care management.

Table (1): Distribution of the studied females According to demographic characteristics (n=66)

Items	No	%
Female's age		
20< 25	9	13.6
25<29	23	34.9
≥ 30	34	51.5
Mean ±SD	**30.07±7.57**	
Educational level		
Can't read & write	4	6.1
Primary	23	34.9
Preparatory	35	53.0
Secondary	3	4.5
University	1	1.5
Place of residence		
Urban	11	16.7
Rural	55	83.3
Marital status		

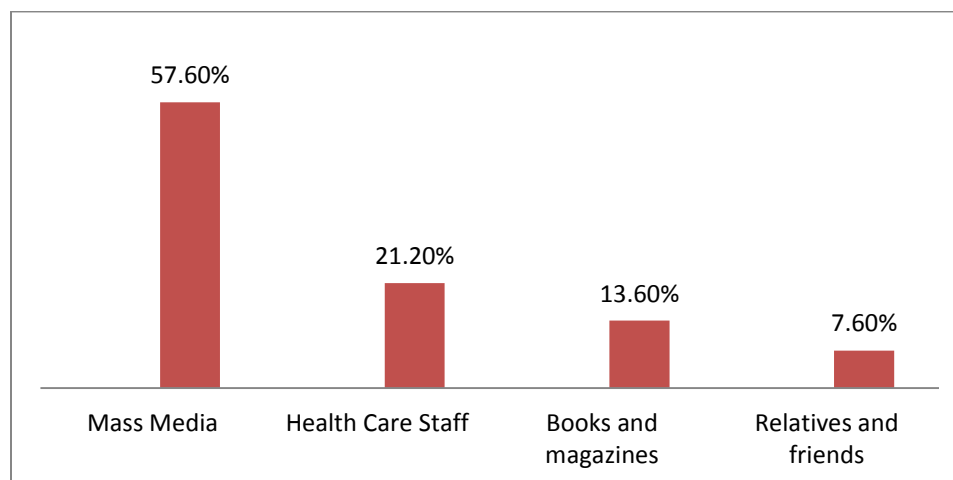|		
Married	50	75.8
Not Married	11	16.7
Divorced	5	7.5
Occupation		
Housewife	47	71.2
Worker	19	28.8

Figure (1): Distribution of the studied females according to source of information regarding systemic lupus Erythematosus (n =66)

Table (2): Distribution of the studied females according to obstetric history (n= 55)

Items	N0	%
Gravida		
Primigravida	16	29.1
2-3	20	36.4
4-5	17	30.9
>5	2	3.6
Para		
Nulliparous	19	34.5
Primipara	16	29.1
2-3	15	27.3
4-5	4	7.3
>5	1	1.8
No of previous pregnancy with SLE (n=36)		
Non	9	25.1
1	13	36.3
2	11	30.2
≥3	3	8.4
previous pregnancy complication with SLE:(n=22)		
Abortion	18	81.8
Preeclampsia	3	13.7
Fetal congenital anomalous	1	4.5

Mode of delivery (n=36)		
Normal Vaginal delivery	14	38.8
Cesarean section	22	61.2
previous labor complications with SLE (n=14)		
Premature labor	4	28.6
Premature rupture of membrane	10	71.4

Table (3): Distribution of the studied females regarding medical history (n=66)

Items	N0	%
Onset of the disease		
< one year	7	10.6
1-4	26	39.4
5-10	14	21.2
>10	19	28.8
Other chronic diseases		
Yes	18	27.3
No	48	72.7
Family history of SLE		
Yes	24	36.4
No	42	63.6
Medical follow up		
Monthly	9	13.6
Every two months	20	30.3
Every three months	15	22.7
Every six months	10	15.2
Irregular follow up	12	18.2
Risk factors*		
Emotional	44	66.7
Physical	24	75.8
Sunlight	12	18.2
Eating pattern	22	33.3
Sleep disturbance	50	36.4
Hormonal	35	53.0

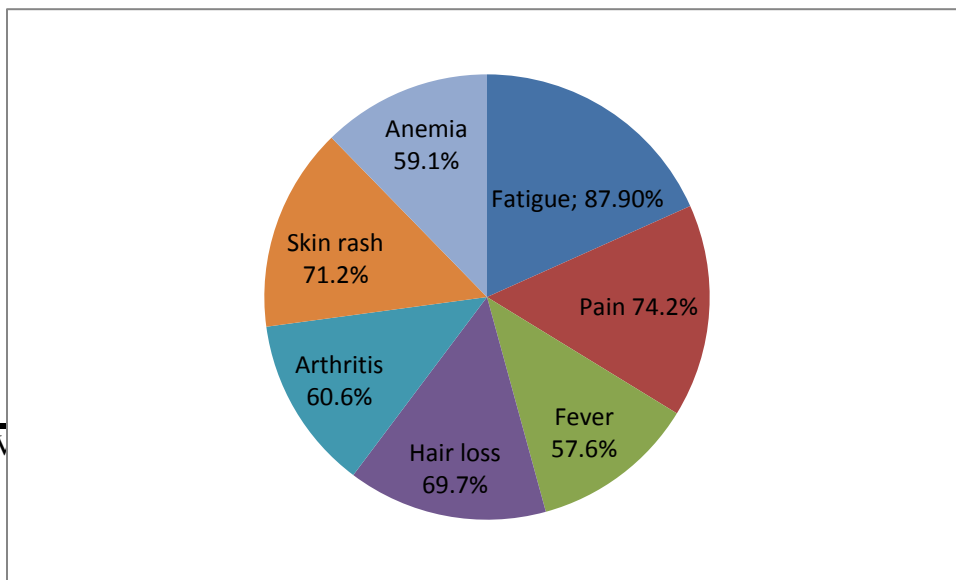 ***Responses are not mutually exclusive**

Figure (2): Distribution of the studied females regarding to systemic lupus erythematosus symptoms (n=66)

Table (4): Distribution of the studied females according to knowledge level pre and one month after self-care management (n=66)
* Statistically significant difference (p≤0.05), ******Highly statistically significant difference

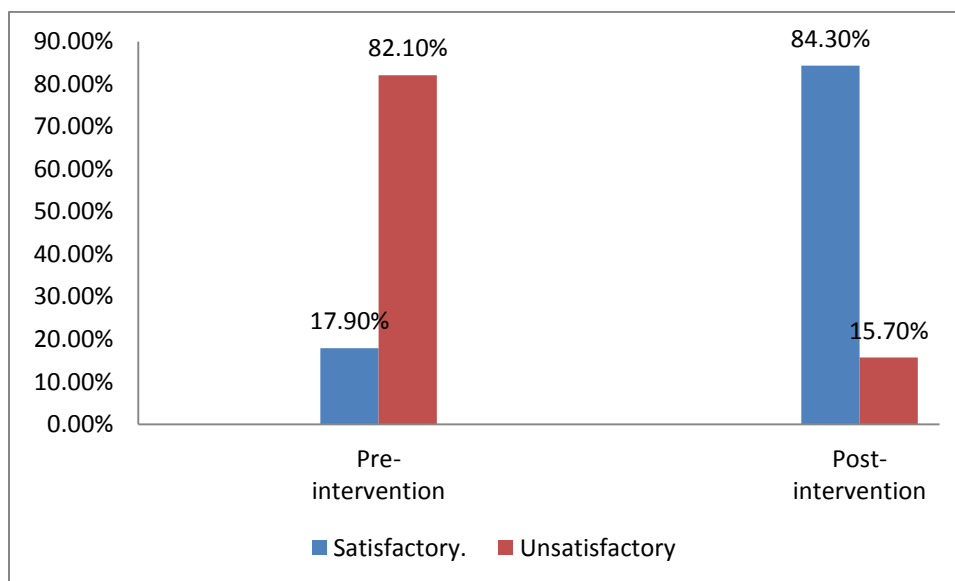| Items	Pre self-care management				One month after self-care management				x^2 Test	P- value
	correct		incorrect		correct		Incorrect			
	NO	%	NO	%	NO	%	NO	%		
1. Definition of systemic lupus.	18	27.3	48	72.7	56	84.8	10	15.2	44.41	0.000**
2. Causes of systemic lupus.	9	13.6	57	86.4	47	71.2	19	28.8	44.78	0.000**
3. Types of systemic lupus.	7	10.6	59	89.4	54	81.8	12	18.2	67.32	0.000**
4. Risk factors of systemic lupus.	3	4.5	63	95.5	61	92.4	5	7.6	98.47	0.000**
5. Clinical manifestations of systemic lupus.	12	18.2	54	81.8	53	80.3	13	19.7	50.95	0.000**
6. Diagnostic tests of systemic lupus.	10	15.2	56	84.8	50	75.7	16	24.3	48.88	0.000**
7. Treatment of systemic lupus.	8	12.2	58	87.8	52	78.8	14	12.2	59.15	0.000**
8. Complications of systemic lupus.	11	16.7	55	83.3	48	72.7	18	27.3	41.95	0.000**

(p≤0.001).

Figure (3): Distribution of the studied females regarding total knowledge about SLE pre and one month after self-care management (n=66)

Table (5): Distribution of the studied females according to fatigue severity pre and one month after self-care management (n=66)

Fatigue Items	Pre self-care management	One month after self-care management	Paired t test	P value
	Mean ±SD	Mean ±SD		
1. Motivation is lower when being fatigued.	6.2576 ±.61456	2.9545 ±.71105	30.614	<0.001**
2. Exercise brings on fatigue.	6.1061 ± .80630	2.6818 ±.82572	20.131	<0.001**
3. Being easily fatigued.	5.6970 ± .74358	2.6364 ±.93868	18.020	<0.001**
4. Fatigue interferes with physical functioning.	5.6364 ±.75725	2.5909 ±.58117	23.696	<0.001**
5. Fatigue causes frequent problems.	5.8030 ±.63778	2.8182 ± .80210	23.204	<0.001**
6. Fatigue prevents sustained physical functioning.	5.9545 ±.68908	2.4242 ± .63393	27.168	<0.001**
7. Fatigue interferes with carrying out certain duties and responsibilities.	6.0758 ± .80976	2.7424 ± .50568	30.084	<0.001**
8. Fatigue is the most disabling symptoms.	5.9394 ±.90942	2.7576 ± .87812	21.990	<0.001**
9. Fatigue interferes with work, family, or social life.	5.8939 ±.58517	2.5606 ± .65934	27.150	<0.001**
Total	53.3636 ±2.47222	24.1667 ±2.62288	57.596	<0.001**

 * Statistically significant difference (p≤0.05), **Highly statistically significant difference (p≤0.001).

Table (6): Distribution of the studied females according to pain interference level pre and one month after self-care management (n=66)

Pain Interference items	Pre self-care management	One month after self-care management	Paired t test	P value
	Mean ±SD	Mean ±SD		
General Activity	6.2576 ±1.57996	3.0455±.99895	15.505	<0.001**
Mood	6.6364± 1.41025	2.5758±1.05336	19.948	<0.001**
Walking ability	6.5758± 1.61779	2.1970±.70645	19.720	<0.001**
Normal work (includes both work outside the home and housework)	6.4242±1.35942	2.2879±.98863	21.991	<0.001**
Relations with other people	6.3030±1.66382	2.4697± .93183	15.780	<0.001**
Sleep	5.9394±1.51788	3.0606±1 .18684	15.445	<0.001**
Enjoyment of life	5.9394± 1.48716	2.9545± 1.31771	13.211	<0.001**
Total	44.3788 ± 3.29925	18.5909 ± 3.29091	44.219	<0.001**

 * Statistically significant difference (p≤0.05), **Highly statistically significant difference (p≤0.001).

Table (7): Mean Lupus PRO scores of studied females pre and one month after self-care management (n=66)

Lupus PRO Items	Pre self-care management Mean ±SD	One month after self-care management Mean ±SD	Paired t test	P value
Lupus Symptoms	3.3788±1.33319	9.3182±1.47970	-23.863	<0.001**
Cognition	1.8333 ±.75617	5.1818 ±.94314	-23.791	<0.001**
Lupus Medication	4.6364 ±1.60419	6.4242 ±1.05336	-10.473	<0.001**
Procreation	2.7121 ±1.17362	6.2879 ±1.17362	-21.924	<0.001**
Physical Health	6.9394 ±1.17511	15.8788 ±1.27116	-37.502	<0.001**
Pain-Vitality	7.2879 ±1.87095	17.1212 ±1.13022	-36.990	<0.001**
Emotional Health	7.7424 ±1.47085	17.0152 ±1.60281	-39.115	<0.001**
Body Image	5.7727 ±1.39002	12.9697 ±1.63585	-32.650	<0.001**
Desires-Goals	3.6818 ±1.24232	10.1515 ±1.25566	-28.160	<0.001**
Social support	2.7576 ±.74546	5.1061 ±1.15197	-13.143	<0.001**
Coping	4.4394 ±1.02475	8.1970 ±1.54142	-20.791	<0.001**
Satisfaction with care	5.0303 ±1.21490	10.5455 ±.91453	-28.515	<0.001**
Total Lupus PRO score	83.2424±4.19912	97.1667 ±3.85340	20.854	<0.001**

* Statistically significant difference (p≤0.05), **Highly statistically significant difference (p≤0.001).

Table (8) Correlation between studied females' total knowledge score, fatigue, pain and total lupus PRO score pre and one month after self-care management (n=66)

Variables		Pre self-care management				One month after self-care management			
		Knowledge	Fatigue	Pain	Lupus PRO	Knowledge	Fatigue	Pain	Lupus PRO
Knowledge pre intervention	R	1	.037	.044	.226	-	-	-	-
	p-value		.770	.728	.068	-	-	-	-
Fatigue pre intervention	R	.037	1	.049	-.137	-	-	-	-
	p-value	.770		.697	.272	-	-	-	-
Pain pre intervention	R	.044	.049	1	.041	-	-	-	-
	P-value	.728	.697		.750	-	-	-	-
Lupus PRO pre intervention	R	.226		.041	1	-	-	-	-
	p-value	.068		.750		-	-	-	-
Knowledge one month after intervention	R	-	-	-	-	1	.351**	-..434**	-.256*
	p-value	-	-	-	-		0.000	0.000	0.05
Fatigue one month after intervention	R	-	-	-	-	.351**	1		.351**
	p-value	-	-	-	-	0.000			0.000
Pain one month after intervention	R	-	-	-	-	-.434*	.152	1	310*
	p-value	-	-	-	-	0.05	.222		0.05
Lupus PRO one month after intervention	R	-	-	-	-	-.256*	.351**	.310*	1
	p-value	-	-	-	-	0.05	0.000	0.05	

Discussion

Systemic lupus erythematosus is an autoimmune, systemic and a heterogeneous disease associated with widespread inflammation and tissue damage. It is associated with variations in signs, symptoms, and disease activity. Also, it is characterized by generalized body pain and most importantly fatigue [24]. Therefore, this study aimed to evaluate the effect of self- care management on health outcomes and symptoms for females with systemic lupus erythematosus.

Concerning age, the present study results illustrated that more than half of the studied females aged more than 30 years old. This finding agrees with Wageeh et al., (2020) [17] in a study "effect of nursing education on knowledge and self-care for patients with systemic lupus erythematosus" who reported that the majority of the studied subjects age ranged from (35-45) years old. While this results inconsistent with Abd El latifa , Hassana and Gomaab (2018) [25] who studied "effect of systemic lupus on patient's self-esteem and quality of life" and showed that half of the study sample was aged between 20 and 30 years . Also, Yu et al., (2020) [26] conducted a study entitled "trends of hospital palliative care utilization and its associated factors among patients with systemic lupus erythematosus in the United States" and found that more than half of the study sample was older than 50 years. It seemed that SLE occurred most frequently between the age ranges 20-39 years. This high predisposition of childbearing age produced a major concern for care of this age group as well SLE is more common among females in the reproductive age as a result of hormonal changes in adolescence, and perinatal period till premenopausal age. Regarding the level of education, the present study results showed that more than half of the studied females had preparatory school. This finding is in accordance with Wageeh et al., (2020) [17] who revealed that the majority of the subjects were educated, while, Zhang etal., (2019) [27], who studied "lack of patient education is risk factor of disease flare in patients with systemic lupus erythematosus" clarified that half of the studied sample had a high education.

As regard place of residence the present study finding clarified that more than half of the females were living in rural areas, this finding is supported by Abd El-Azeem et al., (2018) [28] who studied " effect of health promotion program on quality of life for patients with systemic lupus erythematosus" and revealed that more than half of the studied sample were living in rural areas.

As regards to marital status the present study results indicated that three quarters of the females were married. This finding goes on the same line with Zhang etal., (2019) [27] who clarified that about three quarters of the patients were married. In the same context, this result is congruent with O'Riordan, Doran and Connolly (2017) [29] who studied "fatigue and activity management education for individuals with systemic lupus erythematosus" and mentioned that the majority of the participants were married. From the

researchers' point of view these findings reflecting that SLE is a long-term disability disorder affecting the young patients during their productive years as well as the hospital serves the surrounding rural areas with minimal fees, finally; differences in results between researches could be due to differences of tools used for data collection and sitting at which the study was conducted.

Regarding the source of information about systemic lupus erythematosus the present study results illustrated that about two thirds of studied females had obtained information regarding systemic lupus erythematosus from mass media. This results are supported by Bin Haikel and Al Tulaihi (2018) [30], who conducted a study in Riyadh, Saudi Arabia about "awareness of systemic lupus erythematosus among primary health care patients" and clarified that more than half of participants had heard the term systemic lupus erythematosus and recognized the disease through the internet way (online resources). While Macejova et al., (2020) [21], in the study titled "living with systemic lupus erythematosus: a profile of young female patients" described that the most frequent sources of SLE related information were mostly physician.

Regarding previous obstetric history, the results of the current study revealed that more than one fourth of studied females were primigravida, while the rest of them were multigravida with more than one third had previous 2-3 pregnancies. Furthermore, about two fourth of the studied females was nulliparous while the rest had previous

labor experience. This study findings agrees with Abd El-Salam et al.,(2019) [31], who conducted a study entitled "assessment of quality of life among pregnant women with systemic lupus erythematosus " and reported that about one fifth of the study women were primigravida while the rest of them were multigravida with more than two fifth having previous 2-3 pregnancies.

Continuing talking about obstetric history, the results of the present study clarified that about two fifth and one third of the studied females had one and two pregnancies in the presence of SLE, as well; the most reported complications during previous pregnancies were abortion followed by pre-eclampsia. Also, the most associated complications with delivery included premature rupture of membrane. These study findings are supported by Abdwani et al., (2018) [32], who studied "neonatal and obstetrical outcomes of pregnancies in systemic lupus erythematosus" and found that about half of the studied sample had previous obstetric history of abortion, about two fifth had preeclampsia and the minority had preterm labor.

With reference to onset of systemic lupus erythematous, the present study revealed that about two fifth of studied females had the disease from one year to less than five years. This result goes on the same line with El Fadeel, and El-Deen (2020) [16], who reported that half of the study group and more than one third of the control group had SLE for less than 5 years. Also, Gheita etal., (2021)[13], who studied "adult systemic

lupus erythematosus in Egypt" mentioned that disease duration was 4 years.

As regard other chronic diseases the results of the present study results revealed that more than two thirds of the studied females didn't have other chronic diseases. This finding are supported by Elsayed and Mesbah (2018) [33] who studied "effect of health education based intervention on self-care among systemic lupus erythematosus clients" and revealed that three quarters of patients didn't have other chronic diseases. On the contrary, Kankaya and Karadakovan (2020) [7] who studied "effects of web-based education and counseling for patients with systemic lupus erythematosus: self-efficacy, fatigue and assessment of care" found that more than half of study sample had other comorbidities.

Regarding risk factors that increase symptoms, the present study results clarified that, three quarter, more than two thirds and more than half of studied females had physical, emotional and hormonal risk factors for SLE respectively. This finding is consistent with Mohamed, EL-Bastawesy and Hegy, 2020) [9] who studied "impact of an education program on self-care agency and self-rated abilities among patients with systemic lupus erythromatosis" and stated that more than one third of the patient's symptoms increase due to physical and emotional tiredness.

Similarly; this result is in accordance with Kusnanto et al., (2018) [34], who stated in a study about "self-care model application to improve self-care

agency, self-care activities, and quality of life in people with systemic lupus erythematosus" that the precipitating factor was physical stress and tiredness .

In relation to medical follow up the study results showed that one third of studied females had follow up every two months. Macejova et al.,(2020) [21] mentioned that more than two fifth had follow up every one month, and more than one third had follow up every two months which support the present study findings. However, Elsayed and Mesbah (2018) [33], showed that one third of the studied patients had follow up every six months. According to researcher's' point of view the most studied females reported that they came to hospital every two months as the outpatient clinics policy changed from regular follow-up and obtaining medications monthly to every two months because of Covid -19 pandemic.

Regarding symptoms of systemic lupus erythematosus as reported by the studied female, the present study results illustrated that the most common symptoms were fatigue, pain, skin rash as well as hair loss and complaining of arthritis. This finding is consistent with Cornet et al., (2021) [35] in a study entitled " living with systemic lupus erythematosus" and reported that fatigue is recognized as one of the most prevalent and common symptom affecting more than three quarter of studied females with SLE.

Similarly Bin Haikel and Al Tulaihi, (2018) [30], reported that the most common symptoms of lupus are complaints of fatigue and health

malaise. As well; many patients experience symptoms that include skin rash, photosensitivity and mouth ulcers. In addition Mahmoud et al., (2018) [36],   in a cohort study of "clinical and immunological pattern and outcome of Egyptian systemic lupus erythematosus patients" reported that common presenting features of SLE occurring at the onset of the disease were arthritis**.**

Continuing talking about symptoms Abdel Masieh et al., (2019) [37],   who studied "systemic lupus erythematous: symptoms and signs at initial presentations" mentioned that more than half of study sample had arthritis. Also a recent study conducted by Elgendi, (2021) [38],   concluded that pain, tenderness and swelling of the joints are frequent symptoms for SLE females.

Regarding the total knowledge of studied females regarding systemic lupus erythematous the results of the current study clarified a noticeable progress among studied female's total score of knowledge pre and one month after self-care management with a highly statistically significant difference between pre and one month after self-care management. These results confirms the research hypothesis (H1) which stated that knowledge scores of studied females regarding SLE will expect to be improved post implementation of self-care management.

This results was congruent with Wageeh et al., (2020) [17], who show that there was a high statistically significant difference in patient knowledge regarding SLE in the pre-

posttest for the study subjects with a p value =0.001. According to researchers' point of view deficient in knowledge before carrying out self-care management, may be due to unavailability of educational programs to give females required information about disease. As well increasing female's ability to manage their problems after increasing their awareness and acquiring healthy behaviors through educating them.

Moreover, the study finding was supported by Elsayed and Mesbah (2018) [33], who mentioned that, after implementation of the intervention, there were improving mean and standard deviation of studied patients' knowledge regarding systemic lupus erythematous disease with statistically significant differences between pre and post intervention. In this respect Mostafa and Abd-Elrehem (2017) [39], who studied "self- management guidelines: effect on awareness of patients with systemic lupus erythmatosus" added that more than two thirds of the patients included in their study had satisfactory awareness level regarding SLE post-implementation of self-management guidelines with highly statistical significance.

Concerning studied females fatigue the current study showed that, there were statistically significant differences in fatigue between pre and one month after self-care management with significant reduction in the level of fatigue in the studied females was observed post self-care management which supported hypothesis two which stated that studied females will exhibit

improvement in fatigue and pain post implementation of self-care management. This result is in accordance with Kankaya and Karadakovan (2020) [7], who studied "effects of web-based education and counseling for patients with systemic lupus erythematosus: self-efficacy, fatigue and assessment of care" and reported a significant reduction in the level of fatigue in the experimental group that had been observed in measurements after the intervention.

Similarly, Youssef, (2019) [3], who studied "effect of exercises training on fatigue, depression and physical activity in patients with systemic lupus erythematosus" reported that a significant difference post treatment than pre-treatment in fatigue severity with p<0.001. According to researchers' clinical experience, this could be due to positive effect of self-care management as well using non pharmacological management therapies and coping strategies such as relaxation techniques, increasing physical activities gradually and exercise as well as improving females diet and instruct on the importance of vitamin D supplement in dealing with fatigue demonstrated a beneficial effect on fatigue

As regard studied female's pain, the present study findings revealed that, there were statistically significant differences among the studied females between pre and one month after self-care management regarding to pain. As well a significant reduction in the level of pain in the studied females was observed post self-care management.

These results also confirmed hypothesis two.

This finding is in accordance with Mohamed et al., (2018) [40], who studied "effect of self-management guidelines on health outcomes for patients with systemic lupus erthematosus" and concluded that there was a high statistically significant difference regarding pain. This could be due to positive effect of self-care management as well using non pharmacological management methods such as relaxation exercises such as deep breathing exercise, heat/cold application, exercises and positioning.

In concern to mean Lupus PRO scores of studied females the present study result displays that there were highly statistical significant differences regarding all Lupus PRO items between pre and one month after self-care management which support hypnosis three of the study which stated that studied female will reveal improvement in health outcomes post implementation of self-care management.

This could reflect the importance of self-care management in improving health outcome for SLE females. In this respect Elsayed and Mesbah (2018) [33], illustrated highly statistical significant improvement regarding all Lupus PRO items post intervention.

These findings are compatible with Williams et al., (2017) [11], in a study entitled "effective self-management interventions for patients with lupus" who clarified that self-management interventions that incorporate both social support and health education had a positive effect in improving health

outcome through reduced pain, improved function and delayed disability among patients with lupus.

In the same context Gholizadeh et al.,(2019) [41] who studied " body image mediates the impact of pain on depressive symptoms in patients with systemic lupus erythematosus" reported that the Lupus PRO- pain & vitality and Lupus PRO-body image indicate lower scores on the Lupus PRO before intervention which demonstrate elevated symptomatology. This finding is in accordance with Feldman et al., (2013) [42] who studied "designing an intervention for women with systemic lupus erythematosus from medically underserved areas to improve care" and found that the success of an intervention can be measured by improvements in ability to perform daily living activities, maintain a healthy diet, and exercise regularly as outcome measures.

The results of present study revealed a significant positive correlation among studied females total knowledge, pain, fatigue and total Lupus PRO score at the one month after self-care management. This result is consistent with Kusnanto, et al.,(2018) [34], they declared that the self-care activities that had been implemented increased quality of life. In the same context Pellegrini et al., (2018) [43], in the study about "use of physical activity monitors in rheumatic populations" found that self-care activities are carried out to reduce the arthritis pain often experienced by people with rheumatology disorders, such as SLE. This could reflecting the importance of performing physical exercise or sports

in increasing female's vitality, primarily by helping them to overcome fatigue, also effective stress management can help female maintain emotional stability and increase adaptive coping.

Additionally; this result is consistent with Elsayed and Mesbah (2018) [33], who indicated highly positive association among studied subjects total knowledge, self-care practice and total Lupus PRO score post intervention. While Sari, (2016) [44], who studied "systemic lupus erythematosus: correlation between sensory knowledge, self-efficacy, preventive action towards triggers factors, self-care practice and quality of life" found that self-care practices were uncorrelated with health related quality of life and health outcomes in lupus patients.

Conclusion

The study's findings concluded that the implementation of self-care management had a positive and significant effect on females' knowledge level as well as reducing fatigue and pain severity, additionally a significant improvement in total Lupus PRO scores post self-care management were found. There was a highly positive correlation among studied females total knowledge, pain, fatigue and total Lupus PRO score at the post self-care management. Thus, the aim of the study was achieved and research hypotheses were supported.

Recommendations

The following recommendations are suggested:

- A simplified, comprehensive and illustrated Arabic guided images booklet about SLE should be distributed for each newly admitted female diagnosed with SLE.
- Encouraging the holistic approach for caring of SLE females through interdisplinary team including (physician, nurses, social workers and psychologists).
- Design a continuous health promotion program for females with SLE in hospitals in addition to media to help in improving the health status of these females.
- Conducting additional studies on larger samples from a wider range of females.

Further studies are suggested to

- Conduct web-based education to increase female's awareness about SLE.
- Apply educational programs for maternity' nurses about the continuous health promotion for females with SLE in hospitals.

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