Effect of Self-Management Guidelines on Awareness, Pain and Disability among Patients with Systemic Lupus Erythematosus

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Abstract: Background Systemic lupus erythematosus is a common chronic autoimmune inflammatory disease which can affect most organ systems. Effective self- management guidelines are required as they may be of a great value in improving awareness, minimizing pain, fatigue and disability. **Purpose**: To assess the effect of self-management guidelines on awareness, pain and disability among patients with systemic lupus erythematosus. **Design**: a quasi-experimental research design was utilized for this study. **Setting**: The current study was carried out at rheumatology outpatient clinic in Menoufia University Hospital, Shebin El-Kom. **Sampling**: A consecutive sample of 70 adult patients with systemic lupus erythematosus were assigned alternatively into two equal groups (35 patients in each group). **Instruments**: Three instruments were used for data collection: Knowledge of Systematic Lupus Erythematosus Structured interviewing, Visual Analogue Pain Scale and Stanford Disability Index. **Results**: the current study revealed that 82.9% and 77.2% of study and control groups respectively had unsatisfactory total knowledge pre- intervention. While 80% and 74.3% respectively of study group compared to 17.1% and 20% of control group had good total knowledge level at post and follow up self-management guidelines. **Conclusions**: Self-management guidelines had significant effect on improving the total awareness level, reducing severity of both pain and disability among study group (group I) than control group (group II). **Recommendations**: Supervised continuous self-management programs for patients with Systemic lupus erythematosus (SLE) in hospitals should be implemented to improve patient's awareness about Systemic lupus erythematosus (SLE) and its management. Health education program including self management guidelines should be developed and provided for patients having systemic lupus erythematosus.

Key words: Awareness, Pain, Disability, Self-Management Guidelines and Systemic Lupus Erythematosus.

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Introduction

Systemic lupus erythematous (SLE) is chronic, heterogeneous, multi-system autoimmune disease that is persistent and recurrent. It is a complicated multiorgan disease that can lead to organ damage 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 (Mohamady et al., 2022).

Systemic lupus erythematosus has a detrimental impact on many elements of a patient's life, including mental health, quality of life, and everyday functioning, which can lead to lower employment rates and a significant financial burden. According to prior research, patients with a high degree of self-care may have better health outcomes; Physical exercise is recommended for the management of pain and fatigue in patients with inflammatory arthritis thus, the patient must learn self-care knowledge and abilities, as well as identify appropriate strategies to control surrounding settings, in order to maintain optimal health. Because the major causes of mortality from SLE are its consequences, such as end-stage renal disease and cardiovascular disease, rather than the illness itself (Gomez et al., 2021).

Chronic joint's pain is very common in lupus. It can have a huge impact on quality of life, and can also affect the lives of family and those around. Also, it is one of the most common reasons for the initial clinical presentation in approximately 75% of patients with SLE. At the time of diagnosis 90% to 95% of people with lupus will experience muscle and joint pain which, significantly influences everyday functioning of patients and have a negative impact on quality of life (Schur and Wallace, 2022).

Disability decreases the patients' capabilities at work and daily living and is associated with increased health-care costs. Also associated with increased dependence and decreased ability in performing the activities of daily living (ADL). Physical activity and participation in planned exercises such as cycling, walking, swimming, climbing, yoga, dancing, and aerobics are among the non-pharmacological methods commonly used to manage disability and fatigue in patients with SLE (Zahiri et al., 2022)

Lupus awareness is important for the patient to be educated about the symptoms of lupus in order to identify when flares are beginning. In the chronic phase of lupus, these symptoms may show up again and signal the start of another flare. The patient who notices signs of flare can bring them to attention of the physician who will do a careful examination and order tests to check for other evidence. When caught at this stage, a small increase in the dosage of medication may be all that is necessary (Mohamed, 2018)

Nursing plays an important role in the process of management of systemic lupus erythematosus especially during periods of exacerbation of the disease. Because the nurse helps patients to cope with the disease in their everyday

lives, teaches how to deal with lupus symptoms, prevents periods of SLE exacerbations, and provide systematic health education concerning lifestyle changes. The nurse supports patients and their families by giving the necessary help and emotional support, while undertaking educational actions connected with lifestyle and rehabilitation to improve their quality of life. Lifestyle modifications, such as avoiding overexposure to sunlight, stress management, smoking cessation and a diet low in saturated and Trans fats, are also very important (Elmetwaly et al., 2021)

In addition, self-management guidelines include dietary recommendations which include a diet rich in vitamin D. Photo protection is vital, all patients with SLE should avoid direct sun exposure by timing their activities appropriately, light-weight loose-fitting dark clothing covering the maximum portion of the body, and using broad-spectrum (UV-A and UV-B) sunscreens with a sun protection factor. (Parodis and Gomez, 2022).

Self- management guidelines are interventions that aim to provide patients with practises that allow them to participate and take responsibility in disease management in order to function optimally. These practises include acquiring knowledge and a combination of independent sign / symptom monitoring, medication management, enhancing problem-solving and decision-making skills for medical treatment, managing and changing physical activity, dietary

habits, and smoking behaviour (Mohamed et al., 2020).

Self-management guidelines that include Patient education, physical and lifestyle measures, and emotional support play a central role in managing SLE. Patients with SLE should be well educated on the disease pathology, potential organ involvement, and the importance of medication and monitoring compliance. Stress reduction techniques, good sleep hygiene, exercises, and emotional support should be encouraged at the same time, smoking can worsen SLE symptoms, and thus patients should be educated about the importance of smoking cessation (Parodis and Gomez, 2022).

The study carried by Mohamed (2018) mentioned that, self-management guidelines had positive effects on the patients in reducing disability and improving patient awareness. ($P < 0.001$).

According to Mohamady et al., (2022) concluded that patients who recieved Self- Care management had better health outcomes related to pain and disability compared with their counterparts.

Therefore, the current study aimed to examine the effect of self-management guidelines on awareness, pain and disability among patients with systemic lupus erythematosus.

Significance of the Study

Systemic lupus erythematosus (SLE) is a potentially life-threatening chronic autoimmune disease, which can affect most organ systems. SLE has an undesirable outcome on various

features of patient's life such as mental health, quality of life, and daily functioning, which may lead to a decrease in employment rates and heavy economic burden. Patients with high level of self-care might achieve better health outcomes, so the patient needs to acquire self-care knowledge and skills and must find suitable ways to manage surrounding environments to maintain optimal health as the leading causes of death from SLE are the complications of the disease, such as end stage renal disease and cardiovascular disease, rather than SLE itself (Elmetwaly, et al., 2021).

According to the Lupus Foundation of America (2021), at least five million people worldwide have a form of lupus , about 16,000 new cases of SLE per year. In USA, the prevalence of SLE ranged from 5.8 to 130 per 100,000 population. Symptom onset typically is between 20–40 years of age, while in Egypt the overall estimated prevalence of adult SLE was 6.1/100,000 population (1.2/100,000 males and 11.3/100,000 females). (Mohamady et al, 2022). In Menoufia University Hospital the total number of patients were admitted in (2021) was about (470) cases to medical and rheumatology department (Statistical record of Menoufia University Hospital of rheumatology department, 2021). The study's scope is to reduce morbidity, mortality, financial costs, and the duration of hospital stay. Therefore, the aim of this study was to evaluate the effect of self-management guidelines on awareness, pain and disability among patients with systemic lupus erythematosus.

Purpose:

The purpose of the current study, was to assess the effect of self-management guidelines on awareness, pain and disability among patients with systemic lupus erythematosus.

Research Hypotheses:

- Patients who follow the self-management guidelines (study group) are expected to have higher level of awareness than patients who do not follow the guidelines (control group).
- Patients who follow the self-management guidelines (study group) are expected to experience less pain than patients who do not follow the guidelines (control group).
- Patients who follow the self-management guidelines (study group) are expected to have fewer disability score than patients who do not follow the guidelines (control group).

Methods:-

Research design:

A quasi experimental research design (study and control) was utilized to achieve the purpose of this study.

Research Setting:

The study was carried out at Rheumatology Outpatient Clinic at Menoufia University Hospital, in Shebin El-Kom,

Sampling:

Consecutive sample of 70 adult male and female patients with SLE They were assigned alternatively into two

groups, (study& control group). Thirty-five patients for each group: -

- Study group (I): patients received self-management guidelines along with routine hospital care.
- Control group (II): patients exposed to routine hospital care only.

Sampling Technique:

The sample of the study estimated by using the following power analysis equation: Unlimited population:

$$n = \frac{z^2 \text{X} \widehat{P}(1-\widehat{P})}{\varepsilon^2}$$

Finite population:

$$n' = \frac{n}{1 + \frac{z^2 X \widehat{P}(1-\widehat{P})}{\varepsilon^2 N}}$$

based on this assumption, the sample size was estimated to be 70 at confidence interval 80% (Kirby etal., 2002).

Z is the z score

ε is the margin of error

N is population size

N and n′ are sample size

P^ is the population proportion

Inclusion criteria

Adult patients from both sexes (19-65yrs)

Exclusion criteria

Patients who have active severe myositis, nephritis, neurological, cardiac or pulmonary disease and pregnant women as performing physical activity may be painful for them and increase fatigue.

Instruments:

Three instruments were used by the researchers for collecting the necessary data, these instruments were:

Instrument one: Structured interviewing questionnaire.

This instrument was developed by the researcher based on pertinent literature review (Kankaya and Karadakovan, 2020 and Williams, 2018) and guidance of expertise to collect sociodemographic and medical data as well as to assess awareness of patients with SLE. It covered the following parts:

- **Part 1**: Sociodemographic data: It was used to collect specific information from study sample as patient's age, gender, marital status, level of education, occupation and economic status.
- **Part 2**: Medical data: It included questions about patient's past and present medical history beside family history.
- **Part 3**: SLE Knowledge Questionnaire: It was used to assess the knowledge level of patients about SLE. It included questions related to systemic lupus erythematosus as definition, causes, signs and symptoms,….etc.

Scoring system for SLE Knowledge Questionnaire:

Each answer was given two marks if the patient reported completely correct answer, one mark if reported incompletely correct answer and zero if the answer was incorrect or I don't know. Total summation of scores range from zero to twenty-eight. The higher score, the higher awareness level. The

total score was converted into percentage score and was categorized as follows:

- Satisfactory level of awareness ≥ 75% denoted good awareness (21-28)
- Fair level of awareness 50% to < 75 % (14-21)
- Unsatisfactory level of awareness < 50% denoted poor knowledge (0-14)

Instrument two: Visual Analogue Pain Scale (VAS numeric pain Scale)

It was developed by Fitzcarrald et al., (2019) and used by researcher to obtain data related to the presence or absence of joint pain and its severity. The score was ranged from zero to ten to rate the patients intensity of pain.

Scoring system for pain scale:

Pain intensity	Score
No pain	0
Mild pain	1-3
Moderate pain	4-6
Severe pain	7-9
Worst pain	10

Instrument three: Stanford Disability Index:

This instrument was developed by Fries, et al., (1980), and used by researcher to assess patients with SLE regarding their ability to perform activities. It consists of 20 items asking about dressing (1 item), grooming (1 item), arising (2 items), eating (3 items), walking (2 items), hygiene(3 items), reach(2 items), grip (3 items) and activities (3 items).

Scoring system for disability index:

The patient's response for each statement was scored as follows:

Response	Score
No difficulty	0
With some difficulty	1
With much difficulty	2
Unable to do	3

Total Scoring system for the disability index as the following:

Degree of disability	Total Score
Total ability	0-14
Partial ability	15-29
Partial disability	30-44
Total disability	45-60

Validity:

All instruments were tested for their face validity by jury of 5 experts(Professors in the field of Nursing and Medical specialties) to ascertain their relevance and completeness.

Reliability:

Test retest method was used. Value of test retest for instrument one was 0.97. Value of test retest for instrument two was 0.89 and Value of test retest for instrument three was 0.85.

Ethical Consideration:

A written approval was obtained from Ethical and Research Committee in Menoufia University No: 847. All participants were informed of the purpose, methods of research and benefits of the study. Then, a written consent to carry out the study was obtained from each participant. Participation in the study was voluntary and the patients could withdraw from the study at any time without penalty. Confidentiality and anonymity of patients assured through coding all data. Also, participants were informed that instruments would not cause any physical or emotional harm to participants.

Pilot study:

Prior to actual study, a pilot study conducted on 10% (7 patients) of the sample to assess the constructed instruments for feasibility and applicability and the necessary modifications were carried out. The results of the pilot study were excluded from the actual study.

Procedure:

An official letter was sent from the Dean of the Faculty of Nursing to the director of Menoufia University hospital explaining the purpose of the study and methods of data collection. A written permission to carry out the study was obtained

- Patients who fulfill the inclusion criteria were assigned into two equal groups, study group (I) and control group (II).
- The researcher made an initial interview. Each participant of both groups was interviewed individually and assessed for demographic data, medical data and patient's awareness SLE using instruments (I). It will take about 10 to 20 minutes.
- All participants of both groups were assessed for their pain and disability using instruments two and three respectively. It took about 20 to 30 minutes. Data was firstly collected from the control group.
- The control group (II) only received routine hospital care.
- The study group (I) was taught the self-management guidelines that should be followed along with routine hospital care. The study group was divided into 5 groups. Each group contained 7 patients

- An instructional booklet with illustrative pictures was prepared by the researcher about self-management guidelines that included instruction about systemic lupus erythematosus disease, diet counseling, physical activity exercises, how to compensate with the disease and coping skills to adapt with the disease manifestation as fatigue and disability.
- The researcher conducted three teaching sessions for each group of the study group (I) about self-management guidelines (knowledge, physical activity, diet, and stress management and coping strategies). Each session took from 30 to 45 minutes at rheumatology outpatient clinic.
- **During the first session**, the researcher provided each group in the study group information about systemic lupus erythemat osus such as definition, types, causes, signs, symptoms, complication and management to improve patient's awareness. It lasted from 30-45 minutes.
- In addition, in order to enhance patient's ability for doing activities, the researcher provided information about methods of performing physical activity exercises three times week for 6 weeks. Information was provided about exercises such as, Aerobic exercises to improve cardiovascular fitness (cycling for a period of 15 minutes or walking for 30 minute per day three days a week, outdoors, in the late afternoon 6: pm in summer or 4pm in winter as exposure to sunlight can cause flares

in systemic lupus and trigger symptoms of SLE and range of motion exercises for 30 minutes to maintain joint's flexibility. The researcher enhanced patients to get frequent periods of rest to cope with fatigue.

- **During the second session**, the researcher explained to the study group (I) about the importance of healthy diet. It taken about 30-45 minutes.

- Moreover, food high in omega-3 that help protection against heart disease and stroke and reduce inflammation in the body like fish were encouraged at least twice a week to enjoy its anti-inflammatory effects.

- **During the third session**, the researcher reinforced the received information then explained to the study group (I) about stress management and coping. It taken about 30-45 minutes.

- Direct teaching methods such as discussion used during teaching sessions. Also, demonstration for the self-management guidelines had done to study group subjects (I).

- Finally, each patient in the study group (I) was given a copy of the educational booklet.

- The researcher reinforced the participants of the study group (I) by phone to perform the educated self-management guidelines day others day at home.

- The researcher conducted post-test one-month's post third session. As all participants re-assessed for their awareness, pain and disability using instruments I (part three), II and III respectively.

- During follow up period, the researcher conducted follow up test three months post third session of educational intervention to highlight the self-management guidelines effect. As all participants re-assessed again for their awareness, pain and disability using instruments I (part three), II and III respectively.

Statistical Analysis

The collected data were organized, tabulated and statistically analyzed using SPSS software (Statistical Package for the Social Sciences, version 26, SPSS Inc. Chicago, IL, USA). For quantitative data, the range, mean and standard deviation were calculated. For qualitative data, which describe a categorical set of data by frequency, percentage or proportion of each category, comparison between two groups was done using Chi-square test (χ^2). For comparison between means of two groups of parametric data of independent samples, student t test was used. For comparison between means of two groups of non-parametric data of independent samples, Z value of Mann-Whitney test was used. For comparison between means of two related groups (pre and post program intervention data) of parametric data, paired t test was used. For comparison between more than two means of non-parametric data, Kruskal-Wallis (χ^2) was calculated. Correlation between variables was evaluated using Pearson's correlation coefficient (r). P-value at 0.05 was used to determine significance regarding:

o P-value > 0.05 to be statistically insignificant.
o P-value ≤ 0.05 to be statistically significant.
o P-value ≤ 0.001 to be highly statistically significant.
o P-value ≤ 0.0001 to be very highly statistically significant.

Results

Table 1: shows distribution of the studied sample according to their demographic characteristics socio demographic. It illustrated that the mean age of participants in the study and control groups was 39.31±10.67years and 39.08±9.38 years, respectively and majority of them were females (85.7% and 88.6% respectively). As regard to their level of education, about half of both study and control groups (45.7% and 54.3% respectively) had secondary education and in relation to occupation, about two thirds were house wives (42.9%). In addition to more than two thirds of both study and control groups reported that their income was insufficient (60.0% and 57.1%respectively).

Figure 1: showed that 80.0% of the study group were classified as having satisfactory level of awareness, 11.4% had Unsatisfactory level of awareness and 8.6 % had fair level of awareness, while for control group participants, 74.3% were classified as having unsatisfactory level of awareness, 17.1% had satisfactory level of awareness and 8.6 % had fair level of awareness (p-value ‹ 0.001).

Table 2 illustrates distribution of patients in the study and control groups according to their level of pain on pre, post and follow up, 17.1% and 20.0% of patients had mild pain pre intervention among the study and control groups respectively compared. Moreover, 71.4% and 20.0% of patients had mild pain post intervention.

Table 3 clarifies mean self management disability index score of patients (study and control groups) during pre, post and `follow-up tests. Patients in the study group had fewer scores of disability index. Therefore, there were very highly statistical significant differences between the study and control groups pre, post and follow-up implementation of self management guidelines (P<0.001)

Table 4 illustrates Correlation between scores of disability index and pain in the study and control group on pre, post and follow-up. It shows that there was a very highly statistical significant positive correlation between total scores of visual analogue pain scale and disability index scale for study group post implementation phases of self management guidelines. Also, there was a very highly statistical significant positive correlation between total pain and disability scores in the control group at follow up self management guidelines

Table 5 shows correlation between patients' scores of awareness, pain, and disability for both study and control groups. There was a very highly statistical significant negative correlation between the total patient's scores of awareness and their total scores of pains and disability for the study group and control group through self-management guidelines phases (P<0.001).

Table 1: Distribution of the studied sample according to their demographic characteristics (n=70)

	Study (n=35)		Control (n=35)		X²	p-value
	No	%	No	%		
Age/year						
• <35	8	22.9	10	28.6	0.567	.904
• 35-<45	17	48.6	15	42.9		
• 45-<55	6	17.1	7	20.0		
• 55-<=65	4	11.4	3	8.5		
Mean ±SD	39.31±10.67		39.08±9.38			
Gender						
• Female	30	85.7	31	88.6	.128	.721
• Male	5	14.3	4	11.4		
Marital Status						
• Single	10	28.6	12	34.3	.282	.869
• Married	21	60.0	19	54.3		
• Divorced	4	11.4	4	11.4		
Level of Education						
• Illiterate	4	11.4	3	8.6	.733	.865
• Basic education	8	22.9	8	22.9		
• Secondary education	16	45.7	19	54.3		
• Higher or university education	7	20.0	5	14.2		
Occupation						
• Manual work	11	31.4	12	34.3	.486	.922
• Administrative	7	20.0	6	17.1		
• Does not work	2	5.7	1	2.9		
• Housewife	15	42.9	16	45.7		
Monthly income						
• Enough	14	40.0	15	42.9	.059	.808
• non Enough	21	60.0	20	57.1		

Figure (1): Distribution of Patients in the Study and Control Groups according to Their Level of Knowledge about Self Management Guidelines about Self Management on pre, post and follow- up phases (n=70)
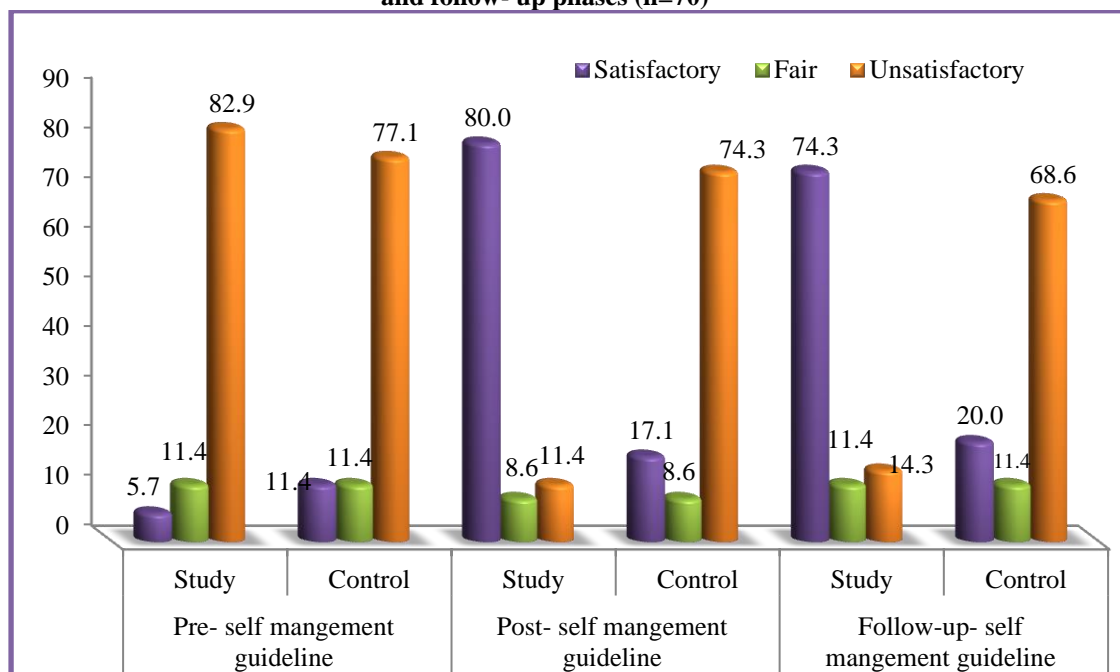
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Table (2): Distribution of patients in the Study and Control Groups according to Their Level of Pain on pre, post and follow up (n=70)

Pain level	Study (n=35)						Control(n=35)						X^2/p1-value	X^2/ p2-value	X^2/ p3-value
	Pre		Post		Follow-up		Pre		Post		Follow-up				
	No	%	No	%	No	%	No	%	No	%	No	%			
No pain	0	0.0	3	8.6	3	8.6	0	0.0	0	0.0	0	0.0	.235/.889	26.19/.000**	17.70/.001**
Mild pain	6	17.1	25	71.4	29	82.8	7	20.0	7	20.0	17	48.6			
Moderate pain	20	57.2	3	8.6	3	8.6	18	51.4	17	48.6	11	31.4			
Sever pain	9	25.7	4	11.4	0	0.0	10	28.6	11	31.4	7	20.0			
Mean ±SD	5.21±1.54		2.84±0.91		2.42±1.22		5.44±1.26		4.51±2.11		4.43±2.01				

P1 comparison between study and control pre self-management guidelines
P2 comparison between study and control post self-management guidelines
P3 comparison between study and control follow-up self-management guidelines
** Highly statistically significance p<0.001
*statistically significance p<0.05 X^2 Chi-Square test

Table (3): Mean Self Management Disability Index Score of Patients (Study and Control Groups) During Pre, Post and follow-up Tests (n=70)

Total disability Index items	Study group (n=35)			Control group (n=35)			t/p1-value	t/ p2-value	t/ p3-value
	Pre	Post	Follow-up	Pre	Post	Follow-up			
	Mean ±SD	Mean ±SD	Mean ±SD	Mean ±SD	Mean ±SD	Mean±SD			
Dressing & grooming	2.62± 1.41	1.80±1.07	.51±.85	2.91±1.83	2.54±1.40	2.42±1.33	.729/.469	2.486/.015*	7.149/.000**
Arising	2.97±.98	1.68±.99	1.31±1.18	2.97±.98	2.82±.98	2.80±.90	.000/1.000	4.834/.000**	5.912/.000**
Eating	.74±1.26	.20±.53	.05±.23	1.05±1.43	1.00±1.28	.85±1.28	.971/.335	3.407/.001**	3.618/.001**
Walking	2.17±1.40	1.02±1.58	.62±.94	2.25±1.50	2.08±1.46	2.17±1.48	.247/.806	2.904/.005*	5.191/.000**
Hygiene	3.82±3.24	1.42±2.32	.77±1.64	2.45±2.61	2.57±2.64	2.34±2.68	1.948/.056	1.917/.059	2.948/.004*
reach	2.65±.90	1.17±1.09	1.28±1.17	2.20±1.10	2.22±1.11	2.00±1.08	1.892/.063	3.999/.000**	2.640/.010*
Grip	2.05±3.29	.31±1.18	.22±.68	1.85±2.74	2.08±2.79	1.85±2.70	.276/.784	3.458/.001**	3.455/.001**
Activity	1.80±1.49	.71±1.22	.22±.73	1.54±1.24	1.34±1.05	1.11±1.10	.783/.436	2.298/.025*	3.954/.000**
Total	18.85±9.43	8.34±4.26	5.02±2.66	17.25±8.31	16.68±7.78	15.57±8.07	.753/.454	5.560/.000**	7.336/.000**

t1 between study and control pre self-management guidelines
t2 between study and control post self-management guidelines
t3 between study and control follow-up self-management guidelines
** Highly statistically significance p<0.001
*statistically significance p<0.05

Table (4): Correlation between scores of disability index and pain in the study and control group on pre, post and follow-up tests (n=70)

		Disability index scores					
		Pre		Post		Follow-up	
		R	p-value	R	p-value	R	p-value
Total Pain score	Study	.182	.296	.994	.001**	.897	.023*
	Control	.069	.692	.460	.129	.811	.042*

** Highly statistically significance p<0 001
 *statistically significance p<0 05
 r Correlation coefficient

Table (5): Correlation between patients' scores of awareness, pain and disability for both study and control groups through self-management guidelines phases (n=70)

Variables		Awareness Score					
		Pre		Post		Follow-up	
		R	p-value	R	p-value	R	p-value
Pain level	Study	-.124	.047*	-.625	.003*	-.721	.001**
	Control	-.027	.049*	.204	.044*	.017	.021*
Disability	Study	-.169	.035*	-.721	.026*	-.842	.000**
	Control	-.271	.031*	.196	.026*	.212	.024

** Highly statistically significance p<0 001
 *statistically significance p<0 05
 r Correlation coefficient

Discussion

The results of the current study illustrated that the majority of the study group participants had more satisfactory level of knowledge than control group. Regarding the total awareness score among studied groups, the findings revealed that there were highly statistical significant difference between study and control group regarding total awareness score post and follow- up self management guidelines. From the researchers point of view, these results may be related to the methods of teaching guidelines and learning instructions e.g. illustrative colored booklet Meanwhile, the low awareness level before the intervention demonstrates the patient's need for self management guidelines.

This result agrees with the results of Ahmed et al., (2023) who reported that the self-care guidelines, was associated with improved level of awareness. Also, Mary et al., (2021) mentioned that the education-based self-management intervention is effective in improving the awareness levels among patients with SLE and it can also be effective for patients to manage their symptoms. Sedrak et al., (2020) mentioned that designed nursing education protocol were effective in improving knowledge level and self-care for patient with systemic lupus erythmatosus.

Moreover, Mohamed, (2018) reported that the systemic Lupus Erythematosus self-management guidelines had positive effects on the patients in improving patient awareness

Additionally, This result was in the same line with Mohamady et al., (2022) who revealed that, Implementation of self-care

management had a positive and significant effect on females' awareness level as well as reducing fatigue and pain severity,

So, The first hypothesis which revealed that, patients who followed the self-management guidelines (study group) have higher awareness score than patients who didn't follow guidelines (control group) was accepted through the current study research findings.

Regarding to the patients severity of pain level, The findings of the present study revealed that there was reduction in the level of pain severity between participants in the study group than participants in the control group on post intervention and follow-up the implementation of self-management guidelines (P<0.001). So, using non pharmacological management methods such as range of motion, relaxation exercises such as deep breathing exercise, distraction, guided imagery, heat/cold application, to help patients manage their pain in which the patients can take an active role in pain management was associated with decreased patient pain.

This result was consistent with Mohamady et al., (2022) who revealed that, Implementation of self-care management had a positive and significant effect on reducing pain severity. Also, these results were in line with Pellegrini et al., (2018) who clarified that using physical activity monitors in rheumatic populations could increase vitality, primarily by helping them to overcome pain, also effective stress management can help female maintain emotional stability and increase adaptive coping.

So, the second hypothesis which revealed that Patients who followed the self-management guidelines (study group) experience less pain level than patients who didn't follow guidelines (control group) was accepted through the current study research findings.

For patients disability index, it revealed that there was reduction in the level of disability between participants in the study group than participants in the control group on post intervention and follow-up the implementation of self-management guidelines (P<0.001). This result agrees with Yousef et al., (2018) who revealed that, Implementation of self-care management had a positive and significant effect on reducing disability. Also, These results were in line with, Mostafa and Abd-Elrehem., (2018) who cleared that, there were highly statistically significant differences between the mean and standard deviation of disability index among the patients under the study as regards dressing and grooming, arising, eating, walking, personal hygiene, reach object, grip and various activities pre and post implementation of systemic lupus health promotion program. Moreover Mohamed (2018) reported that the systemic Lupus Erythematosus self-management guidelines had positive effects on the patients in reducing disability

So, the third hypothesis which revealed that, patients who followed the self-management guidelines (study group) experience less disability score than patients who didn't follow guidelines (control group). was

accepted through the current study research findings.

Regarding the Correlation between the scores of visual analogue pain scale and disability index on pre, post and follow-up tests the findings revealed that, there was a highly statistical significant positive correlation between total scores of visual analogue pain scale and disability index scale for study group post implementation phases of self management guidelines. These results were in line with Zhao et al., (2023) who mentioned that, there are association between pain, functional disability and disease activity, and decline in health-related quality of life in patients with systemic lupus erythematosus.

Regarding the correlation between total patients' scores of awareness, total scores of pains and disability the findings revealed that there was a negative correlation between the total patient's scores of awareness and their total scores of pains and disability for the study group and control group through self-management guidelines phases (P<0.001).

Conclusions:

Based on the findings of current study, it can be concluded that:

- Self-management guidelines had significant effect on improving the total awareness score among study group (group I) than control group (group II).
- Self-management guidelines had a positive impact on reducing pain and disability score among study group (group I) than control group (group II).

Recommendations:

A) Recommendations for patients:

- A simplified, comprehensive and illustrated arabic guided images booklet about SLE should be distributed for each newly admitted patient diagnosed with SLE.
- A similar study can be replicated at different settings and on a larger probability sample to allow for greater generalization of the findings.

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