

Self- Management Guidelines: Effect on Awareness of Patients with Systemic Lupus Erythmatosus

¹Heba Abdel-Azem Mostafa ,*Talal Ahmed Abd-Elrehem

Lecturer of Medical Surgical Nursing *Professor of Dermatology
Faculty of Nursing, Fayoum University-Egypt

Abstract: *Systemic Lupus Erythmatosus (SLE) is a prototypic autoimmune disease with a diverse array of clinical manifestations, which is characterized by the production of antibodies to components of the cell nucleus. It is a complex multi system disease difficult to monitor. Good self-management is essential to managing lupus; as individuals with SLE can improve their prognosis by learning about many aspects of the illness as well as closely monitoring their own health with their care providers.*

Aim of the study: *the study was aimed to assess the effect of self-management guidelines on awareness of patients with SLE. Study design:* *a quasi-experimental study was utilized in this study.*

Setting: *the study was conducted at the Rheumatology unit at Cairo University Hospital.*

Subjects: *a purposive sample of 75 Adult patients with age from 18 to 45years old and diagnosed with SLE.*

Data collection: *data were collected by two tools as follows: Health Need Assessment Questionnaire and SLE awareness's quiz. Results:* *More than two thirds of the studied patients had satisfactory awareness level post implementation of self-management guidelines. The study*

concluded that: *More than two thirds of the studied patients had satisfactory awareness level, post implementation of the self-management guidelines. Moreover, there was statistical significant relation between patient's levels of awareness pre and post implementing of self-management guidelines. The study*

recommended *that An Arabic guided booklet about SLE should be distributed for each newly admitted patient diagnosed with SLE. An Egyptian Lupus Organization should be developed to be in contact with the problems of these patients.*

Keywords: *Self-management, Guide lines, Lupus awareness.*

Date of Submission: 30-10-2017

Date of acceptance: 16-11-2017

I. Introduction

Systemic lupus erythematosus (SLE) is a prototypic autoimmune disease with a diverse array of clinical manifestations, which is characterized by the production of antibodies to components of the cell nucleus (Pisetsky 2001). It is a complex multisystem disease difficult to monitor. Not only does SLE potentially affect just about every bodily part, but it also affects each organ's different structural components with varying frequencies. Nonspecific constitutional features of SLE, some of which dominate the clinical picture, are fatigue, fever and weight loss (Song, Sohng & Yoo 2000). Known treatments for SLE do not cure it, and patients experience repeated aggravation and improvement (Bruce & Burns 2014).

Self-management is essential to managing lupus or SLE. It's vital to teach patient the warning signs of a flare. Warning signs may include increased fatigue, joint pain, rash, or fever. When the patient notice any of these signs, should take steps to control his/her symptoms (Lorig, 2010). It 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 these signs can bring them to the 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 (DeCastro, Morales & Wagner, 2011). A patient needs to acquire self-care knowledge and skills, and must find appropriate 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 (Rahman and Isenberg, 2010).

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 the 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. (DeCastro, Morales & Wagner, 2011).

Significance of the Study:

Systemic Lupus Erythmatosus is a complex disease to diagnose, treat and manage. In Egypt it is reported that; about 85cases monthly are admitted to the rheumatology department with different signs and symptoms (Information and Statistics Center of Cairo University Hospital, 2012). The disease occurs ten times more often in women than in men, especially in women in child-bearing years ages15 to 45. (David, 2011).

II. Aim Of The Study

The present study aimed to:

1. Assess the needs of the patients with Systemic Lupus Erythmatosus.
2. Plan and implement self-management guidelines for patients with Systemic Lupus Erythmatosus.
3. Evaluate the effect of self-management guidelines on awareness of patients with SLE.

Research hypothesis:

- self-management guidelines will affect the awareness of patients with S L E.

III. SUBJECTS AND METHODS

I. Technical Design:

The technical design entails the study design, setting, subjects, and tools for data collection.

Research Design:

A quasi-experimental design was utilized to accomplish the aim of this study.

Research Setting:

The present study was conducted at the Rheumatology unit at Cairo University Hospital.

Subjects:

A purposive sample was utilized in the current study. The sample composed of (75) adult female patients from 18 to 45years old, with different educational levels who were admitted to the rheumatology department with different signs and symptoms .

Tools of data collection: Two Tools were used in the current study as follows:

1. Health Need Assessment Questionnaire.
2. SLE awareness's quiz.

1. Health Need Assessment Questionnaire-HAQ: it's a Self-administered questionnaire filled by the patients with SLE, to assess and identify their health needs. It's developed by **Song, Sohng & Yoo(2000)** , Translation and back translation from English to Arabic is done for this tool. The questionnaire constructed of 5 parts as following:

-Part 1: Demographic characteristics' of the patient. It was adopted from **Przeł Lek (2014)**. It was used to assess; age, sex, phone number, marital status, occupation, treatment costs, smoking, and medical history.

-Part 2: Disability index. It was adopted from **Stanford HAQ 20-Item Disability Scale (2015)**. It composed of 20 statements designed to assess dressing & grooming, arising, eating, walking, hygiene, reach, grip, and activities, also it used to assess any used assistive devices or help form another person for doing those activities.

-Part 3: Discomfort and pain scale. It was adopted from **Myrthe, Ottenhoff, Dick, and Rob de Jong (2011)**. It was used to assess severity of pain and discomfort; it's composed of a horizontal line where each end represents opposite ends of a continuum). It is labeled with “no pain” (with a score of 0) at one end and “very severe pain” (with a score of 100 at the other. Patients are instructed to place a vertical mark (number) on the line to indicate the severity of their pain. This part includes also the symptoms as stated by the patient.

-Part 4: Drug Side effects. It was adopted from **Cerner Multum & Wolters (2011)**. It includes questions to assess the prescribed medications, and any arising problems during the past 6 months.

-Part 5: Patient satisfaction. It was adopted from **The RAND Corporation (2014)**. It was used to assess satisfaction of the patient about his/ her health and also the effect of the disease on his/ her job and activities of daily living during the past 6 months.

Scoring system

- **Scoring of part 1, part 4& part 5:** the patients' answers were tabulated in percentage and frequency values.
- **Scoring Conventions for the Disability Index**

The patient response for each statement with 4 answers as follow: without any difficulty= 0, with some difficulty = 1, with much difficulty=2, unable to do = 3. The score is calculated by multiplying the highest score (3) by the number of questions (20) to yield the final composite score (60 grades) and then graded as following: $\geq 50\%$ (=30 grades) disabled patient, and $< 50\%$ considered able patient.

- **Scoring Conventions for Discomfort and Pain Scale:**

The patient response graded as follow; 0= no pain, 10- 50 = moderate pain, and 51 - 100 = sever pain.

2- **SLE awareness's quiz:** it's a Self-administered quiz to the patients with SLE. It is used to assess the knowledge level of patients with SLE; it's developed by **Belotti (2003)**. Translation and back translation from English to Arabic is done for this tool. The quiz includes 20 multiple choice questions related to Systemic Lupus Erythmatosus which they are divided into 4 main categories with 5 questions for each one as follows: definition and incidence of SLE, signs and symptoms of SLE, complications of SLE, and treatment & self-management of SLE.

Scoring system:

The total score of knowledge was 20 marks. Each correct answer was given one mark and the incorrect answer was given zero. It was categorized as follows: $\geq 80\%$ (=12 marks) satisfactory level of knowledge, and $< 80\%$ unsatisfactory level of knowledge.

-Self management guidelines for the patients with Systemic Lupus Erythmatosus : The guidelines were developed by the researcher in simple Arabic language guided by related literature **Lupus Foundation of America (2012)**. The guidelines divides into 4 parts as follows; (1) general knowledge about SLE which include (Definition- causes- manifestation- treatment- life style changes), (2) guidelines for self-management of general problems of patient with SLE which include (infections – skin care- diet regulations- avoidance of medications complications).

The guidelines were revised by a group of five expertises in Medical Surgical Nursing and two expertise from rheumatology physicians at faculty of Medicine, at Cairo University for the content validity. Based on the opinion of a panel of expertise some modifications were done, and then the final forms were developed.

II- Operational Design

• **Preparatory phase:**

It included reviewing of related literature, and theoretical knowledge of various aspects of the study using books, articles, Internet, periodicals and magazines to develop data collection tools.

• **Validity & Reliability:**

Validity: assessing face and content validity of the suggested tools through a jury of 7 experts who composed of: 3 professors and 4 lecturers of Medical Surgical Nursing, faculty of Nursing, Cairo University.

Reliability: Alpha Chronbach test was used to measure the internal consistency of the 5 tools used in the current study.

• **Pilot Study:**

A pilot study was carried out on 10% of the patients, who were later excluded from the main sample study. The pilot study was done in the Rheumatology Unit, Cairo University to ensure clarity, applicability, relevance, feasibility of conduction of study tools and time needed for each tool. Based on the findings of the pilot study, necessary modifications and clarifications of some questions were done to have more applicable tools for data collection. Some questions and items were omitted, added or rephrased and then the final forms were developed.

Ethical considerations:

-An official permission was obtained before conduction of the study.

-The aim of the study was explained to the subjects to obtain their cooperation. Oral consent was obtained from the patients to ensure willingness to engage in the study.

-The researcher maintains anonymity and confidentiality of subjects' data.

-Patients were allowed to choose to participate or not and they were informed that they have the right to withdraw from the study at any time without giving any reason.

• **Field Work :**

-Data collection was started and completed within 6 months, from May 2017 and end in October 2017.

-Purpose of the study was simply explained to patients who agree to participate in the study prior to any data collection.

-The study tools were filled in and completed by the researcher on 2 stages (pre & post implementation of the self-management guidelines).

-The researcher was available at the inpatients department of Rheumatology, Cairo University hospital 3 days/week at morning and afternoon shifts to collect data from the studied patients.

-Filling in the tools was done according to the patients' understanding and health condition.

The collection of data is done through three phases:

Phase 1: Data collected by the researcher after distribution of the tools for each patient individually, collection of data began by the health assessment questionnaire, it was distributed to be completed by the patient

within (10-15 min), and then collected. After that, the SLE awareness quiz given to the patient to be answered within about (10-20 min).

Phase 2: Three sessions for each patient were established for explanation of the self-management guidelines, each session was completed within (30-45 min).

Phase 3: After the final session, the same tools were distributed again for each patient to be answered to evaluate the effect of self-management guidelines implementation.

III. Administrative Design

An official letter was issued from the faculty of Nursing, Cairo University to the director of Rheumatology unit at which the study was conducted, explaining the purpose of the study and requesting the permission for data collection from the study group.

IV. Statistical Design

The collected data were organized, categorized, tabulated and statistically analyzed using the Statistical Package for Social Science (SPSS) version (20.0) and (Excel2007) to evaluate the studied subjects changes throughout the study phases (pre & post) and to evaluate the differences between the groups under study as regards the various parameters. Data were presented in tables and chart. The statistical analysis include; percentage (%), the arithmetic mean (X), standard deviation (SD), student's "t" test, and Chi-Square (X^2), P value, and Alpha Chronbach test.

V. Results

Table (1): shows the characteristics of the patients under the study, it's revealed that, the mean age for patients included in the study were 33.54 ± 12.02 . Also this table shows that, the majority of the females patients (80%) were non-pregnant, concerning the taken medications, specialized physician visits, diagnostic tests it revealed that all of the patients (100%) had performed all this activities and regarding the occurrence of health problems during the past six months it revealed that all of the patients (100%) had health problems during the past six months.

Table (2): presents the means of the disability index among the patients under the study pre implementation of self-management guidelines, it shows the highest means among the patients under study which were in relation to "with much difficulty" regarding the following questions: - dress yourself, cut your meat, climb up five steps, take a tub bath, get on and off the toilet, reach and get down a 5-pound object, open car doors, and open jars which have been previously opened (4.862, 5.054, 6.704, 6.000, 5.100, 4.794, 5.862, and 6.000) respectively. Also this table shows that, the highest means among the patients under study which were in relation to "with some difficulty" regarding the following questions: dress yourself, stand up from a straight chair, get in and out of bed, wash and dry your body (5.862, 5.000, 5.482, 5.752) respectively.

Figure (1): shows the distribution of the patients with SLE as regards pain sensation, and it reveals that more than two thirds (70%) of the patient under the study complains of pain regarding SLE.

Table (3): shows the percentage distribution of the medications taken during the last six months, it reveals that majority of the patients (86.66 %) of the patients under the study take corticosteroids medications, followed by vitamin D supplements (40%).

Figure (2): reveals distribution of the patients regarding satisfaction about health status pre and post implementation of self-management guideline, it presents that half (50%) of the patients under the study were stated their satisfaction as good, while more than one third (40%) stated as bad pre implementation of self-management guideline.

Table (4): presents mean & standard deviations of the patients regarding disability pre and post-implementation of the self-management guidelines, and reveals that the highest means and standard deviations post implementation of the self-management guidelines were (62.0 ± 0.6 & 78.2 ± 0.9) regarding able and disable patients respectively. Also this table shows a highly statistically significance difference regarding disability among patients under the study.

Table (5): reveals the highest means and standard deviations post implementation of the self-management guidelines were regarding all items of the lupus awareness. Also this table shows a statistically significance difference regarding complications of SLE, and shows a highly statistically significance difference related to treatment and self-management of SLE.

Table (6): showing the percentage distribution of the patients regarding level of awareness pre/post-implementation of the self-management guidelines, it reveals that more than two thirds (66.67%) of the patients included in the study post-implementation of self-management guidelines were had satisfactory awareness level. Also this table shows high statistically significance regarding satisfactory level of awareness.

Table (7): this table shows Overall mean & standards deviations of self-management items regarding pre and post implementation of self-management guidelines, it revealed that, there was a statistically significance difference between pre & post mean scores of the total level of awareness at (p>0.05).

Table (1): Demographic characteristics of the patients under the study (No=75)

Items	(No 75)	%
Age (In years):		
18 - 25	35	46.5
<25 - 45	35	46.5
45+	5	7
Range	18-47	
Mean±SD	33.54±12.02	
Marital status:		
Married	60	80
Unmarried	15	20
Education:		
Read/write	30	40
Intermediate/basic	30	40
High	15	20
Working:		
Working	20	26.5
Not working	55	73.5
Treatment fees :		
Health insurance	20	27
Free	50	66.5
Private	5	6.5
Pregnancy:		
Pregnant	15	20
Un pregnant	60	80
Taken medications during the past six months		
Yes	75	100
No	0	0
Specialized physician visits		
Yes	75	100
No	0	0
Diagnostic tests performed during the past six months.		
Yes	75	100
No	0	0
Health problems during the past six months.		
Yes	75	100
No	0	0

Table (2): Means of the disability index among the patients under the study pre/post implementation of self management guidelines. (No=75)

Items	Without Difficulty		With some Difficulty		With much Difficulty		Unable To do	
	Mean		Mean		Mean		Mean	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post
1. Dress yourself?	1.862	2.765	2.991	5.862	4.862	1.541	1.762	0.341
2. Shampoo your hair?	1.000	2.010	2.601	4.000	3.000	2.601	2.010	2.210
3. Stand up from a straight chair?	2.000	2.000	2.862	5.000	3.000	2.762	2.000	1.120

Self- Management Guidelines: Effect on Awareness of Patients with Systemic Lupus Erythmatosus

4. Get in and out of bed?	2.794	2.854	2.100	5.482	3.774	2.120	1.794	1.694
5. Cut your meat?	1.054	2.054	2.020	4.114	5.054	2.120	1.794	1.294
6. Lift a full cup to your mouth	2.397	2.377	2.594	3.762	2.862	1.694	0.862	0.762
7. Open a new milk carton?	2.020	2.020	3.054	3.021	3.000	3.224	2.000	2.100
8. Walk outdoors on flat ground?	1.991	2.391	2.397	4.210	4.000	1.765	1.100	1.100
9. Climb up five steps?	1.794	1.494	2.004	4.603	6.704	2.004	1.631	2.631
10. Wash and dry your body?	2.580	2.450	2.891	5.752	4.862	2.871	0.954	2.954
11. Take a tub bath?	1.862	2.862	2.501	3.000	6.000	2.631	2.347	2.347
12. Get on and off the toilet?	2.000	2.000	2.570	4.150	5.100	2.460	1.000	1.000
13. Reach and get down a 5-pound object	2.000	2.000	1.601	3.414	4.794	1.621	1.901	3.901
14. Bend down to pick up clothing from the floor?	2.794	1.354	2.560	4.022	4.054	2.560	3.601	2.601
15. Open car doors?	2.053	2.143	2.862	3.745	5.862	1.862	2.470	0.470
16. Open jars which have been previously opened?	1.397	2.346	3.000	4.002	6.000	2.110	1.842	1.842
17. Turn faucets on and off?	1.000	2.010	2.000	4.100	3.000	1.010	1.000	1.000
18. Run errands and shop?	2.691	1.467	2.794	3.105	4.005	2.394	2.000	3.000
19. Get in and out of a car?	2.401	2.462	2.154	4.254	3.154	2.113	2.790	1.790
20. Do chores?	1.080	1.070	2.367	3.544	4.844	1.373	0.054	2.054

Fig. (1): Percentage distribution of the patients with SLE as regards pain sensation related to the disease pre self-management guidelines intervention (No. 75)

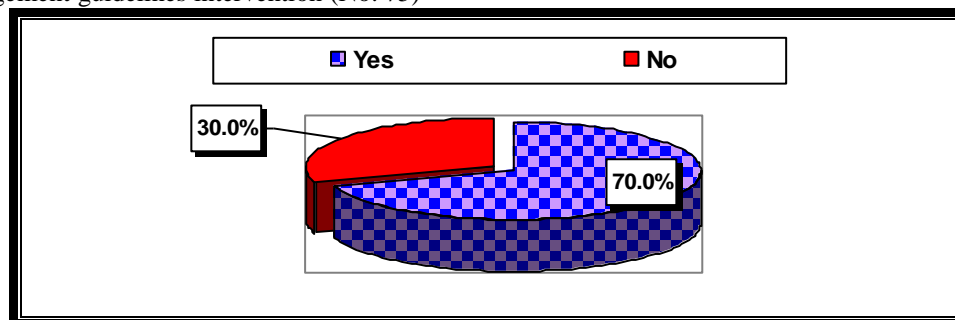


Table (3): Percentage distribution of the medications taken during the last six months (No=75).

Items	Frequency	%
Vitamin D supplements	21. 30	22. 40
Calcium	23. 10	24. 13.34
Corticosteroids	25. 65	26. 86.66
Estrogens	27. 5	28. 6.66
Osteoporosis drugs	29. 5	30. 6.66

Fig. (2): Percentage distribution of the patients regarding satisfaction about health status pre and post implementation of self-management guideline.

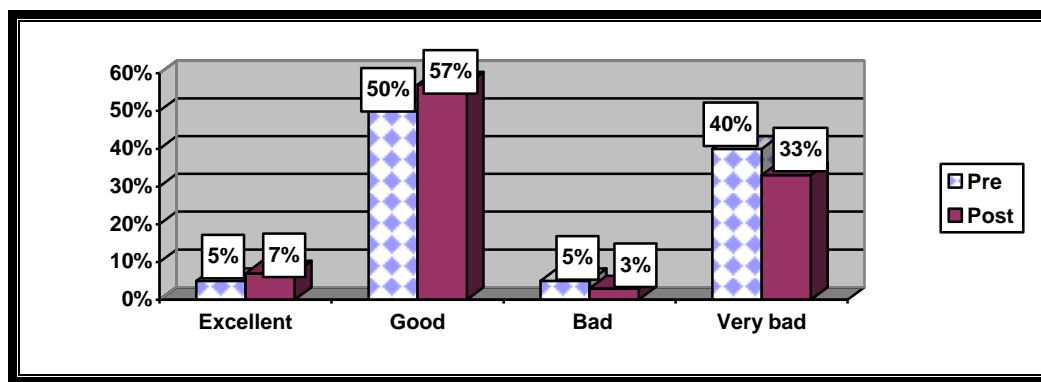


Table (4): Means & standard deviations of the patients regarding disability pre and post-implementation of the self-management guidelines (No=75)

Disability index	Pre				T-test		
	Mean ± SD	Mean ± SD	Mean ± SD	Mean ± SD	t	P-value	Sig.
Able	52.1±0.8	62.0±0.6	52.1±0.8	62.0±0.6	14.3	0.02*	S
Disable	69.5±0.7	78.2±0.9	69.5±0.7	78.2±0.9	43.6	0.006**	HS

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

Table (5): Mean & standard deviations of the patients regarding lupus awareness pre and post implementation of the self-management guidelines (No=75)

Lupus awareness items	Pre		Post	t-test	p-value	Sig.
	Mean ± SD	Mean ± SD	Mean ± SD			
Definition and incidence of SLE	65.4±0.3	92.0±0.4	1.6	0.05	NS	
Signs & symptoms of SLE	62.0±0.6	78.2±0.9	0.03	0.9	NS	
Complications of SLE	58.2±0.4	75.6±0.7	4.30	0.03*	S	
Treatment & Self-management	52.1±0.8	69.5±0.7	3.60	0.001**	HS	

Table (6): Percentage distribution of the patients regarding level of awareness pre/post-implementation of the self-management guidelines (No=75)

Items	Pre				T-test		
	No	%	No	%	t	P-value	Sig.
Un satisfactory	60	80	25	33.33	9.83	0.01	S.
Satisfactory	15	20	50	66.67	17.2	0.001**	HS.

Table (7): Overall mean & standards deviations of self management items regarding pre and post implementation of self-management guidelines (No=75)

Items of self-management	Pre		Post	T-test	P-value	Sig.
	Mean ± SD	Mean ± SD	Mean ± SD			
Level of awareness	10.7± 3.5	15.8± 5.6	11.4	0.03*	S.	

VI. Discussion

Systemic Lupus Erythematosus affects all aspects of a person's life and may require ongoing treatment and lifestyle changes for the person to continue functioning at a desirable level. The problems that experienced by someone with lupus are different. Thus medical treatment and self-management are important ways to intervene and stop the occurring of such problems, which interferes with the lives or even survival of patients suffering from SLE. (Maskarinec & Katz, 2011).

As regards the age group of the patients under the study, the present study revealed that; they were around 18 to 45 years. This in agreement with **Lupus Foundation of America (2012) & Sestak et al., (2011)** who stated that; the most common age for SLE is between 15-45 years which is called the bearing age which means that in this period hormones influencing vulnerability to this disease. Also according to gender of the patients in the current study, it was showed that all of them were females. This in the same line with **Tsokos (2013)** who stated that SLE affecting women nine times than men. This explained by **Sanz (2010)** who mentioned that; the biggest difference in the occurrence of lupus between men and women may be because women experience highest exposure to estrogen hormone, it is also possible that the male hormone, androgen, may have a protective function in lupus.

Regarding the pregnancy, more than three quarters of the patients under the study were not pregnant. This in the same line with **Pope & Aufderheide (2011)** who found that; the majority of females with SLE are usually afraid of being pregnant due to the potential risks such as; pregnancy-induced hypertension and preterm birth. Otherwise some females get pregnant but after counseling with an obstetrician for high-risk pregnancies.

In the present study it was showed that all the patients under the study during the past six months were had take medications, do a specialized physician visits, performing diagnostic tests, and also complains of different health problems. This results in accordance with **Spence & Hochberg (2011)** who was found that patients with SLE are usually receiving medications due to the various symptoms and problems regarding the disease, also it found at least two or three specialized physician should be visited by these patients, and performing different diagnostic tests to confirm the prognosis of the disease, in addition to the patients with SLE are usually have more than one health problems regarding the effect of the inflammatory disease. This might be due to that SLE is a chronic disease, and also the early stating of the incidence.

The current study represents the highest means and standard deviations regarding the items of the disability index pre implementation of self management guideline which stated as "with much difficulty" listed as follow; dress yourself, cut your meat, climb up five steps, take a tub bath, get on and off the toilet, reach and get down a 5-pound object, open car doors, and open jars which have been previously opened. This finding in the same line with **Parez (2011)** who found that; more than half of the patients in his study were unable to perform personal hygiene, cutting meats and lifting objects.

In relation to the pain sensation in the current study, it was found that more than two thirds of patients complain of pain. This results consonant with **Gordon and Smythe (2011)** who reported that; more than three quarters of patients with SLE complain of moderate to sever pain. This results due to the muscle and bone aches regarding the degenerative effects of Lupus on the body systems. This might explain the feeling of generalized pain resulted from the multiple inflammations of blood vessels of various body organs.

It was showed that, the highest means and standard deviations regarding the items of the disability index was observed in post implementation of self management guideline, which stated as "with some difficulty" regarding the following questions: dress yourself, stand up from a straight chair, get in and out of bed, wash and dry your body. These in the same line with **DeCastro, Morales & Wagner (2011)** who was describe the change of the disability level of patients with SLE as it really can be minimized by a restricted health care program with a global supervision from the health care providers with arranged time schedule. This might be to the starting self management guideline with the patients with in a restricted manner and using the written guideline which help the patient to flow their instructions at home and contact with the researcher by phone. Regarding the overall level of disability among the patients under the study, the present study showed statistical significance difference between the levels of disability pre/post implementation of self management guidelines. This is correspondent with **Watson(2011) & Giverson (2011)** who was found the same results after application of self management course on patients with arthritis.

Regarding patient's satisfaction about health status, the current study showed that half of patient's pre implementation of self-management guideline expressed their satisfaction about their health status as good, which increased to be nearly two thirds of the patients post implementation of self-management guideline this results. This finding are not compatible with **Koehler(2011)** who founded that; slightly more than two thirds of patients stated their satisfaction on their health status as bad. This difference might due to cultural diversity.

According to Lupus awareness quiz among patients under the study, it was founded that; the items of Lupus complications, and treatment & self management showed statistically significant improvement post implementation of self management guidelines. This finding in the same line with **Yariz, Qweeb, and Etail (2014)** who reported that; three quarters of patients wit SLE are usually acquiring information about the nature of disease, pathology, treatment, prognosis and life style changes, also the present study revealed that; more than two thirds of patient had satisfactory awareness post implementation of self management guidelines. This is consistent with **Sohng, Murdaca, Colombo & Puppo (2011)** who was found that; the same results after implementing self management course on Korean patients with SLE. This might be due to that knowledge is usually accepted to be taught by patients with chronic illness to be aware of their own status.

Regarding the overall items of self management, the present study showed statistical significance difference regarding level of awareness and also showed highly statistically significance regarding self efficacy level and fatigue severity among the patients under the study regarding implementing of self management guidelines. This is correspondent with **Nicol & Warier (2011)** who was found the same results after application of self management course on patients with arthritis.

VII. Conclusion

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

More than two thirds of the studied patients had satisfactory awareness level, post implementation of the self management guidelines. Moreover, there was statistical significant relation between patient's levels of awareness pre and post implementing of self-management guidelines.

Recommendations

Based on the results of the present study, the following recommendations are suggested:

- Design a systematically continuous self management programs for patients with SLE in hospitals in addition to media such as: newspapers, television, and radio to help in improving the health status of these patients.
- An Arabic guided images booklet about SLE should be distributed for each newly admitted patient diagnosed with SLE.
- An Egyptian Lupus Organization should be developed to be in contact with the problems of these patients.
- Further researches about self management of patients with SLE are highly recommended to reach the peak level of health satisfaction among those patients.

References

- [1]. Bellotti M. (2003): Systemic lupus erythematosus Quizes. *Lancet*. Feb 17;369(9561):587-96.
- [2]. Bruce K., & Burns M. (2014): Systemic lupus erythematosus. *N Engl Med*. Dec 1;365(22):2110-21.
- [3]. Cerner Multum W. & Wolters T. (2011): Novel evidence-based systemic lupus erythematosus responder index. *Arthritis Rheum*. Sep 15;61(9):1143-51.
- [4]. David T. (2011): Systemic lupus erythematosus and the neutrophil. *N Engl J Med*. Aug 25;365(8):758-60.
- [5]. DeCastro L, Morales W, &Wagner W. (2011): Clinical Manifestations of Systemic Lupus Erythematosus. In: Harris ED, et al, eds. *Kelley's Textbook of Rheumatology*. 7th ed. Philadelphia, Pa: WB Saunders; p.p.1201-24.
- [6]. Giverson U. (2011): EULAR recommendations for the management of systemic lupus erythematosus. Report of a Task Force of the EULAR Standing Committee for International Clinical Studies Including Therapeutics. *Ann Rheum*;67(10):195–205.
- [7]. Gordon K. & Smythe R. (2011): Systemic Lupus Erythematosus: clinical and immunologic patterns of disease expression in a cohort of 1,000 patients, 6th, Philadelphia, Pa: WB Saunders,p.p.458-489.
- [8]. Koehler F. (2011): Recommendations for adults patients with autoimmune inflammatory rheumatic diseases, 2nd ed, Mosby. Boston, Toronto, London,pp.61-70.
- [9]. Lorig K. (2010): Management of Systemic Lupus Erythematosus. *Textbook of Rheumatology*. 7th ed. Philadelphia, Pa: WB Saunders; p.p.1225-47.
- [10]. Lupus Foundation of America. (2012): Guidelines for screening, treatment, and management of lupus nephritis. *Arthritis Care Res (Hoboken)*.64(6):797-808.
- [11]. Maskarinec W. & Katz T. (2011): The influence of personality traits on reported adherence to medication in individuals with chronic disease: an epidemiological study in West Sweden. 6(3):e18241. doi: 10.1371/journal. Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden.
- [12]. Myrthe J, Ottenhoff T., Dick U., & Rob de Jong. (2011): Prognosis, mortality and morbidity in systemic lupus erythematosus,7th ed. Philadelphia: Lippincott Williams & Wilkins; p.p.1333-53.
- [13]. Nicol T. & Warier M. (2011). Glucocorticoids in systemic lupus erythematosus. *Clin Exp Rheumatol*. Sep-Oct 2011;29(5 Suppl 68):S126-9.
- [14]. Parez F. (2011): Enhancing patient self-management in clinical practice. *Bull Rheum Dis* 49:1-4, 2001.
- [15]. Pisetsky D.S. (2001) Systemic lupus erythematosus: epidemiology, pathology, and pathogenesis. In *Primer on the Rheumatic Diseases*, 12th edn(KlippelJ.H., CroffordL.J., StoneJ.H. & WeyandC.M. eds), Arthritis Foundation, Atlanta, pp. 329–335.
- [16]. Pope L. & Aufderheide R. (2011). Efficacy and safety of belimumab in patients with active systemic lupus erythematosus: a randomised, placebo-controlled, phase 3 trial. *Lancet*. Feb 26 2011; 377(9767):721-31.
- [17]. Przegł Lek. (2014). Socio-economic evaluation among patients with chronic illness, Philadelphia: Lippincott Williams & Wilkins; p.p.838-850.
- [18]. Rahman G. & Isenberg D. (2010): Influence of race/ethnicity on response to lupus nephritis treatment, 5th ed, Mosby, New York p.p.128-140.
- [19]. Sanz Y. (2010): Experimental reproduction of skin lesions in lupus erythematosus by UVA and UVB radiation. *J Am Acad Dermatol*. Feb 2010;22(2 Pt 1):181-7.
- [20]. Sestak A., Fürnrohr B., Harley J., & Namjou B. (2011): The genetics of systemic lupus erythematosus and implications for targeted therapy. *Ann Rheum Dis*. Mar 2011;70 Suppl 1:i37-43.
- [21]. Sohng T., Murdaca G., Colombo B., & Puppo F. (2011): Emerging biological drugs: a new therapeutic approach for Systemic Lupus Erythematosus. An update upon efficacy and adverse events. *Autoimmun Rev*. Nov 2011;11(1):56-60.
- [22]. Song B.E., Sohng K.Y. & Yoo Y.S. (2000) A study of anxiety, depression, and disease activity index in patients with systemic lupus erythematosus. *The Journal of Rheumatology Health* 7, 258–268.
- [23]. Spence D. & Hochberg E. (2011). Efficacy and safety of belimumab in patients with active systemic lupus erythematosus: a randomized, placebo-controlled, phase 3 trial. *Lancet*. Feb 26 2011;377(9767):721-31.
- [24]. Stanford health assessment questionnaire. (2015): a review of its history, issues, progress & documentation. *J heumatol* , 30(1):167-8.
- [25]. The Rand Corporation. (2014): Study of patients satisfaction (1994, Harvard University Press / 1994;ISBN 0-674-74850-6).
- [26]. Tsokos G. (2013): Systemic lupus erythematosus. *N Engl J Med*. Dec 2011;365 (22):2110-21.
- [27]. Watson R. (2011): Morbidity and mortality in systemic lupus erythematosus during a 10-year period. A comparison of early and late manifestations in a cohort of 1000 patients. *Medicine (Baltimore)*;82:299-308.
- [28]. Yariz Y., Qweeb W., & Etail T. (2014): Therapeutic opportunities in systemic lupus erythematosus: state of the art and prospects for the new decade. *Ann Rheum Dis*; 69:1603–1.