

Impact of an Education Program on Self-Care Agency and Self-Rated Abilities among Patients with Systemic Lupus Erythromatosis

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Abstract

Background: Systemic lupus erythematosus (SLE) is an autoimmune disease with potential variety and severity of manifestations and unpredictable course present challenges and repercussions in all arenas of life. **The aim** of the current study was to evaluate the impact of education program on self-care agency and self-Rated abilities among patients with systemic lupus erythromatosis at Mansoura university hospital. A quasi experimental **research design** was utilized. **Setting,** the study was conducted at Rheumatology and Immunology outpatient clinic at Mansoura University Hospital, Egypt. A purposeful **sample** consisting of all patients with Systemic Lupus Erythematosus (SLE) without any organ damage who registered at the rheumatology and immunology unit during the period of the beginning of August 2019 to end of December 2019. Three **tools** were used in data collection; a structured interviewing questionnaire, Self -Rated Abilities for Health Practices Scale (SRAHP), and Exercise Self Care Agency scale. **Results,** revealed that one third of studied subjects fall in age group from 30-40 years old, most of them were female and more than half of them were married in addition to more than two fourth of patients had disease for more than 4 years. Related to educational program there were positive impact on self-rated abilities for health practices and self-care agency after implementation of the education program. **Conclusion** Application of the education program through Self-care interventions has positive impact on improving self-care agency (SCA) and self-rated abilities for health practices that permitting patients to integrate mutually social support and self-care activities. **Recommendation;** Continuous education programs for patient with systemic lupus erythematosus in order to improve their health status, independence and self-care activities, and replication and expanded studies are also needed.

Keywords: Education program, self-care agency, self-rated abilities for health practices, Systemic lupus.

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Introduction

Globally, systemic lupus erythematosus (SLE) is a significant community health problem with obvious variances in SLE prevalence.

SLE is a multisystem autoimmune diseases portrayed by a variety of auto antibodies in the blood and various system and organ involvements as skin, joints, lungs, heart, kidneys, and brain which is marked by acute

periodic flare ups of symptoms impacting any organ system and consequential in potentially life-threatening complications (**Mak, Isenberg, & Lau, 2013**).

There are 5 million person ages with SLE international, 90% of whom are females between 15 and 44 years. SLE is often more life-threatening in people of African, Hispanic, Chinese, and Asian plunage. SLE identification proceeds to rise since health workers and have more prominent mindfulness of SLE. Five years survival rate for majority of patients with SLE and more than most of them for 10 years. The expanded life expectation of patients with SLE is related to advancements in attaining the needs of long-term care, and the independence of individuals with SLE has enhanced an urgent domain in SLE management (**Harmayetty, Efendi, Ns, & Gunawan, 2018**).

There's no known particular etiology SLE, in spite of the fact that its advancement is likely impacted by hereditary, hormonal, environmental and drug factors (**Liang, Tian, Cao, Chen, & Wang, 2014**). The clinical symptoms of SLE are troublesome to anticipate that include fatigue, skin rashes, joint pain, headaches, epilepsy, cerebrovascular accidents, movement disorders and neurological symptoms as anxiety, depression, cognitive disorders and psychosis, its presentation and course are disorders and psychosis, its presentation exceedingly variable,

extending from sluggish to fulminant (**Brown et al., 2012**).

Intervention of systemic lupus erythematosus (SLE) commonly relies on disease significance and illness appearances. Numerous studies have established the great enhancements in the treatment of SLE, but the disease cannot be cured currently (**Kan et al., 2013**). Also has a negative impact on various aspects of a patient's life, such as mental wellbeing and daily functioning which may produce low employment rates and over whelming financial burden (**Yelin et al., 2007**). Subsequently, it particularly dangerous to improvement better-quality self-care agency in patients with SLE may achieve better health outcomes(**Yang et al., 2018**).

Self-care agency, is a dynamic element of self-care deficit nursing theory, which well-defined as individual's ability to constantly evaluate health-related requirements and achieve self-care activities projected for promoting and sustaining health and well-being (**O'Regan et al., 2019**). Additionally, Self-Rated Abilities for Health Practices Scale (SRAHP) evaluate self-perceived ability for utilization of health-advancing activities. SRAHP encompasses four subscales: exercise, nutrition, responsible health practice, and psychological well-being (**Becker, Gates, & Newsom, 2004**).

Now, the self-care agency required to be funded extra awareness in

clients with chronic illness, chiefly centering on diabetes, hypertension, coronary heart disease, and rheumatoid arthritis (RA). Contrariwise, rare studies have been directed to estimate the level of self-care agency in patients with SLE (Ovayolu, Ovayolu, & Karadag, 2012). Ssystemic Lupus Erythematosus is a multifaceted disease to diagnose, treat and manage accompanying with important mortality, morbidity, so applying education program in patients with SLE to enrich self-care agency (SCA) and self-rated abilities for health practices enabling patients to incorporate mutually societal support and self-care to shrunk pain, deal with fatigue, enhanced function and delayed disability among patients with lupus (Orem & work, 1989).

Application of an education program through Self-care interventions were definite as interventions that direct to equip clients with skills to effectively take an interest and take obligation within the care of their disease in arrange to operate ideally through obtaining information and combination of at least two of the following: encouragement of independent sign/symptom supervising, medication compliance, enhancing problem-solving and decision-making skills for medical treatment management, and varying their physical activity, dietary, and/or smoking behavior (Yuen, Cunningham, & Management, 2014).

Significance of Study

SLE has an undesirable outcome on various features of a client's life, for example mental health, quality of life, and daily functioning, which might result

in low employment values and heavyweight economic load (Yelin, 2007). According to previous studies, patients with high level of self-care agency might achieve better health outcomes (Yang, 2018). Modes that highlight on growing client independence in this area self-care activities contain a model of self-care projected by Orem. Orem articulates that nurses be capable of apply a supportive educational system by advancing nursing agency in the form of health promotion activities to improve the self-care deficit (Harmayetty et al., 2018)

The model of self-care is commonly utilized in nursing research in the case of chronic disease, and has revealed good results (Powell, Kreuter, Stephens, Marti, & Heinemann, 1991). The self-care model is able to too be useful in cases of SLE to improve self-care agency (SCA) and self-care activities so as to permit patients with SLE to improve their quality of life individually. So, this study aimed to evaluate the impact of education program on self-care agency and self-rated abilities among patients with systemic lupus erythromatosis at Mansoura university hospital.

Aim of the Study

The aim of the current study was to evaluate the impact of education program on self-care agency and self-rated abilities among patients with systemic lupus erythromatosis at Mansoura university hospital.

Research Hypothesis

▪ The self-care agency of the studied subjects regarding systemic lupus

erythematosus will be improved after applying the education program.

▪ The self-rated abilities of the studied subjects will be improved after applying the education program.

Subjects and Methods

Research Design

A Quasi-experimental research design was utilized in this study.

Research Setting

This study was conducted at Rheumatology and Immunology outpatient clinic at Mansoura University Hospitals, Egypt. This clinic in the hospital is specialized for patients with systemic lupus erythematosus for monthly follow up visits and suitable for direct contact with the patients and applying the educational program.

Subjects:

A purposeful sample consisting of all patients with Systemic Lupus Erythematosus (SLE) without any organ damage who registered at the rheumatology and immunology unit during the period of the beginning of August 2019 to end of December 2019.

Inclusion criteria: Adult conscious patients aged from 18 years to 60 years old from both sexes, patients didn't participate in any previous educational program regarding systemic lupus erythematosus and willing to participate and communicate in the study.

Exclusion criteria: Patients diagnosed with neurotic and/or psychotic disorders, presence of other severe comorbidities that might hinder their independence in health care management, like malignancy or stroke, and patients having hearing or speaking problems that may affect patients' ability to understand or participate in the study. The sample size was 86 adult patients.

Tools for Data Collection

Three tools were used in data collection:

Tool 1

A structured patient interviewing questionnaire, developed by the researchers in simple Arabic language consisting of 2 parts: Part 1: Sociodemographic data sheet including (age, sex, marital status, residence, with whom live (husband, wife, mother, father, and siblings), level of education, occupation, and monthly income). Part 2: Medical History data Sheet: consisted of 3 closed ended questions; duration of disease, signs and symptoms and aggravating factors of symptoms.

Tool 2

Self -Rated Abilities for Health Practices Scale (SRAHP), A structured self-reported questionnaire adapted from (Drake, 2018) and translated to simple Arabic language. SRAHP is a 28-item, 5-point scale to measure self-perceived ability to implement health-promoting behaviors. SRAHP contains four subscales: Exercise, Nutrition,

Responsible Health Practice, and Psychological Well Being. Each subscale has seven items. Respondents are asked to rate the extent to which they are able to perform health practices related to these four domains. Items are rated from 0 (not at all) to 4 (completely).

Scoring system: Subscales are (Nutrition: Items 1-7), (Psychological Well Being: Items 8-14), (Exercise: Items 15-21), (Responsible Health Practices: Items 22-28). There are no reversed scored items. Subscale scores are summed to obtain a total score. Total scores range from 0-112. Higher scores indicate greater self-efficacy for health practices and categorized as Low < 37.3, Moderate 37.3 – 74.6 and High > 74.6

Tool 3

Exercise Self Care Agency scale: A self-administered instrument adapted from (Liang et al., 2014) and translated to simple Arabic language. ESCA consists of four subscales, including active versus passive response to situations, motivations, the knowledge base, and the sense of self-worth. It has 43 items on a 5-point Likert-type scale ranging from 0 (it does not describe me) to 4 (it completely describes me).

Scoring system: The total score ranges from 1 to 172, which is equally divided into three levels: low (<56.76), moderate (56.76–113.52), and high (>113.52). Higher scores indicate higher level of self-care agency.

Tool validity: The content validity of the tools was checked by a panel of seven experts from the Medical-Surgical & Community Health Nursing, modifications were done based on their opinions.

Test reliability: Testing reliability of the proposed tools was assessed using Cronbach's alpha test, showed high reliability of the tools as: Tool II (SRAHP): (0.650) & Tool III (ESCA): (0.818).

Pilot Study

A pilot study was carried out on 8 patients (10%) in order to test clarity and applicability of the tool. The pilot study was also used to estimate the time needed for each subject to fill in the questions. Modifications were done based on the results of the pilot study. Patients participated in the pilot study were excluded from the main study sample.

Ethical Considerations

An official permission was obtained from director of Mansoura University Hospitals obtain the permission for data collection before conducting the study explaining the aim. An oral consent was taken from all patients participated in the study after explanation of purposes and nature of the study; they were given the right to withdraw at any time, or refuse to answer specific question without giving any reason. The researcher assured maintaining anonymity and confidentiality of subject's data.

Field Work

The actual field work started from the beginning of August, 2019 to the end December 2019. The study comprised the following phases:

Preparatory Phase

Preparatory Phase started from the beginning of August, 2019 to the beginning of September 2019. (A period of one months). It included developing the structured tools and the education program based on the review of related literature. Represented by using booklets, pursuers, and power point presentations, it was written in a simple Arabic language and supplemented by photos and illustrations.

Contents of educational Program:

- **Booklet** was designed to meet clients' needs and to fit into their interest and levels of understanding. It consisted of different topics as follows: an overview about systemic lupus erythromatosis; definition, risk factors, aggravating factors, manifestations, diagnosis, medical treatment, side effects of medication and complications.

- **Oral explanation with pictures** and to a lesser extent internet regarding self -care practices including physical activity, healthy diet, stress management and responsibility towards health practice.

- **Pamphlets & oral explanation** about managing SLE symptoms independently and self-care activities.

Methods of Teaching:

All patients received the same intervention content using the same teaching methods, there were: Lectures/Discussions, and Presentation.

Media of Teaching:

Illustrated booklet, Pamphlets & oral explanation.

Implementation Phase

- The implementation phase started from the beginning of September, 2019 to end of December, 2019. The program was implemented in period of four months two times a week (Saturday and Tuesdays) including pretest, program implementation, and post-test for patients in the study group; the program was carried out over 10 to 12 weeks.

- For the pre-test; the time consumed to fill the demographic, medical history, self-rated abilities for health practices scale and self-care agency scale was from 30 to 40 minutes for study group.

- For post-test; the time taken was about 20-30 minutes for testing self-rated abilities for health practices scale and self-care agency scale.

- The educational program was presented in three sessions. It was conducted through lectures and group discussions. First session was theoretical; which state immediately after pretest included "Overview about systemic lupus erythromatosis; definition, risk factors, manifestations, and complications".

- Second session was practical given to patients during the second month of follow up visit which involved physical activity(including activities of daily living and physical exercise), healthy diet, stress management (including relation technique and modification of lifestyle), responsibility towards health practice (as symptoms should monitor and reported, negative changes should report and required information as needed).

• Third session which is combination of theoretical and practical session given to patients during third monthly follow up visit which involved how to managing SLE symptoms independently and its recurrence, relapses of trigger factors, self-care activities performed at home, the problems encountered in doing self-care and additional health information were given to respondents in need. Each session lasted about 45-60 minutes and was accompanied by feedbacks. These educational sessions were done either individually or in groups (5-10) patients based on the number of patients in each room.

Evaluation Phase

Post-test evaluation was applied to each patient in the study group to evaluate impact of the program after one month from the completing of the program during the fourth monthly follow up visit.

Statistical Analysis

Data were fed to the computer and analyzed using IBM SPSS software package version 20.0. (Armonk, NY:IBM Corp) Qualitative data were described using number and percent. Quantitative data were described using range (minimum and maximum), mean, and standard deviation. Significance of

Table 3 states that there were highly significant statistical differences between pretest and posttest in study group in all subscales of self-rated abilities for health practices after implementation of the education program with p value ($P < 0.001^*$). there were highly significant statistical differences between pretest and posttest in study group in Overall self-rated abilities for

the obtained results was judged at the 5% level. The used tests were Marginal Homogeneity Test (Used to analyze the significance between the different stages), Paired t-test (For normally distributed quantitative variables, to compare between two periods).

Results

Table 1 shows that 79.1% of the patients were female and 30.0% of the patients aged between 30 and 40 years old, with mean age around 33.31 ± 10.42 . As regards to marital status 54.7% of the patients were married while 60.5% of the patients were from rural areas. 38.4% of female patients live with their husband and 55.8% had secondary school education. As regards to job 52.3% of the patients are working but 68.6% of them hadn't enough monthly income.

Table 2 reveals that 44.2% of patients had disease for more than 4 years; According to factors that increase symptoms; 36% of the patient symptoms increase due to physical tiredness and 32.6% of patient symptoms increase due to emotional tiredness.

Figure 1 illustrates that 79.1% of patients had malaise while 53.5% of the patients suffering from headache and 37.2% had arthritis.

health practices after implementation of the education program with p value ($P < 0.001^*$).

Table 4 shows that there were highly significant statistical differences between pretest and posttest in study group in the levels of self-rated abilities for health practices after implementation of the education program with p value

($P < 0.001^*$). there were highly significant statistical differences between pretest and posttest in study group in total score of self-rated abilities for health practices after implementation of the education program with p value ($P < 0.001^*$).

Table 5 reports that there were highly significant statistical differences between pretest and posttest in study group in the levels of exercise for self-care agency after implementation of the education program with p value ($P < 0.001^*$). There were highly significant statistical differences between pretest and posttest in study group in total score of exercise for self-care agency after implementation of the education program with p value ($P < 0.001^*$).

Discussion

Systemic lupus erythematosus (SLE) is a long-term condition with varied natural history and multisystem involvement. It can occur at any age and is more common in women than in men. Till now there is no cure for lupus, but medical treatment and lifestyle changes can help control it. Patient with lupus who have proper medical care, and sufficient education can significantly improve function and self-care agency (**Brown et al., 2012**).

Regarding demographic characteristics of the studied sample, the present study showed that, more than three quarters of the participants were females, this finding was in accordance with (**Elsayed & Mesbah, 2018**) who stated that most of patients were females. And more than half of them were married, which in contrast with (**Hassan & Gomaa, 2018**) whose sample showed that less than half of the sample was

single, that lead to a possibility of non-getting married in the future, which would affect their self-esteem.

The main age of the participants was 33.31 ± 10.42 , and more than one half of them had secondary school education. This finding was in line with the fact that about 80–90% of all systemic lupus erythematosus cases concern women in the age of 20 to 40 years (mean age at diagnosis: 29 years) (**Olesińska & Saletra, 2018**).

Concerning the onset of the disease, the result revealed that more than one third of patients had disease for more than 4 years. This finding was supported with (**Macejová et al., 2013**) who found that the onset of disease among participants was from 1 to 5 years. According to factors that increase symptoms; more than one third of the patient's symptoms increase due to physical and emotional tiredness. This is may be due to , that more than half of studied sample are working which lead to do more efforts, and exposed to daily work tension that affect directly on their health status. The studies show that adequate level of physical activity has positive impact on physical, mental and social health in patients with chronic diseases, also patients with SLE tend to limit their physical activity for many reasons, fear of joint pain, bleeding (resulting from hematological disorders), and increased risk of fracture (**Olesińska & Saletra, 2018**).

The current study showed that, more than three quarters of patients had malaise, and half of them suffering from headache. From 50 to 90% of patients with SLE experience constant fatigue or malaise, and consider it the most common symptoms of the disease (**Holloway et al.,**

2014). Most related factors which influence the feeling of malaise include: disease activity, sleep disorders, depression, anxiety, despondency, pain, emotional disorders, obesity, reduced physical activity, and the treatment used in SLE (Sterling et al., 2014).

Also 37.2% of patients suffering from arthritis. Joint pain is one of more frequent reasons why patients visit a physician. Pain significantly affect every day functioning of patients, limits their abilities to perform activity of daily living, as well as household duties, perform physical exercises and even personal hygiene (McElhone, Abbott, Gray, Williams, & Teh, 2010). The use of non-pharmacological therapies is helpful for those patients as hot baths, ensuring muscle relaxation, behavioral therapy, and additional orthopedic equipment such as crutches, walking sticks, supports and walkers make moving more easier (Wallace, 2019).

Self-care can facilitate SLE patients in achieving improvements in living independently (Harmayetty et al., 2018). The current study revealed that more than half of patients had high level of overall exercise of self-care agency after implementation of the program. This result was in accordance with (Harmayetty et al., 2018) who stated high SCA after the program. So patient education is a significant component of disease management plans which includes general information, treatment strategies to enhance the individual's self-care agency (Yazdany & research, 2011).

The finding of the current study reflected that there were highly significant statistical differences between pre and post - test in study group in all subscales of self-rated abilities for health

practices after implementation of the education program, there was a remarkable improvement in nutrition, exercises, psychological wellbeing, and responsible health practices. This finding was in agreement with (Elsayed & Mesbah, 2018) who illustrated highly statistical significant improvement regarding all SRA post program. Also (Wagner et al., 2001), who illustrated that the success of an intervention can be measured by improvements in ability to do activity of daily living, maintain a healthy diet, and exercise regularly as outcome measures.

Moreover, the present study showed that, there were highly statistically significant improvement regarding total score of overall exercise of self-care agency (35.05 ± 20.29), and total score of self-rated abilities for health practices levels (65.88 ± 6.59) after implementation of the program. This may be due to that more than three quarters of the studied sample were females, and more than half of them had secondary education, so this improvement because of women are more willingly to seek health care, and gain more information about how to manage the disease better from health care providers. On the other hand, woman is considered the first caregiver of the whole family so she tends to be in a good health to be able to provide this care for her family. This result was in the same line with (Yang, 2018) who found that the level of self-care agency in women was higher than that in men.

The results of the current study indicated highly improvement in self-care agency, and self-care rated abilities among the studied sample after implementation of the educational program. This finding was in accordance

with (Yazdany & research, 2011), who stressed that health education program and active involvement of members of the community affected by systemic lupus erythematosus in related interventions is integral to health improvement. While in

contrast with (Elsayed & Mesbah, 2018) who showed that self-care practices were uncorrelated with health related quality of life and health outcomes in lupus patients.

Table (1): Distribution of the studied patients according to patient's socio demographic characteristics in study group (n = 86)

Sociodemographic data	No.	%
Sex		
Male	18	20.9
Female	68	79.1
Age		
<20	10	11.6
20 – 30	24	27.9
30 – 40	26	30.2
40 – 50	21	24.4
≥50	5	5.8
Mean ± SD.	33.31 ± 10.42	
Marital statuses		
Single	12	14.0
Married	47	54.7
Divorced	18	20.9
Widow	9	10.5
Residence		
Rural	52	60.5
Urban	34	39.5
Who are you live with?		
Wife	13	15.1
Husband	33	38.4
Sons	26	30.2
Parents	12	14.0
Sister	2	2.3
Educational level		
Universally	28	32.6
Secondary	48	55.8
Read and write	4	4.7
Illiterate	6	7.0
Job		
Worked	45	52.3
Not worked	41	47.7
Monthly income		
Not enough	59	68.6
Enough	27	31.4

Table (2): Distribution of the studied patients according to patient's medical history in study group (n = 86)

Medical history items	No.	%
Disease duration		
Less than one year	23	26.7
From one year – 2 years	13	15.1
From 2<4	12	14.0
≥4 years	38	44.2
Factors that increase symptoms		
Emotional tiredness	28	32.6
Physical tiredness	31	36.0
Photosensitivity	8	9.3
Insomnia	15	17.4
Hormonal changes	4	4.7

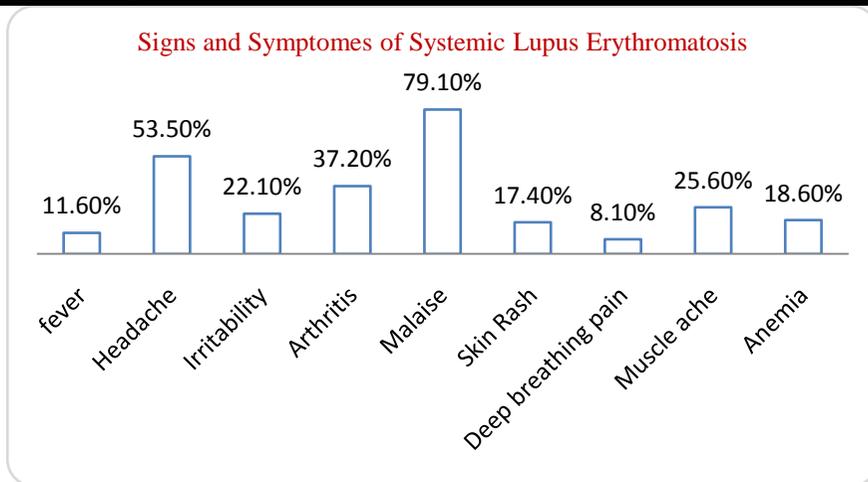


Figure 1. Signs and symptoms of systemic lupus erythromatosis patients (n = 86).

Table (3): Comparison between pre and post according to Self-Rated Abilities for Health Practices in study group (n = 86)

Self-Rated Abilities for health practices.	Pre	Post	t	p
Nutrition				
Total score	10.91 ± 3.96	16.79 ± 2.96	12.	<0.
% score	38.95 ± 14.16	59.97 ± 10.57	381*	001*
Psychological Well Being				
Total score	11.34 ± 3.55	17.17 ± 3.50	14.	<0.
% score	40.49 ± 12.68	61.34 ± 12.48	061*	001*
Exercise				
Total score	11.42 ± 3.52	17.71 ± 2.87	13.	<0.
% score	40.78 ± 12.58	63.25 ± 10.26	645*	001*
Responsible Health Practices				
Total score	11.20 ± 3.60	22.12 ± 2.35	25.	<0.
% score	39.99 ± 12.86	78.99 ± 8.39	403*	001*
Overall Self-Rated Abilities for health practices				
Total score	44.86 ± 11.35	73.79 ± 7.38	22.	<0.
% score	40.05 ± 10.13	65.88 ± 6.59	707*	001*

t: Paired t-test p3: p value for comparing between pre and post *: Statistically significant at $p \leq 0.05$

Table (4): Comparison between pre and post according to Self-Rated Abilities for health practices in study group (n = 86)

Self-Rated Abilities for health practices levels	Pre		Post		Test of sig.	p
	No.	%	No.	%		
Low	21	24.4	0	0.0	MH=83.0*	<0.001*
Moderate	62	72.1	50	58.1		
High	3	3.5	36	41.9		
Total score	44.86 ± 11.35		73.79 ± 7.38		t=22.707*	<0.001*
% score	40.05 ± 10.13		65.88 ± 6.59			

MH: Marginal Homogeneity Test tp: Paired t-test p3: p value for comparing between pre and post *: Statistically significant at $p \leq 0.05$

Table (5): Comparison between pre and post according to exercise for Self-Care Agency in study group (n = 86)

Overall exercise for self-care agency	Pre		Post		Test of sig.	p
	No.	%	No.	%		
Low	24	27.9	12	14.0	MH=88.0*	<0.001*
Moderate	50	58.1	29	33.7		
High	12	14.0	45	52.3		
Total score	75.44 ± 25.41		103.29 ± 34.90		t=6.650*	<0.001*
% score	18.86 ± 14.77		35.05 ± 20.29			

MH: Marginal Homogeneity Test
Statistically significant at $p \leq 0.05$

tp: Paired t-test p₃: p value for comparing between pre and post *

Conclusion

The results of the current study concluded that; Application of education programs through Self-care interventions has positive impact on improving self-care agency (SCA) and self-rated abilities for health practices that allow patients independence, compliance with medical treatment, participate in self-care activities and health improvement.

Recommendations

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

Continuous educational programs for patient with systemic lupus erythromatosis in order to improve their health status.

Replication and expanded studies are also needed.

Conflicts of interest disclosure

No conflicts of interests.

Financial support

- **No funding was received.**

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