- *Basic Research*

Influence of Self-Management Instruction on Outcomes of Health for Systemic Lupus Erythematosus Patients

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Abstract

Introduction: Systemic lupus erythematosus (SLE) is an autoimmune multisystem inflammatory, chronic disease that is accompanied by momentous morbidity, mortality, and reduced quality of life. Proper self-management reduces mortality and disability, improves quality of life, and decreases healthcare expenses and improves self-efficacy. **Aim***:* This study objective to evaluate the influence of self-management instruction on, outcome of health and self-efficacy for SLE patients at Mansoura University Hospital. **Design of study***:* A quasi-experimental design was utilized. **Setting***:* The study was conducted at medical inpatient and outpatient departments in addition to rheumatology outpatient clinics on Saturdays, Tuesdays, and Thursdays. **Subject***:* A purposive sample of 65 patients admitted to inpatients of medical departments and medical and rheumatology outpatients before and after implementation of self-management instruction were included in the study. The study was conducted between February 2021 and August 2021. **Tool***:* A questionnaire on health assessment and questionnaire on health outcomes in the fatigue and pain severity scales were used in the study. **Results***:* After implementation of self-management instruction, there were a highly statistically significant difference as regards severe pain, awareness, and generalized health status (P < 0.001). **Conclusion**: There were positive effects on SLE patients post implementation of instruction in decreasing fatigue and improving of pain and disability. **Recommendation**: An education program of patient to improve care of SLE patients by written and demonstrated guidelines need to be accessible in all SLE clinics and departments.

Keyword*s:* Self-management instruction, Outcomes of health, Systemic lupus erythematous

Introduction:

Systemic lupus erythematosus (SLE) is an autoimmune multisystem inflammatory and chronic disease that is accompanied by momentous morbidity, mortality, and reduced quality of life (**Harry et al., 2019**). SLE is manifested by acute periodic flare-ups of symptoms affecting any organ system and triggering potentially life-threatening complications. Patients have significantly increased healthcare expenses over the course of their life owing to recurrent physician visits and complex medication regimen (**Williams et al., 2019**).

While there is no treatment for SLE, early diagnosis, appropriate medical management, and lifestyle modification can diminish flares and accordingly prevent complications (**Phillip et al., 2019**). Disease management has become extremely vital than treatment for increased patient survival and prevention and management of chronic complications. Nursing can play an important role in the treatment process of SLE, especially during periods of disease exacerbation, because the nurse helps patients to cope with the disease in their daily lives, teaches how to deal with SLE symptoms, prevents periods of SLE exacerbations, and provides systematic health education concerning lifestyle changes (**Petrocchi, Visintini, De Marchi, Quartuccio, & Palese, 2021**).

The nurse supports the patient and family by providing essential support and performs educational actions in line with lifestyle changes and rehabilitation to improve their quality of life**.** Lifestyle modifications, such as prevention of excessive exposure to sunlight, stress management, smoking cessation, and diet low in saturated and trans fats, are also highly imperative (**Choi et al., 2021**).

In previous studies, it was found that education and counselling given to patients and their families definitely affected patient outcomes and improve self-efficacy, which is vital in disease management. As SLE care advances, patients are expected to be involved in self-management plans to control their symptoms, lessen flares, and lessen comorbidities. Proper self-management reducing mortality and disability, improve quality of life, and lower health care expenses. Consequently, self-management instructions is a fundamental part of the chronic disease standard of care (**Twumasi, Shao, Dunlop-Thomas, Drenkard, &Cooper, 2020**).

Self-management intervention is planned to augment social support and offer health education, decrease pain, enhance function, and delay disability in patients with SLE (**Williams et al., 2019**).

Significance of the study: SLE is a chronic autoimmune disease with altering degrees of systemic involvement and disease courses. There are five million individuals with SLE globally; of these, 90% are female and aged 15–44 years. SLE identification is increasing since health workers and the public have better awareness of SLE. Patients with SLE have survival rates of >90% and 87.4% at 5 and 10 years, respectively. The improved life expectancy in patients with SLE is due to enhancements in meeting the needs of long-term care, and the independence of patients with SLE has become an important component in SLE

management, for the most part of the community **(Kusnanto, Sari, Harmayetty, Efendi, & Gunawan, 2018)**.

Thus, a significant understanding of the disease will aid patients to recognize how to be compliant with the treatment and preserve optimal self-care and follow precautions that will be helpful in decreasing the expected complications, Subsequently, patients with SLE are in need for nursing education to improve their knowledge level about their disease to overcome systemic complications **(Mohama., Abo-ElNoor, & Abd-Elall, 2020)**.

Aim of the study:

The study objectives to evaluate the influence of self-management instruction on outcome of health and self-efficacy for SLE patients at Mansoura University Hospital.

Objectives

1. Determine the status of health assessment for SLE patients.
2. Design self-management instruction for SLE patients (planning)
3. Apply self-management instruction for SLE patients (implementation)
4. Estimate the influence of self-management instruction application on outcomes of health regarding including fatigue, pain & self-efficacy among SLE patients (evaluation)

Materials and Method:

(I). Technical Design:

Study design:

A quasi-experimental design was used toward achieve the purpose of the study.

Setting:

The research was implemented at inpatient and outpatient medical departments in addition to rheumatology outpatient clinics on Saturdays, Tuesdays, and Thursdays at Mansoura University Hospital.

Subjects:

A purposive sample of 65 patients was included in the study. The sample size was calculated using G*Power program using the following data: effect size, 0.5, α-error prop, 0.05; two-tailed; and power (1-β err prop), 99.7 %, using paired t-test to detect difference between two dependent means of patients admitted to inpatient and outpatient medical departments in addition to rheumatology outpatient clinics from February 2021 to August 2021. The inclusion criteria were age of 20–60 years, willingness to participate in the study, normal consciousness, and ability to communicate. The exclusion criteria were health complications, such as stroke, paralysis, cognitive dysfunction, renal failure, and cancer.

Study period: The study was conducted between February 2021 and August 2021.

Data collection tools:

This study included four tools:

Tool I: Questionnaire of health assessment: A questionnaire of self-administered for SLE patients, to evaluate health status of patients. It was adapted by **Teh, Castelino, McElhone, & Abbott (2021)** and the researcher modified it. It has the following parts:

   Part 1: Patient demographic criteria (marital status, age, smoking, sex, occupation, and treatment cost)

   Part 2: Index of disability to measure eating, waking up, walking, dressing, grooming, and hygiene

   Part 3: Drug adverse effects to evaluate recommended drugs and any cause of difficulties in the last 6 months. It had been translated and retranslated.

   <u>**Scoring system:**</u>

Part 1 & 3 scoring: Answers of patients were presented in values of frequency & percentage.

Part 2 scoring

The answers of patients for every item by four responses were as follows: without any difficulty = 0, with some difficulty = 1, with much difficulty = 2, and unable to perform = 3. Score calculation by multiplying the highest score of 3 by the total number of questions (N = 20) to create the combined score sixty marks and then ranked as follows: disabled patient if ≥ fifty percent & able patient if < fifty percent.

Tool II. Questionnaire of outcomes of health: A scale of self-administered was used to estimate the effect on fatigue and pain severity in SLE patients with. It consists of nine items. It was adopted from **McMorrow, Leung, Strand, & Kim (2021)** and had been translated & retranslated.

<u>**Scoring system**</u>

Fatigue scale scoring

Patient response for every item was ranked from one to three as follows: disagree equal one, to some extent equal two & agree equal three.

There is a dichotomy in fatigue scoring. Patients with score above sixteen are suffering of fatigue relevant to disease .while score less than sixteen indicate the health is normal

Pain scale scoring:

Patient response was ranked as follows: no pain equal zero, mild pain equal one to three, moderate pain equal four to six & sever pain equal seven to ten.

- Unsatisfactory if <51 (<60%)
- Satisfactory if 51–68 (60%–80%)
- Good if 68–85 (>80%)

Tool III. Scale of self-efficacy: It is a scale of self-administered for SLE patients, to evaluate the self-efficacy, expected adaptation& coping after complete types of stressful life actions was experienced. It is adopted from **Wang, Luo, Zhang, & Lee (2021).** It consisted of ten items linked to SLE. It had been translated & retranslated.

Scoring system:

Patient response for every item included four points such as: not at all trueequal one, hardly true equal two, moderate true equal three & exactly trueequal four. Summation , 4. The scores of the answers to all ten statements was summed in the range from ten to forty, after that; subsequently, it is classified into two groups: <20 is low self-efficacy and >20 is self-efficacy considered high.

Tool IV. Quiz of SLE awareness: they are a questions of self-administered to evaluate knowledge level for SLE patient's; it's. It is adopted from **Mohamed Elmetwaly, Younis Ahmed, & Mohamed Mohamed (2021).** It contained twenty multiple choice questions revealed to SLE. It had been translated and retranslated.

Scoring system:

The total SLE awareness score was 20. Every one right response was indicated by 1 and false was indicated by 0. It was classified as follows: aware if ≥60% and not aware if <60%.

Advocated self-management instruction as regards to SLE: The instruction was designed in Arabic language by simple method in a CD form containing PowerPoint presentations and videos were developed and provided to patients as a gift covering all items related to SLE after a serious review of the related literature; then, medical surgical nursing and medical expertise were reviewed by a jury.

(II) Operational design:

Preparatory phase:

To gain robust tools, the researchers scrutinized the literature review, such as articles, books, and Internet sources.

Content validity and reliability:

1. Validity

Extensive review of the current national and international literatures related to the study was conducted using textbooks, articles, magazine, Internet, and other related researchers. Tools were adopted and modified by the researcher and then tested for content validity by a panel of seven experts (three professors and two assistant professors in the nursing field and two professors in faculty of medicine specialized in rheumatology). All consulted experts are affiliated with Mansoura University. They reviewed every tool to ensure that the tools are clear, comprehensive, understandable, relevant, applicable, and simple for implementation, and some modifications were applied accordingly.

2. Reliability

The reliability test was applied using Cronbach's alpha and was in the questionnaire of health assessment (0.780), which is acceptable. The questionnaire of health outcomes has good reliability (0.827); the scale of self-efficacy has acceptable reliability (0.775); and the quiz of lupus awareness has acceptable reliability (0.726).

Pilot study

Particularly, 10% of participants who were selected randomly from patients under study were excluded from the study. The purpose of the pilot study was to ascertain the clarity and tool applicability and evaluate the needed time to answer the interview sheet. Based on the finding of the pilot study, modification was made to make the tool more applicable to patients.

Procedure of data collection:

The data were collected at the beginning of February 2021 to August 2021 at the inpatient and outpatient medical departments in addition to rheumatology outpatient clinics on Saturdays, Tuesdays, and Thursdays in Mansoura University Hospital. Data collection was conducted in four phases:

Phase 1. Preparatory phase (assessment): The researcher introduced herself to each patient sample and provided them a brief idea about the aim of the study. Then, oral and written consent was obtained from each participant. The interview sheets were distributed by the researchers to every participant separately; collection of data was started using tool I, which took approximately 20–30 min on average. Tool IV tool took approximately 15–20 min on average. Finally, tools II and III were distributed at the end of the session, taking approximately 10–15 min for every scale.

Phase 2. Planning phase (developing educational instructions)

The researchers assessed the educational needs of the patients with SLE and then conducted a literature review and Internet search for relevant information to construct the educational instructions under the guidance of the supervisors. A simple Arabic CD containing PowerPoint presentations and videos were developed and provided to patients as a gift covering all items related to SLE.

The educational booklet includes definition of SLE and autoimmune diseases, fast facts about SLE, categories of lupus, symptoms of SLE, etiology, diagnosis, complication, treatment of SLE, diet, exercise, nutrition, immunizations, pregnancy and contraception, medications for SLE, life with lupus, and prevention of fatigue due to lupus.

Phase 3. Implementation phase: Two sessions were applied to all patients for clarification of self-management instruction; every session took 45–60 min on average.

Session 1: It took 15–20 min. The patient answered the tools with researcher helpful clarification, and then self-management instruction were identified, regarding the definition of lupus and immune diseases, quick facts about lupus, symptoms, causes, types of lupus,

diagnosis, complications, and treatment. The patient was allowed to bring the CD to watch at home.

Session 2: It took 30–40 min with the aim of reviewing what has been explained before in the last session, and patient instructions about lupus were provided, which included the effect of lupus on the patient life, how to live with lupus and home care, advice for patients during sun exposure to avoid problems resulting from exposure to the sun rays, tips on diet for patients, exercise, how to overcome fatigue resulting from lupus, how to take care of the joints to reduce pain, and tips for pregnancy and childbirth and postpartum and during lactation and birth control methods. Different teaching methods, discussion, CD, and videos were used to facilitate information on patients and attract their attention. The researcher also modified their misconceptions and then asked them to provide response and see how they benefit.

Phase 4. Evaluation phase: The evaluation phase focused on determining the effect of self-implementation instruction in patients with SLE. At the end, similar tools (tools I, IV, II, and III) were answered by every patient another time.

(III). Ethical Consideration:

All relevant ethical issues were considered, including the research approval, which was obtained before initiation of the study. The aim and nature of the study was explained to each patient; then, an oral and written consent for participation in the study was obtained from each participant, ensuring patients' privacy and confidentiality of the collected data during the study. Voluntary participation was applied as they were given an opportunity to refuse the participation and they were assured that their information would be used for research purposes only and any patient has the right to withdraw any time deprived of the effect on his/her treatment in the hospital.

(IV). Statistical Design:

The collected data were coded, processed, and analyzed using Statistical Package for the Social Sciences version 20. Qualitative data were presented as number (N) and percent (%). Quantitative parametric data were presented in mean and standard deviation, while nonparametric data were presented in median, minimum, and maximum. Chi-square test was used for testing significance of categorical data. In the comparison of quantitative data before and after implementation, paired t-test was used for parametric data and Wilcoxon rank test was used for nonparametric data.

Results:

Table 1: This table showed that the mean age of studied patients was 21.66 ± 13.01 years. The majority of participants were female (84.6%). Regarding marital status, 70.8% of participants were married. Moreover, about one-third of patients (38.5%) had middle education level. With reference to occupation, the majority of the studied patients (75.4%) were unemployed. More than one-third of patients (44.6%) were treated at state expense regarding fees paid for treatment.

Table 2: This table showed that the devices that patients want to use (46.2%) were trusses. However, the cane was used by 32.3% of participants before implementation of the instruction and 26.2% after implementation of the instruction. Moreover, no statistically significant difference on the need for assistive devices between before and after implementation of self-management instruction was shown.

Table 3: This Table showed that statistically significant difference concerning disability index activities, such as eating (P = 0.042) & walking (P = 0.047), before and after implementation of self-management instruction.

Table 4: This table showed that no statistically significant difference concerning the assistive devices needed among SLE patients -before and after implementation.

Table 5: This table showed that no statistically significant difference concerning the disability index activities before and after implementation.

Table 6: This table showed that more than three-fifths (64.6%) of patients in the study complained of moderate pain and less than one-fifth (16.9%) complained of severe pain before implementation of self-management instruction, while, after implementation of self-management instruction, no patient had severe pain and 12.3% of patients did not have pain. Moreover, this table presents a high statistically significant difference in severe pain (P < 0.001).

Table 7: This table shows that more than three-quarters of patients (78.5%) had normal health after implementation of instruction. Furthermore, this table showed statistically significant difference as regards fatigue severity (P = 0.014).

Table 8: This table showed that the majority of participants (72.3%) had high self-efficacy after implementation. Furthermore, it is showed statistically significant difference in self-efficacy (P = 0.007).

Table 1: Frequency and percentage distribution of studied patients with SLE related to demographic characteristics (N = 65):

Items	N	%
Age		
20 < 25	21	32.3
25 < 45	35	53.85
45 < 60	9	13.85
Range	20<-60	
Mean ± SD	21.66 ± 13.01	
Sex		
Female	55	84.6
Male	10	15.4
Marital status		
Single	17	26.2

Married	40	61.5
Divorced	3	4.6
Widow	5	7.7
Education		
Uneducated	15	23.07
Read& write	6	9.23
Middle education	25	38.5
University education	19	29.2
Working		
Not working	49	75.4
Working	16	24.6
Treatment fees		
Free	18	27.7
State expense	29	44.6
Private	6	9.2
Health insurance	12	18.5

Table 2: Frequency & percentage distribution of assistive devices needed using amongst SLE patients concerning waking up, eating, walking& dressing before and after implementation
(N = 65):

Items	**Before**		**After**		**Chi-square**	
	N	**%**	**N**	**%**	**X²**	**P-value**
Wheelchair	5	7.7	2	3.1	1.359	0.244
Cane	21	32.3	17	26.2	0.595	0.441
Walker	2	3.1	2	3.1	0.475	0.491
Special or built-up chair	4	6.2	7	10.8	0.894	0.344
Trusses	30	46.2	29	44.6	0.031	0.860
Devices used for dressing	2	3.1	0	0.0	2.031	0.154
Built up or special utensils	2	3.1	2	3.1	0.000	1.000

Table 3: Percentage and frequency distribution of disability index activities among studied SLE patients before and after implementation (N = 65):

Items	Before		After		Chi-square	
	N	%	N	%	X^2	P-value
Grooming & dressing	43	66.2	42	64.6	0.034	0.854
Waking up	34	52.3	31	47.7	0.277	0.599
Eating	4	6.2	0	0.0	4.127	0.042*
Walking	30	46.2	19	29.2	3.963	0.047*

Table 4: Frequency and percentage distribution of the needed assistive devices for SLE patients concerning reach, hygiene, errands& gripping before and after implementation of the instruction (N = 65):

Items	Before		After		Chi-square	
	N	%	N	%	X^2	P-value
Raised toilet seat	65	100.0	63	96.9	2.031	0.154
Bathtub seat	49	75.4	43	66.2	1.339	0.247
Bathroom long-handled appliances	23	35.4	19	29.2	0.563	0.453
Reach long-handled appliances	11	16.9	8	12.3	0.555	0.456
Jar opening	35	53.8	31	47.7	0.492	0.483
Bathtub bar	3	4.6	0	0.0	3.071	0.080

Table 5: Frequency and percentage distribution of disability index activities (reach, errands, hygiene, gripping & opening things, & chores) amongst SLE patients before and after implementation (N = 65):

Items	Before		After		Chi-square	
	N	%	N	%	X^2	P-value
Hygiene	33	50.8	27	41.5	1.114	0.291
Gripping and opening things	43	66.2	41	63.1	0.135	0.714
Reach	5	7.7	4	6.2	0.119	0.730
Chores& errands	51	78.5	46	70.8	1.015	0.314

Table 6: Frequency and percentage distribution of pain severity among studied SLE patients before and after implementation (N = 65):

Degree of pain	Before		After		Chi-square	
	N	%	N	%	X^2	P-value
No pain	0	0.0	8	12.3	8.525	0.004*
Mild	12	18.5	8	12.3	0.945	0.331
Moderate	42	64.6	49	75.4	1.795	0.180
Severe	11	16.9	0	0.0	12.017	<0.001**
Total	65	100.0	65	100.0	20.338	<0.001**

Table (7): Fatigue severity in patients with SLE before and after implementation of instruction (N = 65):

Fatigue	Before		After		Chi-square	
	N	%	N	%	X^2	P-value
Normal health	38	58.5	51	78.5	6.021	0.014*
Fatigue-related disease	27	41.5	14	21.5		

Table (8): Relationship between frequency and percentage of the studied patients with SLE with respect to self-efficacy scale before and after implementation of the instruction (N = 65):

Self-efficacy	Before		After		Chi-square	
	N	%	N	%	X^2	P-value
Low self-efficacy	33	50.8	18	27.7	7.260	0.007*
High self-efficacy	32	49.2	47	72.3		

Discussion

SLE interrupts all aspects of an individual's life and may require ongoing management and lifestyle modifications for the individual to remain functioning at a required level. The complications that develop in patients with SLE are different; thus, medical management is important to avoid such problems, which lead to distress in patients with SLE **(Giacomelli et al., 2020).**

Moreover, the disease-induced interruption to lifestyle and activity of daily living compromises the quality of life of patients. Patients can be more vigorously involved in their clinical outcome and quality of life improvement with acceptable support and patient learning from the nurse (**Manzano et al., 2021**). This study was conducted to develop and implement self-management instruction for SLE patients, as well as evaluating its outcome. Studied patients' demographic characteristics exposed that, regarding age, more than half of patients were aged between 25 and <45 years. In the same line, the **Lupus Foundation of America (2012)** found that the majority forSLE patients were aged between 15 and 45 years, due to the influence of hormone vulnerability to this disease in this period. The results of this study showed that there were more women than men. This was in agreement with the study by **Furr, Abrams, Flowers, and Bennett (2018)**, who reported that most participants in his study were women. Moreover, **Dhanhani (2010)** found that most participants were women. This proves the scientific fact of the disease that women are more affected than men in most previous studies. **Sanz (2010)** who showed that this variation in SLE between two sexes might be a hormonal effect due to estrogen in women. Androgen hormone in men acts as protective factor against lupus.

As regard to marital status, the finding of this study revealed that married patients consisted of two-thirds of the participants. These findings were in agreement with those of **Furr et al. (2018),** who reported that the majority of participants were married. Moreover, **O'Riordan et al. (2017)** reported that the majority of participants were married. This may be due to the nature of the disease, which more commonly develops in the third decade, and in the Egyptian culture, this age is the age of marriage.

Regarding the educational level, the finding revealed that about one-third of participants

have middle level of education. The study agrees with finding of **Ritterhouse, Crowe, and Niewold (2012),** who scrutinized the influence of the guidelines of self-management on patients with diabetes mellitus and indicated that exclusion of illiterate patients is very appropriate to help these patients read the instructions themselves, which showed the effect of better understanding specially at home. This result was in contrast with those of **Brittain (2016)**, who revealed that more than one-fifth of participants had bachelor's degree.

Regarding the working status of patients, the result of this study revealed that the majority of studied patients were unemployed. This finding was in contrast with those of **Harding (2015),** who found that the majority of the studied patients were working full time. Moreover, **O'Riordan et al. (2017)** reported that more than half of participants were employed. This difference may be due to the different economic and social life between foreign and Arab countries and development of complications or sex.

Regarding the indicator of disability before and after the implementation of self-administration instructions, this study showed that more than 60% of patients were able to perform some activities without any problems with three disability indicators: lifting a cup of foil or glass to the mouth, turning on the taps, and opening jars respectively before implementation. The capacity increased in the majority of patients without any problem with three indicators of obstruction: raising a mug or glass of foil to your mouth, opening the jars, and twisting the spigots after execution. These results were similar to those of **Koehler (2011) and Wang and Osmond (2010),** who found that most patients with SLE are unable to perform their usual activity of daily living. This may be indicated in case of muscle & joint pain through disease. Therefore, more than ninety percent of patients with SLE have disability.

In relation to the fatigue severity among studied patients, it was revealed that more than half of studied patients agreed that fatigue interferes with three disability symptoms, physical functioning, exercise, carrying out certain duties and responsibility, and easy fatigue before implementation, which decreased after implementation of self-management instruction. More than one-third agreed that fatigue interferes with three disability symptoms, easy fatigue, exercise, carrying out certain duties, and physical functioning and responsibility. This finding is in the same line with those of the **Lupus Foundation of America (2011),** which indicated the effect of the guidelines when followed by the patients as it could decrease the fatigue among them. This is concordant with the results of **Miljeteig and Graue (2009),** who reported in their study that there was a significant progress in perceived levels of fatigue and scores of general health after education program participation by teaching and counseling for SLE patients. This result might be due to the need of these patients to decrease their fatigue to properly act in their lives.

Similarly, regarding fatigue severity, there was a statistically significant difference in fatigue severity before and after implementation of self-management instruction that is in contrast with the result of **Liang, Tian, Cao, Chen, and Wang (2014)**, who reported that

there was no statistically significant difference in fatigue level between patients receiving control treatment or intervention.

The present study showed that there were high statistically significant differences in pain assessment using the numeric pain rating scale before and after implementation of self-management instruction. Moreover, **Williams et al. (2017)** explained that interventions of self-management that include both health education and social support had a positive effect in improving health outcome through pain reduction, function improvement, and delay in disability for SLE patients. This demonstrates a positive effect of applying self-management instruction through the patient to reduce pain caused by SLE.

The finding of this study showed that there was a highly statistically significant difference in reported health outcome score before implementation of self-management instruction, which slightly decreased after implementation of self-management instruction. A similar result was reported in the study of **Elsayed and Mesbah (2018),** who showed highly statistically significant improvement in patients with SLE after intervention. This could reflect the health education interventions' importance and health outcome improvement in patients with SLE. **Feldman et al. (2013)** revealed that the intervention had been successful and can be measured by improvements in activities of daily living, healthy diet maintenance, and regular exercise as outcome measures. This agrees with this result.

Concerning levels of self-efficacy for SLE patients, this study revealed that more than 50% of participants had low self-efficacy before implementation, which decreased to more than a quarter after implementation. This conclusion agreed with that of **Muhammad (2018),** who reported low self-efficacy in patients with SLE after applying educational guidelines. This result may be because of the encouraging elements that have changed with difficulty.

Conclusion

SLE patients' self-management instruction had positive effects on decreasing disability of patients, severity of fatigue, severity of pain, self-efficacy improving & awareness of patient. There was high statistically significant difference in pain severity, awareness level, and generalized health status post implementation of self-management instruction.

Recommendations

In light of the study findings, an educational program for improvement of care of SLE patients by written and demonstrated guidelines needs to be accessible in all SLE clinics and departments. More research in the future for SLE patients' self-management is highly recommended to discover the effect of the intervention of self-care on SLE symptoms controlling and to reach the health satisfaction peak level. An Egyptian Lupus Organization should be developed to be in contact with the problems of those patients.

Funding

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الملخص العربي
تأثير تعليمات الرعاية الذاتية على النتائج الصحية لمرضى الذئبة الحمراء

المقدمة: الذئبة الحمراء الجهازية هو مرض مناعى شائع يصيب العديد من اجهزة الجسم بطريقة مستمرة ومتكررة. و الأعراض لمرض الذئبة الحمراء يصعب التنبؤ بها، وتشمل أعراض عصبية مثل القلق، والاكتئاب، والاضطرابات المعرفية والذهان، والتعب، والطفح الجلدي، وآلام المفاصل والصداع والصرع، والحوادث الوعائية الدماغية، واضطرابات الحركة. لا يعرف مسببات معينة لمرض الذئبة الحمراء، و لكن يوجد عوامل قد تؤثر فى حدوث مرض الذئبة الحمراء مثل العوامل الوراثية والهرمونية والبيئية، و المخدرات. على الرغم من أن مرض الذئبة الحمراء ليس مرض قاتل، فعدم وجود الشفاء العلاجي يترك معظم المرضى يعانون من المرض على مدى طويل، والتي يمكن أن تؤثر سلبا، على الجانب العاطفى ،النفسي ،الاجتماعي وجودة الحياة.

الهدف من الدراسة : تقييم أثرتعليمات الرعاية الذاتية على الوعى المعرفى ، الحالة الصحية والكفاءة الذاتية لمرضى الذئبة الحمراء فى مستشفى الجامعة بالمنصورة .

تصميم البحث: تم إستخدام دراسة شبه تجريبية فى البحث.

مكان الدراسة: تم تنفيذ هذه الدراسة في عيادة الباطنة والروماتيزم وأقسام الباطنة بمستشفى الجامعة بالمنصورة.

العينة: شملت عينة البحث 65 مريض من عيادات وأقسام الباطنة والروماتيزم بمستشفى الجامعة بالمنصورة خلال 7 شهور إبتدا من فبراير 2021 الي أغسطس 2021..

الخلاصة:

بناء على نتائج هذه الدراسة الحالية يمكن أن نستخلص ما يلى:

أوضحت الدراسة أن تعليمات الرعاية الذاتية لمرضى الذئبة الحمراء لها آثار إيجابية على المرضى في الحد من شدة العجز، التعب، الألم، تحسين الكفاءة الذاتية و المعلومات لدى المرضى. لا يوجد أحد من المرضى لديه ألم بدرجة شديدة ونسبة قليلة (12.3٪) من المرضى تحت الدراسة ليس لديهم أي ألم. كما أظهرت فروق ذات دلالة إحصائية عالية فيما يتعلق بالألم الشديد. أكثر من ثلاثة أرباع المرضى (78.5٪) الذين شملتهم الدراسة لديهم مستوى صحى طبيعى فيما يخص التعب الناتج عن المرض بعد تطبيق إرشادات الرعاية الذاتية. كما أظهرت فروق ذات دلالة إحصائية فيما يتعلق شدة التعب.بينما وجد أن أكثر من ثلثي المرضى (72.3٪) الذين شملتهم الدراسة لديهم إرتفاع فى مستوى الكفاءة الذاتية بعد تنفيذ إرشادات الرعاية الذاتية. كما أظهرت فروق ذات دلالة إحصائية فيما يتعلق بمقياس الكفاءة الذاتية.أيضا غالبية المرضى (89.2٪) التى إشتملت عليهم الدراسة لديهم مستوى و عى معرفى كافى عن المرض بعد تنفيذ إرشادات الرعاية الذاتية. كما أظهرت فروق ذات دلالة إحصائية عالية تجاه مستوى الوعي المعرفى .

توصيات البحث:

بناء على نتائج هذه الدراسة يمكن أن نوصى بما يلى:

1. تصميم برنامج التعليمي للمرضي لتحسين رعاية مرضى الذئبة الحمراء من خلال إرشادات مكتوبة ومثبتة متاحًا في جميع عيادات وأقسام مرضي الذئبة الحمراء.

2. يوصى بشدة بإجراء مزيد من الأبحاث في المستقبل للرعاية الذاتية لمرضى الذئبة الحمراء لاكتشاف تأثير تدخل الرعاية الذاتية على التحكم في أعراض مرضي الذئبة الحمراء والوصول إلى مستوى ذروة الرضا الصحي.

3. يجب تطوير منظمة مصرية لمرض الذئبة لتكون على اتصال بمشاكل هؤلاء المرضى.