
▪ **Basic Research**

Effect of Continuous Care Model on Self-Care Practices and Quality of Life of Patients with Systemic Lupus Erythematosus

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Abstract

Background: Systemic Lupus Erythematosus (SLE) is a chronic autoimmune disease which affects multiple body organs or systems. The patients' quality of life and ability to work is very much affected by this disease. **Aim:** This study aimed to evaluate the effect of continuous care model on self-care practices and quality of life of patients with systemic lupus erythematosus. **Research design:** A quasi- experimental design was used. **Setting:** The study was carried out at Rheumatology Out Patient Clinic at Benha Teaching Hospital in Benha City. **Sample:** A purposive sample of 112 systemic lupus erythematosus patients was included and equally divided into control and study group (56 patient in each group). **Three tools** were used to collect the data, tool I: An interviewing questionnaire consisted of three parts, patients' demographic data, patients' medical history and patients' knowledge regarding systemic lupus erythematosus. Tool II: Patients reported self-care practices questionnaire. Tool III: World Health Organization Quality of Life BREF to assess patients' quality of life **Results:** The present study denoted that there was a significant improvement in the total levels of study group' knowledge, self-care practices and quality of life post one and three months of continuous care model implementation compared with control group. Also, quality of life was best predicted among study group by marital status, monthly income, total knowledge, and total self-care practices post care model ($p=0.041^*$, 0.049^* , $<0.001^{**}$, and $<0.001^{**}$) respectively and was best predicted among control group by occupation, times of follow up visits and total self-care practices ($p=0.046^*$, $<0.001^{**}$, and 0.048^*) respectively. **Conclusion:** Continuous care model efficiently improved systemic lupus patients' knowledge, self-care practices and quality of life. **Recommendations:** Implementing continuous care model for all patients with systemic lupus erythematosus to enhance their knowledge, self-care practices and quality of life.

Key words: Continuous Care Model, Patients, Self-Care, Quality of Life, Systemic Lupus

Introduction

Systemic lupus erythematosus (SLE) is a long-term autoimmune disease that damages connective tissues, blood vessels, and membranes in addition to affecting other body systems. The incidence and prevalence of SLE varies widely over the world depending on area and ethnicity, with a range of 0.3 to 23.2 per 100,000 person-years for incidence and 0 to 241 per 100,000 for prevalence. A common aspect of SLE epidemiology is that the disease primarily affects women throughout their reproduction years, despite the high levels of regional and ethnic diversity. SLE is more prevalent in women than in men, with a 9:1 ratio (**Chung et al., 2021; Abdelzaher et al., 2023**).

The etiology of systemic lupus erythematosus is still poorly understood and its cause is unknown. It seems to result from a complicated interaction between genetic predisposition and environmental factors that cause an individual to cross the illness threshold. SLE can be described by an ongoing illness or by remissions and flare-ups that come and go, during which the body's tissues and organs are mistakenly attacked by the immune system (**Dixon et al., 2022**).

Systemic lupus erythematosus symptoms vary from person to another and can be mild to severe. Joint pain and swelling, fever, chest pain, hair loss, mouth ulcers, enlarged lymph nodes, fatigue, and a red rash, which is most frequently on the face, are common symptoms. Lupus-related inflammation can impact a wide range of bodily organs, including the joints, skin, kidneys, blood cells, brain, heart, and lungs. A chronic autoimmune condition known as lupus can harm any organ in the body (**Raafat, 2021**).

Quality of Life (QoL) is considered as persons perception of their situation and level of satisfaction with their circumstances. QoL encompasses a wide range of variables, such as social, environmental, economic, and health-related factors. Enhancing life quality is the aim of healthcare through using of educational theories and models. The ability to comprehend the effects of diseases and enhance the standard of nursing care is now crucial in a more holistic approach of management. Researchers must be aware of the various ways that particular illnesses affect patients' lives and how effective treatment may enhance patients' quality of life (**Ugarte-Gil, 2023**).

The subjective and multidimensional concept of quality of life includes aspects such as one's physical and occupational well-being, psychological health, interaction with others, and internal perceptions. The burden of a low quality of life can result from SLE, which is a source of impairment. People with SLE appear to have a low quality of life, which seems to restrict daily activities, particularly due to joint pain caused by SLE relapses, depression and withdrawal from society, alterations in interpersonal relationships, challenges in finding

employment, difficulties in playing social roles, and a high risk of infertility (**Abu-Shakra et al., 2019**)

One of the most essential requirements for clinical practices and research is the use of nursing models. Competent nurses use a variety of methods, including care models. The Continuous Care Model (CCM) is a regular process for effective, collaborative, and ongoing interaction between the nurse and patient for determining patient needs and worries, educating them to accept continuous health behaviors, and supporting the patient in maintaining health promotion and improvement. Orientation, sensitization, control, and evaluation are the four phases of CCM. The patient is introduced by CCM as an important component of ongoing care in the medical process as well as CCM result in empowerment and involvement of the patient and family in problem-solving (**EL Sayed et al., 2020**).

Nurses are essential in delivering high standard, efficient, and secure patient care. Effective management of SLE demands an integrated strategy comprising primary and secondary care. In addition, nurses should focus on the necessity of ensuring that patients receive care of high-quality wherever they are seen. Also, nurses help patients to benefit from receiving specialized treatment, whether it is provided in a hospital or community setting and provide consultations and interventions for the treatment of SLE which may improve patients' health and quality of life (**Zahiri et al., 2022**).

Significance of the study:

There are many different clinical and immunological signs of systemic lupus erythematosus in Egypt, some of which are similar to those in other countries and others of which are different in the same country. In Egypt, the estimated prevalence of adult SLE was 6.1/100,000 (1.2/100,000 in men and 11.3/100,000 in women). There were 3345 cases of adult-onset SLE (Ao-SLE) and 316 cases of juvenile-onset SLE (8.6%). South had the highest age at onset and Cairo had the lowest ($p < 0.0001$) (**Raafat, 2021**).

The continuous care model is one of the caring models, which aims to offer a plan for accepting and enhancing patient knowledge and responsibility for ongoing care and controlling illness and associated complications. Considering that without follow-up, even the most effective educational programs eventually lose their desired effect. In light of this, combining follow-up and ongoing care with education might help patients with SLE adhere to healthy practices, reducing the risk of complications and ultimately enhancing quality of life (**Izmirly et al., 2021**).

Aim of the study:

The aim of this study was to evaluate the effect of continuous care model on self-care practices and quality of life of patients with systemic lupus erythematosus through:

- Assessing patients' knowledge regarding systemic lupus erythematosus.
- Assessing patients' self-care practices regarding systemic lupus erythematosus.
- Designing, implementing and evaluating effect of continuous care model on self-care practices and quality of life of patients suffering from systemic lupus erythematosus.

Research hypotheses

H1: knowledge and self-care practices of patients with systemic lupus who will receive the continuous care model will be improved than those who don't receive it.

H2: Continuous care model will improve quality of life of systemic lupus patients than those who don't receive the model.

Subjects and method:**Research design:**

A Quasi- experimental design was used to accomplish the aim of the study (study/control group- pre, post one and post three months test).

Setting:

The study was conducted at Rheumatology Out- patient clinic affiliated to Benha Teaching Hospital in Benha City, Egypt. Additionally, this setting was chosen as it serves a large sector of Qalyubia Governorate and the surrounding regions. Due to the accessibility of treatments, drugs, and follow-up for the disease, SLE patients attend.

Sampling:

Sample type: A purposive sample of 112 patients with systemic lupus erythematosus were recruited and meeting the following inclusion criteria: aged ≥ 25 years, did not have any other co-morbid conditions, and agreed to participate in the study. Exclusion criteria were a loss of coordination and involvement in prior similar interventions. The samples were randomly separated into two groups, 56 patients in the study group receiving continuous care model implementation and 56 patients in the control group receiving basic hospital care.

Sample Size: The sample size was calculated using Stephen Thampsons equation (**Fearon et al., 2017**):

$$n = \frac{N \times p(1-p)}{((N-1) \times (d^2 \div z^2)) + p(1-p)} = 112$$

N = Population size is 340, p = Ratio provides a neutral property is equal to 0.12, d = the error rate is equal to 0.05 and z = Class standard responding to the level of significance equal to 1.96. the sample size is 112 SLE patients.

Tools of data collection:

Three tools were used for the data collecting process after reviewing the pertinent literature.

Tool I: An interviewing questionnaire. It was comprised of three parts:

Part I: Patients' demographic data containing seven closed ended questions in form of multiple-choice type such as age, gender, marital status, educational level, occupation, residence and monthly income.

Part II: Patients' medical history includes eight closed ended questions as time since diagnosis, times of hospitalization due to illness, the medical examinations being performed, times of visits to outpatient clinic for follow up, at any time of the year flare-ups are repeated, the average number of flare-ups during one month, presence of family history of lupus and the degree of kinship.

Part III: Patients' knowledge, it was consisted of six closed ended questions as definition, risk factors, signs and symptoms, diagnostic methods, treatment methods and complications of systemic lupus erythematosus.

Scoring system

Knowledge scoring was assigned as follows, completely correct answer= (2), incompletely correct answer = (1) and (0) was given for don't know. The total knowledge score= 12 and it was classified into three levels as: Good level when score $\geq 75\%$ (≥ 9 scores), fair when score $50\% < 75\%$ ($6 < 9$ score) and poor when the score $< 50\%$ (< 6 scores).

Tool II: Patients reported self-care practice questionnaire adopted from (Sahebalzamani et al., 2016 & Dief et al., 2020) It was made up of 26 items divided into: **Physical activity** involved 5 items such as (avoiding strenuous activities, perform moderate intensity activities, walk for half an hour daily...etc.).

Follow up and medications: involved (5) items as (make regular follow up, do the necessary medical examinations regularly, take medications as ordered. etc.).

Nutrition involved (5) items about (intake of three meals daily, avoid eating high salt foods, eat fresh vegetables and fruits, intake of foods high in omega-3...etc.).

Reducing joint pain involved (5) items which are (take a rest when feeling pain, do warm compresses to relieve pain, take anti-inflammatory as prescribed, perform regular exercise

etc.).

Prevention of lupus flares included (5) items as (stay out of the sun between 10 am and 4 pm, avoid stress and nervous pressure, take enough sleep and rest, use relaxation techniques, be careful with certain foods and supplements.....etc.) utilized pre, post one and three months of care model.

Scoring system

Scores of (1) for “done” and (0) for “not done” were assigned to each response. The reported self-care practices had a total score of 26, it was classified into two levels, adequate level at $\geq 60\%$ (≥ 16 score) and inadequate at $< 60\%$ (< 16 score)

Tool III: World Health Organization Quality of Life- BREF (WHOQOL-BREF) adopted from (WHO, 1996) and modified by the researchers to assess the quality of life domains for patients with systemic lupus erythematosus. It was composed of 29 items divided into four domains: **Physical health** included (8) items as (your health condition prevents you from taking care of yourself, find it difficult to walk because of health condition, find difficulty to sleep at night because of illness, feel tired most of the time. etc.).

Psychological health involved (8) items such as (feel that you have the ability to cope with illness, feel afraid of the cost of the treatment, feel anxious about the present and future life because of illness... etc.).

Social relations included (7) items as (the disease affects your social relationships, illness makes you isolated from people, family and friends help you during flare-ups...etc.).

Environment, involved (6) items such as (enjoy a healthy environment at home, can stay away from sources of pollution and infection, have the ability to adapt to the environmental conditions of your disease ..etc.).

Scoring system

A three-point Likert scale is used for rating the WHOQOL-BREF. Each response was given a score between 0 and 2, where never = 0, sometimes = 1, and always = 2. The domain score is calculated by summation of items scores within each domain. The total score of WHOQOL-BREF =58 score which is the sum of the scores of four domains' items. A higher score implies better quality of life. Total scores of WHOQOL-BREF were ranged from 0 to 58. Therefore, the total quality of life score was classified into three categories: High QOL score at ($\geq 75\%$) (44-58 score), moderate score at ($50 < 75\%$) (29- 43 score), and low score ($< 50\%$) (< 29 score).

Content validity

Three experts in the field of Community Health Nursing and two experts in Medical Surgical Nursing afforded separate evaluations of the tools' intelligibility of sentences,

relevance of content, arrangement of items, and correctness of scoring and recording of items. from the experts' opinions the tools were valid.

Reliability

Cronbach's alpha coefficient was employed to calculate the tool's reliability. Internal consistency of knowledge was 0.868, internal consistency of self-care practice was 0.872, and WHOQOL-BREF was 0.671. This only proves that this tool is an instrument with good reliability.

Ethical considerations

The Scientific Research Ethical Committee at Faculty of Nursing, Benha University gave its approval for this study. Each participant in the study was notified of the objectives, advantages, study activities and events to gain their trust. Following that, a consent was obtained from each patient. All information collected was kept private and anonymous. Patients also had the choice to leave the study at any time and without providing any reason.

Pilot study

In order to ensure the tool's clarity and understandability, the applicability of the study tools was evaluated through a pilot study that involved 10% of patients with systemic lupus erythematosus (11 patients). The pilot study was incorporated into the whole sample without any modifications being made.

Procedure

The permission was officially obtained to conduct the study after providing clarification of the study's aim to the administrator of Benha Teaching Hospital. the researchers made three weekly visits to the previously mentioned setting on Saturday, Monday, and Wednesday from 9 am to 1 pm. Following that, structured interviews were done separately with each patient; on average, 4-6 patients were interviewed every week. Data were collected from the patients while they are waiting for examination. The researchers organized sessions schedules with the patients in order to provide them with the needed content and materials. Data collection extended over a period of ten months, from the beginning of June 2022 until the end of March 2023. In this study, the researchers applied the four stages of CCM orientation, sensitization, control, and evaluation to patients with SLE.

The orientation stage: The first stage during which the researchers met the patients, introduced themselves and established relationships with patients. They also explained the aim of study, stages of the model to patients, identified the available communication channels, such as phone calls or the WhatsApp application, and the necessity of scheduling phone calls. The researchers also clarified the goals and benefits of continuous interaction between the researchers and the studied patients to ensure continuity of care. The data

collecting tools needed to be filled during this stage, which required between 20 and 30 minutes and took around 8 weeks (pretest).

Sensitization stage: The goal of the sensitization stage was to improve the involvement of patients in the ongoing care process and to raise their knowledge and self-care practice about SLE through the distribution of SLE-related educational materials and the planning of educational sessions. Every patient received 6 sessions, each one lasting 45-60 minutes and taking place three days a week at a separate room beside the rheumatology outpatient clinic. These sessions were held for small groups, ranged from 7-9 patients per group. Patients were divided into 6 groups. Discussion, questions and answers, and power point presentations were all used as teaching methods. Obtaining feedback on what was provided during the prior session, and presenting the objectives of the new one taking into consideration the need to use simple language to accommodate with the patients' educational level. The care model sessions were presented **as follows:**

Session (I): The researchers described the chronic nature of SLE, its definition, risk factors, signs and symptoms, SLE diagnostic methods, treatment modalities, and complications.

Session (II): Included providing an explanation about the importance of engaging in self-care practices for managing and controlling SLE, such as ensuring proper nutritional practices, such as consuming a low-fat diet and avoiding a high-sodium intake, increased intake of carbohydrates, eating three meals per day, consuming fresh fruits and vegetables, avoiding beverages with caffeine and drinking plenty of water.

Session (III): The researchers explained the benefits of engagement in a physical activity schedule and creating some physical activity routines to the patients such as walking half an hour daily, avoiding strenuous activities and consistently conducting activities of daily living.

Session (IV): Explanation was given to SLE patients regarding the importance of adhering to a regular follow-up and checkup schedule and following physician recommendations regarding medication use for SLE included taking the proper dosage at the appropriate times and avoiding the use of analgesics without prescription.

Session (V): researchers explained how to deal with fatigue and reduce joint pain, including making warm and cold compresses, taking breaks throughout work hours and while experiencing pain, and scheduling daily relaxation time.

Session (VI): The researcher emphasized the importance of adhering to the proper methods to reduce lupus flares through associated consequences such as exacerbating factors and stopping bad habits including smoking, and unhealthful sleep patterns, and using stress reduction strategies. In addition, QOL domains, the importance of promoting quality of life

and the relation between patients with SLE's commitment to self-care practices and QOL are recognized. Educational booklet was delivered to the patients at the completion of this session.

Control stage: The purpose of the control stage was to assess the quality of care that patients received, to reinforce and incorporate positive self-care practices and behaviors, and foster patient involvement in their own care. Through this stage weekly telephone calls were made between the researchers and SLE patients (8) calls (when allowed for the patient) throughout a period of two months. The time needed for each call is 10 minutes and differs according to patients' requirements and understanding. Also, speech and question-answer sessions considering the type and nature of needs of the patients were made through WhatsApp applications. The researchers motivated the patients to ask questions to address their needs.

Evaluation stage: Posttest was done for control and study groups, post one and three months of continuous care model implementation aimed to evaluate the effect of the continuous care model utilizing the same tools used pre continuous care model implementation.

Statistical analysis:

Data analysis was performed using the SPSS software (version 25). Numerical data were expressed as mean, standard deviation (SD) and range. Qualitative data were expressed as frequency and percentage. Chi-square tests were used to compare nominal variables in the two groups. Fisher's exact test was applied on smaller sample sizes, alternative to the chi-square test, when the frequency count is < 5 for more than 20% of cells. For comparing the mean scores in two groups were used to the independent t-tests. Pearson method was used to test correlation between numerical variables. Linear regression was used for multivariate analyses on quality of life score as dependent factor. A p-value < 0.05 was considered significant, and < 0.001 was considered highly significant.

Results

Table (1): Displays that the mean age of the control and study group was 35.53 ± 6.66 and 34.88 ± 6.69 years respectively, 80.4% and 69.6% of both groups were females respectively. While, 48.2% of the control group and 55.4% of the study group had intermediate qualification. Regarding residence 67.9% and 73.2% of the control and study group were from urban areas respectively and 60.7% and 55.4% of both groups had insufficient income.

Table (2): Illustrates that 75% and 64.3% of control and study groups were diagnosed by the disease from less than 5 years respectively. While 50% of the study group was hospitalized one time due to illness and 41.1% of the control group were hospitalized twice.

Less than one fifth of the two groups visited the outpatient clinics for follow up as needed and had twice flare ups during a month respectively. Moreover, less than two fifths of both groups had repeated flare ups during the change of seasons.

Table (3): Reveals that there was no statistically significant difference between the study and control groups regarding all knowledge items about systemic lupus erythematosus pre continuous care model implementation ($p > 0.05$). However, a highly statistically significant difference was observed between both groups regarding all knowledge items post one and three months of continuous care model implementation ($p \leq 0.001$).

Figure (1): Portrays that the good total knowledge level of the study group improved from 3.6% pre continuous care model implementation to 83.9% and 67.9 % post one and three months of continuous care model implementation respectively. While 8.9% and 10.7% of the control group had good total knowledge level post one and three months of continuous care model implementation respectively compared with 5.4% pre continuous care model implementation

Table (4): Shows that there was a highly statistically significant difference between the study and control groups regarding all reported self-care practices items post one and three of continuous care model ($p \leq 0.001$). However, there was no statistically significant difference between both groups regarding reported self-care practices items pre care model ($p > 0.05$).

Figure (2): Illustrates that 21.4% of the control group had adequate total selfcare practices level pre continuous care model compared with 23.2% and 14.3% post one and three months of care model respectively. While the adequate total self-care practices level of the study group increased from 16.1% pre care model to 92.9% and 80.4% post one and three months of continuous care model respectively.

Table (5): Indicates that there was a highly statistically significant difference between the study and control groups regarding quality of life domains post one and three months of continuous care model implementation ($p \leq 0.001$). However, there was no statistically significant difference between both groups about quality of life domains pre continuous care model implementation ($p > 0.05$). While there was a highly statistically significant difference between the study and control groups regarding total quality of life post one and three months of continuous care model implementation ($p \leq 0.001$).

Figure (3): Shows that 1.8% of study group had high total quality of life level pre continuous care model implementation, in comparison with 76.8% and 73.2% post one and three months of continuous care model implementation. While 3.6 of control group had high total quality of life level pre continuous care model implementation, in comparison with 5.4% and 8.9% post one and three months of continuous care model implementation.

Table (6): Illustrates that there was a highly significant positive correlation between total knowledge and total self-care practice of the control and study groups pre, post one and three months of care model implementation ($p \leq 0.001$).

Table (7): Multivariate linear regression model in this table reveals that quality of life score post care model among patients with systemic lupus was best predicted among control group by occupation, times of follow up visits and total self-care practices ($p=0.046^*$, $<0.001^{**}$, and 0.048^* , respectively), accounting for 76.5 % of the variance of quality of life score. As regards study group, it was best predicted by marital status, monthly income, total knowledge, and total self-care practices post care model ($p= 0.041^*$, 0.049^* , $<0.001^{**}$, and $<0.001^{**}$, respectively), accounting for 95.2 % of the variance of quality of life score.

Table (1): Distribution of both studied groups according to their demographic characteristics, control group (n=56), and study group (n= 56).

Patients' demographic data	Variables	Control group N=56		Study group N=56		X ²	P value
		No.	%	No.	%		
Age (year)	20-<30	18	32.1	17	30.4	0.355	0.837 ^{n.s}
	30-<40	23	41.1	26	46.4		
	≥ 40	15	26.8	13	23.2		
	Mean ± SD	35.53± 6.66		34.88± 6.69		t= -0.524	0.601 ^{n.s}
Gender	Male	11	19.6	17	30.4	1.714	F _E p 0.275 ^{n.s}
	Female	45	80.4	39	69.6		
Marital status	Single	9	16.1	6	10.7	6.542	0.088 ^{n.s}
	Married	35	62.5	45	80.4		
	Widowed	8	14.3	5	8.9		
	Divorced	4	7.1	0	0.0		
Educational level	Can't read and write	8	14.3	6	10.7	1.466	0.690 ^{n.s}
	Read and write	5	8.9	7	12.5		
	Intermediate qualification	27	48.2	31	55.4		
	University qualification	16	28.6	12	21.4		
Occupation	Not Working	16	28.6	22	39.3	1.434	F _E p 0.318 ^{n.s}
	Working	40	71.4	34	60.7		
Residence	Urban	38	67.9	41	73.2	0.387	F _E p 0.679 ^{n.s}
	Rural	18	32.1	15	26.8		
Monthly income	Insufficient	34	60.7	31	55.4	0.330	F _E p 0.702 ^{n.s}
	Sufficient	22	39.3	25	44.6		

(n.s) Not Significant (P>0.05)

F_Ep: p value for Fisher exact for chi square

Table (2): Distribution of both studied groups according to their medical history, control group (n=56), and study group (n= 56).

Medical history	Variables	Control group N=56		Study group N=56		X ² test	P value
		No.	%	No.	%		
Time since diagnosis	<5 years	42	75.0	36	64.3	1.582	0.453 ^{n.s}
	5-<10 years	9	16.1	12	21.4		
	10-15 years	5	8.9	8	14.3		
Times of hospitalization due to illness	Once	26	46.4	28	50.0	2.646	0.266 ^{n.s}
	Twice	23	41.1	16	28.6		
	Three times or more	7	12.5	12	21.4		
The medical examinations being performed #	Blood tests	11	19.6	4	7.1	7.193	0.126 ^{n.s}
	Imaging examinations	10	17.9	19	33.9		
	Sedimentation rate	10	17.9	6	10.7		
	Examination of antibodies to the nucleus of body cells	11	19.6	11	19.6		
	Examination of antibodies to the nucleic acid	14	25.0	16	28.6		
Times of visits to outpatient clinic for follow up	Examination of immune supplements	11	19.6	19	33.9	4.374	0.112 ^{n.s}
	Once a month	34	60.7	23	41.1		
	Twice a month	14	25.0	22	39.3		
At any time of the year, flare-ups are repeated #	As needed	8	14.3	11	19.6	7.192	0.066 ^{n.s}
	During the winter	47	83.9	39	69.6		
	During the Summer	9	16.1	17	30.4		
	During the Spring	4	7.1	6	10.7		
	During the fall season	0	0.0	0	0.0		
The average number of flare-ups during one month	During the change of seasons	20	35.7	22	39.3	5.087	0.079 ^{n.s}
	Once a month	41	73.2	30	53.6		
	Twice a month	7	12.5	15	26.8		
Presence of family history of lupus	Sometimes there isn't	8	14.3	11	19.6	3.480	FEP 0.079 ^{n.s}
	Yes	21	37.5	12	21.4		
If yes, the degree of kinship is	No	35	62.5	44	78.6	2.357	FEP 0.249 ^{n.s}
	First degree	12	57.1	10	83.3		
	Second degree	9	42.9	2	16.7		

(n.s) Not significant (p > 0.005) FEP: p value for Fisher exact for chi square # not mutually conclusive

Table (3): Comparison of patients' knowledge about systemic lupus erythematosus pre, post one and three months of continuous care model, control group (n=56), and study group (n= 56).

Knowledge items	Response	Control group (n=56)						Study group (n=56)						X ² test P value (1)	X ² test P value (2)	X ² test P value (3)
		Pre Care Model		Post one month of care model		post three months of care model		pre Care Model		Post one month of care model		post three months of care model				
		No.	%	No	%	No	%	No.	%	No.	%	No.	%			
Definition of systemic lupus	Completely correct	0	0.0	0	0.0	0	0.0	0	0.0	45	80.4	43	76.8	FE 0.143 0.850 ^{n.s}	78.756 <0.001**	75.022 <0.001**
	Incompletely correct	26	46.4	34	60.7	32	57.1	28	50.0	11	19.6	13	23.2			
	Don't know	30	53.6	22	39.3	24	42.9	28	50.0	0	0.0	0	0.0			
Risk factors of systemic lupus	Completely correct	0	0.0	0	0.0	0	0.0	0	0.0	43	76.8	40	71.4	FE 0.527 0.629 ^{n.s}	87.040 <0.001**	83.310 <0.001**
	Incompletely correct	12	21.4	12	21.4	13	23.2	9	16.1	13	23.2	16	28.6			
	Don't know	44	78.6	44	78.6	43	76.8	47	83.9	0	0.0	0	0.0			
Signs and symptoms of systemic lupus	Completely correct	0	0.0	0	0.0	0	0.0	0	0.0	49	87.5	45	80.4	FE 0.340 0.698 ^{n.s}	88.780 <0.001**	79.256 <0.001**
	Incompletely correct	20	35.7	34	60.7	32	57.1	23	41.1	7	12.5	11	19.6			
	Don't know	36	64.3	22	39.3	24	42.9	33	58.9	0	0.0	0	0.0			
Diagnostic methods of systemic lupus	Completely correct	0	0.0	0	0.0	0	0.0	0	0.0	48	85.7	44	78.6	FE0.346 0.695 ^{n.s}	88.258 <0.001**	73.698 <0.001**
	Incompletely correct	19	33.9	23	41.1	20	35.7	22	39.3	8	14.3	7	12.5			
	Don't know	37	66.1	33	58.9	36	64.3	34	60.7	0	0.0	5	8.9			
Treatment methods of systemic lupus	Completely correct	0	0.0	0	0.0	0	0.0	0	0.0	43	76.8	41	73.2	FE 2.333 0.181 ^{n.s}	75.721 <0.001**	73.429 <0.001**
	Incompletely correct	28	50.0	30	53.6	27	48.2	36	64.3	13	23.2	15	26.8			
	Don't know	28	50.0	26	46.4	29	51.8	20	35.7	0	0.0	0	0.0			
Complications of systemic lupus	Completely correct	0	0.0	0	0.0	0	0.0	0	0.0	46	82.1	44	78.6	FE 0.572 0.571 ^{n.s}	81.091 <0.001**	77.091 <0.001**
	Incompletely correct	31	55.4	34	60.7	32	57.1	27	48.2	10	17.9	12	21.4			
	Don't know	25	44.6	22	39.3	24	42.9	29	51.8	0	0.0	0	0.0			

(FE) p value for Fisher exact for chi square

Not significant (p > 0.05)

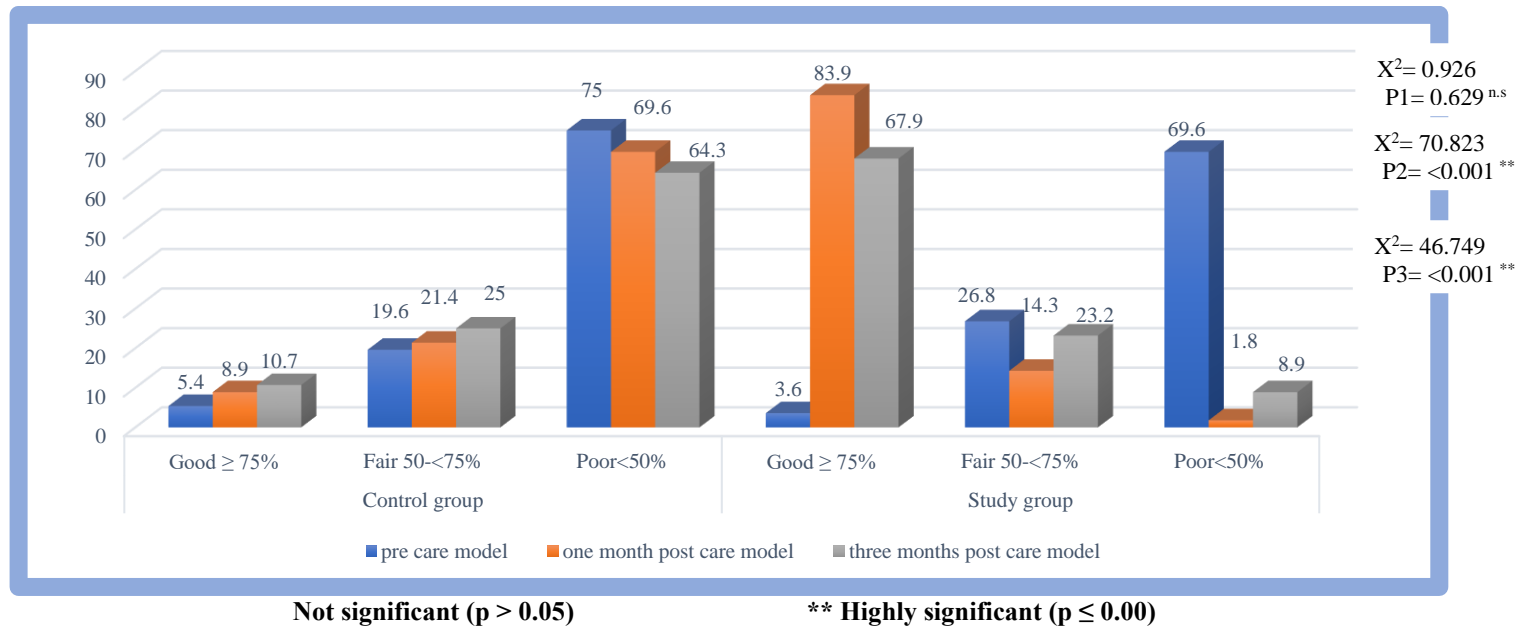
** Highly significant (p ≤ 0.001)

(1) control group (pre care) vs study group (pre care)

(2) control group (post one month of care) vs study group (post one month of care)

(3) control group (post 3 months of care) vs study group (post 3 months of care)

Figure (1): Comparison of patients' total knowledge level about systemic lupus erythematosus pre, post one and three months of care model implementation, control group (n=56), and study group (n= 56).



- (1) control group (pre care) vs study group (pre care)
- (2) control group (post one month of care) vs study group (post one month of care)
- (3) control group (post 3 months of care) vs study group (post 3 months of care)

Table (4): Comparison of reported self-care practices among patients with systemic lupus erythematosus pre, post one and three months of continuous care model, control group (n=56), and study group (n= 56).

Reported self-care practices	Total	Control group (n=56)						Study group (n=56)						X ² test P value (1)	X ² test P value (2)	X ² test P value (3)
		Pre Care Model		Post one month of care model		post three months of care model		Pre Care Model		Post one month of care model		Post three months of care model				
		No.	%	No.	%	No.	%	No.	%	No.	%	No.	%			
Physical activity	Adequate ≥ 60%	9	16.1	12	21.4	14	25.0	12	21.4	45	80.4	41	73.2	FE 0.527 0.629 ^{n.s}	38.905 <0.001**	26.044 <0.001**
	Inadequate < 60%	47	83.9	44	78.6	42	75.0	44	78.6	11	19.6	15	26.8			
Follow up and medication	Adequate ≥ 60%	6	10.7	7	12.5	10	17.9	4	7.1	46	82.1	40	71.4	FE 0.439 0.742 ^{n.s}	54.478 <0.001**	32.516 <0.001**
	Inadequate < 60%	50	89.3	49	87.5	46	82.1	52	92.9	10	17.9	16	28.6			
Nutrition	Adequate ≥ 60%	11	19.6	13	23.2	16	28.6	9	16.1	50	89.3	43	76.8	FE 0.243 0.806 ^{n.s}	49.669 <0.001**	26.111 <0.001**
	Inadequate < 60%	45	80.4	43	76.8	40	71.4	47	83.9	6	10.7	13	23.2			
Reducing joint pain	Adequate ≥ 60%	8	14.3	11	19.6	12	21.4	10	17.9	49	87.5	45	80.4	FE 0.265 0.798 ^{n.s}	51.836 <0.001**	38.905 <0.001**
	Inadequate < 60%	48	85.7	45	80.4	44	78.6	46	82.1	7	12.5	11	19.6			
Prevention of lupus flares	Adequate ≥ 60%	12	21.4	12	21.4	13	23.2	10	17.9	51	91.1	45	80.4	FE 0.226 0.812 ^{n.s}	55.184 <0.001**	36.618 <0.001**
	Inadequate < 60%	44	78.6	44	78.6	43	76.8	46	82.1	5	8.9	11	19.6			

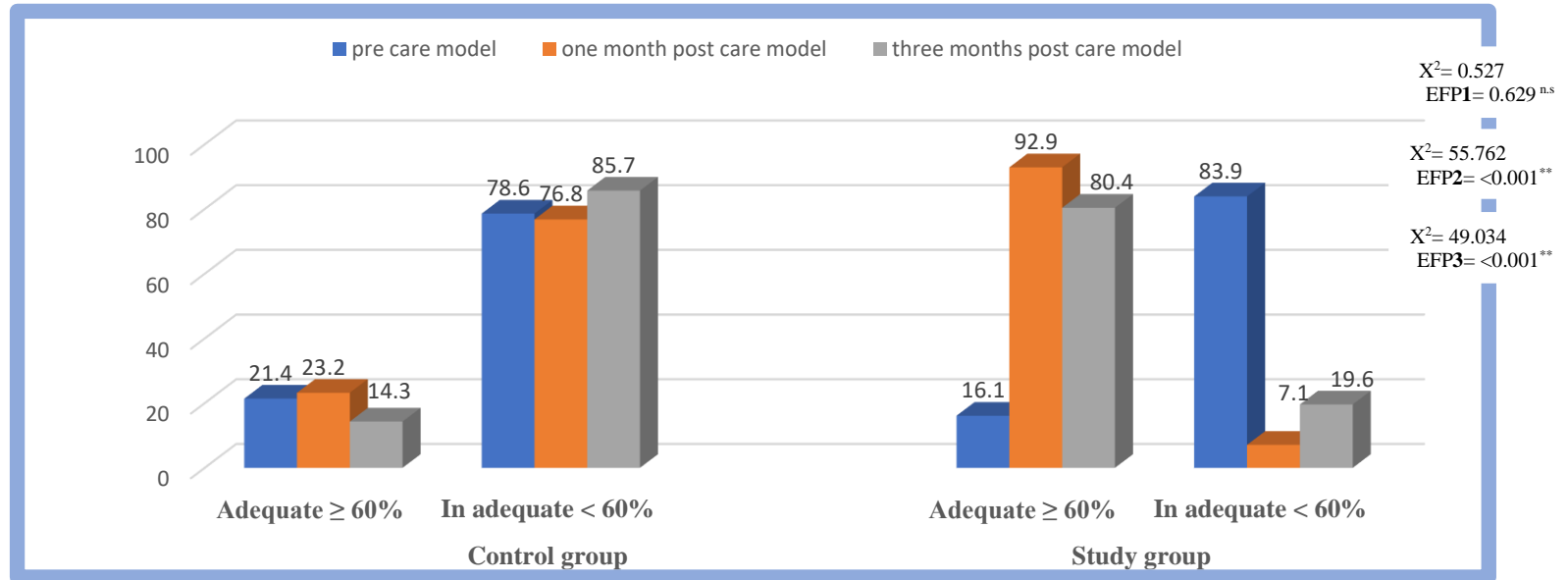
(FE) p value for Fisher exact for chi square Not significant (p > 0.05) ** Highly significant (p ≤ 0.001)

(1) control group (pre care) vs study group (pre care)

(2) control group (post one month of care) vs study group (post one month of care)

(3) control group (post 3 months of care) vs study group (post 3 months of care)

Figure (2): Comparison of total levels of reported self-care practices among patients with systemic lupus erythematosus pre, post one and three months of continuous care model, control group (n=56), and study group (n= 56).



Not significant ($p > 0.05$)

** Highly significant ($p \leq 0.001$)

- (1) control group (pre care) vs study group (pre care)
- (2) control group (post one month of care) vs study group (post one month of care)
- (3) control group (post 3 months of care) vs study group (post 3 months of care)

Table (5): Comparison of quality of life among patients with systemic lupus erythematosus pre, post one and three months of continuous care model, control group (n=56), and study group (n= 56).

Quality of life Domains	Control group (n=56)			% of mean	Study group (n=56)			% of mean	t- test P value (1)	t- test P value (2)	t- test P value (3)
	Pre Care Model	post one month of care model	post three months of care model		Pre Care Model	post one month of care model	post three months of care model				
	X ⁻ ± SD	X ⁻ ± SD	X ⁻ ± SD		X ⁻ ± SD	X ⁻ ± SD	X ⁻ ± SD				
Physical health	4.84± 2.58	5.04± 2.29	5.34± 2.46	33.4%	5.23± 2.29	13.04± 1.69	11.84± 1.96	74%	-0.853 0.396 ^{n.s}	-20.980 <0.001**	-15.347 <0.001**
Psychological	3.04± 1.25	3.02± 1.27	3.30± 1.09	20.6%	2.61± 1.36	14.02± 1.55	10.84± 1.63	67.8%	1.738 0.085 ^{n.s}	-40.976 <0.001**	-28.764 <0.001**
Social relationships	3.13± 1.19	3.16± 1.20	3.25± 1.13	23.2%	2.75± 1.52	11.41± 2.73	10.23± 1.62	73.1%	1.455 0.149 ^{n.s}	-20.703 <0.001**	-26.459 <0.001**
Environment	2.32± 0.66	2.13± 1.19	2.43± 0.66	20.3%	2.18± 0.77	10.32± 2.69	9.19± 1.60	76.6%	1.055 0.294 ^{n.s}	-20.798 <0.001**	-29.280 <0.001**
Total	13.32± 4.07	13.34± 2.89	14.32± 3.88	-	12.77± 3.53	48.79± 8.38	42.11±5.82	-	0.769 0.444 ^{n.s}	-29.923 <0.001**	-29.745 <0.001**

Not significant (p > 0.05)

** Highly significant (p ≤ 0.001)

(1) control group (pre care) vs study group (pre care)

(2) control group (post one month of care) vs study group (post one month of care)

(3) control group (post 3 months of care) vs study group (post 3 months of care)

Figure (3): Comparison of total quality of life among patients with systemic lupus erythematosus pre, post one and three months of of continuous care model, control group (n=56), and study group (n= 56).

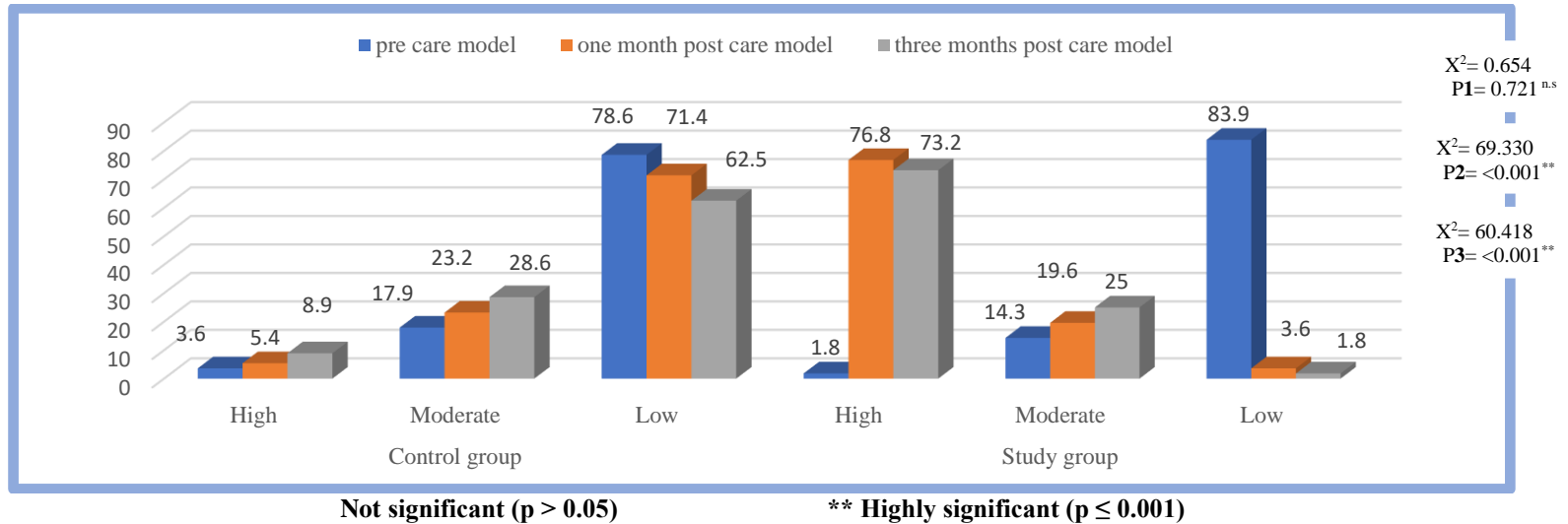


Table (6): Correlation coefficient between patient’s total knowledge and self-care practices pre, post one and three months of continuous care model, control group (n=56), and study group (n= 56)

Total knowledge	Total reported self-care practices					
	Pre care model		post one month of care model		post three months of care model	
	r	P value	r	P value	R	P value
Control group	0.697	<0.001**	0.350	0.008*	0.549	<0.001**
Study group	0.687	<0.001**	0.743	<0.001**	0.565	<0.001**

* Statistically significant p ≤ 0.05

** Highly Statistically significant p ≤ 0.001

Table (7): Multiple linear regression analysis for predictor variables of quality of life among patients with systemic lupus erythematosus post three months of continuous care model, control group (n=56), and study group (n= 56).

Predictor Variable of quality of life	Control group (n=56)					Study group (n=56)				
	Standardized Coefficients	Unstandardized Coefficients		t	Sig.	Standardized Coefficients	Unstandardized Coefficients		t	Sig.
	Beta	B	Std. Error			Beta	B	Std. Error		
(Constant)	34.663	13.476		2.572	.017	-26.539	4.282		-6.198	<0.001**
Age	1.283	1.870	.138	.686	.499	2.293	1.426	.072	1.608	.114
Marital status	.100	.729	.019	.138	.892	1.797	.857	.080	2.097	.041*
Occupation	3.290	1.560	.318	2.108	.046*	.748	1.522	.020	.492	.625
Monthly income	-	-	-	-	-	4.546	2.250	.141	2.021	.049*
Time since diagnosis	-	-	-	-	-	.732	1.820	.011	.402	0.689
Times of follow up visits	-7.249	2.007	-1.342	-3.611	.001**	-	-	-	-	-
Times of flare up recurrence	-.908	.926	-.351	-.980	.337	-	-	-	-	-
Total knowledge post care model	-.049	.353	-.017	-.139	.890	2.811	.421	.352	6.683	< .001**
Total self-care practice post care model	-1.329	.638	-.692	-2.083	.048*	2.104	.182	.968	11.574	< .001**
Adjusted R²= 0.765 P = <0.001**					Adjusted R²= 0.952 P = <0.001**					

(SEB) Standard Error

* Statistically significant $p \leq 0.05$

** Highly Statistically significant (B) Beta Co-Efficient

Discussion

Systemic lupus erythematosus can limit a person's physical, mental, and social functioning. These limitations can impact their quality of life, especially if they experience fatigue. Early diagnosis and effective treatments can help reduce the damaging effects of SLE and improve the chance to have better function and quality of life (CDC, 2023). Hence, the researchers conducted this study to evaluate the effect of implementing continuous care model on self-care practices and QoL of patients with systemic lupus erythematosus.

Regarding the studied patients demographic characteristics, the current study denoted that more than two fifths of the control and study group were aged 30<40 with mean age 35.53 ± 6.66 and 34.88 ± 6.69 years of the control and study group respectively. Also more than three quarters and more than two thirds of both groups were females respectively. While more than two third and more than three quarters of the two groups were respectively married and nearly half of the control group and slightly more than half of the study group had intermediate qualification. These findings supported by Voss et al. (2023), who conducted the study about Survival in systemic lupus erythematosus in a Danish community and reported that the majority of both groups were with age ranged between (35-40) and more than two third of both groups were females and married. Also these results disagreed with Mohamady et al., (2022) who performed a study in Egypt about effect of self-care management on health outcomes for females with systemic lupus and found that 53.0% had preparatory school and 83.3% were living in rural areas.

Concerning medical history of the studied patients, the present study revealed that; more than three quarters and two thirds of control and study groups were diagnosed by the disease from less than 5 years respectively. While half of the study group was hospitalized one time due to illness and two fifth of the control group were hospitalized twice. Which lead to develop disability in varies stage of disease progression. These results were in the same line with Mohamed, (2020) who carried out a study in Egypt on SLE patients about the effect of self-care management program on pain and disability and stated that, two thirds of the control and more than two thirds of study group were diagnosed by the SLE from < 5 years respectively. While less than half of their study group was hospitalized one time due to disease and more than two fifths of the control group were hospitalized two times.

Concerning medical examination, the result of the current study revealed that, one third of the study group performed imaging examinations and one fourth of the control group performed examination of antibodies to the nucleic acid. This might be due to decrease awareness of patients with SLE related to knowledge, self-care and importance of checkup. These findings were supported by Gunawan et al., (2018) who studied "Self-care model application to improve self-care agency, self-care activities, and quality of life in patients with systemic lupus erythematosus" in Indonesia Taibah University Medical Sciences and

found that less than one third of their study group performed imaging examinations and one fifth of their control group made examination of antibodies to the nucleic acid.

The result of the current study revealed that, there was no statistically significant difference between the study and control groups regarding all knowledge items about systemic lupus erythematosus pre continuous care model ($p > 0.05$). This result might be due to the majority of the study participants had insufficient information about disease. However, a highly statistically significant difference was observed between the study and control groups regarding all knowledge items one month post continuous care model and after three months follow up of continuous care model ($p \leq 0.001$). Similarly, this result was in agreement with **Mohammad et al., (2019)** who conducted a study in Rheumatology Research Center (RRC) at Tehran University of Medical Sciences and reported that continuous self-management model significantly improved the level of patient knowledge and their awareness about SLE after model application.

Concerning the total knowledge level, this study declared that less than tenth of the study group had good total knowledge level pre continuous care model, while post one and three months improved to majority and more than two fifths improved had good total knowledge level respectively. This might be related to the effect of care model which focus on continuity of care and in turn the knowledge level is elevated. This finding was in accordance with **Sahebalzamani et al., (2016)** who studied “effects of a continuous care model on patients' knowledge and health-related quality of life in systemic lupus erythematosus In Teheran and found that the continuous care model significantly improved patients' knowledge level and their perceptions of their family members' awareness of their disease. Also, this finding was incongruent with **Kusnantom et al., (2018)** who studied” knowledge of their own disease among systemic lupus erythematosus patient in Surabaya, Indonesia and found that 40% of clients with systemic lupus erythematosus had good knowledge about SLE disease. This finding was in congruent with **Radin et al., (2022)** who reported that through self-care management program patient with SLE in Italy gain better control over their chronic disease. So, awareness of them should be continuous and promoted among the community.

The current study revealed that, there was a highly statistically significant difference was noticed between the study and control groups regarding all reported self-care practices items about systemic lupus post one and three months post continuous care model ($p \leq 0.001$). However, there was no statistically significant difference between the study and control groups regarding self-care practices items about systemic lupus pre continuous care model ($p > 0.05$). This could be attributed to the effectiveness of care model and follow-up. Thus, confirming our initial hypothesis; and result might be due to knowledge play important role for a change in behavior leading to change in practices. These findings were supported with **Elsayed & Mesbah, (2018)** who evaluated the self-care practices of SLE patients based on

health education intervention in Egypt and reported that the studied patients had improved self-care practices after intervention.

Concerning total reported self-care practices level, the existing study showed that minority of study group had adequate total reported self-care practices pre continuous care model, while post one and three months of care model more than three quarters and nearly three quarters had adequate total reported self-care practices. This might be due to the effectiveness of care model and ongoing interaction between researchers and patients. These findings agreed with **Elsayed & Mesbah, (2018)**, who stated that less than fifth had satisfactory total self-care reported practices score pre intervention, while post intervention; satisfactory total self-care reported practices improved to 83.3%.

The present study indicated that there was a highly statistically significant difference between the study and control groups regarding quality of life domains post one and three months of continuous care model. This study were supported by **Mohammad et al., (2019)** who reported that the continuous care model significantly improved patients' knowledge and HRQoL.

However, there was no statistically significant difference between both groups about quality of life domains pre continuous care model. This may be due to lack of knowledge and self-care practice in both groups before CCM that reflected on quality of life domains. This finding was compatible with **Kusnantom et al., (2018)** who applied self-care model to improve self-care activities, and quality of life in patients with SLE” and found that the majority of the Indonesians respondents saw a decrease in their quality of life.

Concerning total level of quality of life, the results showed that less than tenth of study group had high total quality of life level pre continuous care model, in comparison with about three quarters of study group had high QoL post one and three months of care model. This reflects the positive effect of care model on QoL of SLE patients. This result was supported with **Williams et al., (2021)** who performed a study in the United States and clarified that self-management interventions that encompasses both social support and health education had efficient effect in improving HRQoL.

The results of the current study indicated that there was a highly significant positive correlation between total knowledge and total self-care practice of the control and study groups pre, post one and three months of care model. From the researcher point of view this may be due to increasing patient's ability to manage their problems after increasing their knowledge and acquiring healthy behaviors through educating them. This result was in agreement with **Feldman et al., (2021)** who carried out qualitative study, in Canada for women with systemic lupus erythematosus, and stressed that empowerment through health education and active involvement of members of the community affected by systemic lupus

erythematosus in related interventions is integral to health improvement. Also, this study agreed with **Gholizadeh et al., (2019)** who performed a study in California and found that level of knowledge and the degree of satisfaction with their QoL has also significantly improved after applying self-care guidelines.

The present study revealed that quality of life score post care model among patients with systemic lupus it was best predicted by marital status, monthly income, total knowledge, and total self-care practices post care model ($p= 0.041^*$, 0.049^* , $<0.001^{**}$, and $<0.001^{**}$) respectively. This might be related to the great impact of marital status on disease progress because most of married people have more responsibilities, which makes them more tired and complains from fatigue and joint pain. Also, QoL was best predicted by monthly income affects accessibility of health needs and other life demands, total knowledge and self-care practices are correlated with QoL either positively or negatively. From the researcher opinion increasing information about disease leads to increasing patients' awareness and acquiring healthy behaviors. In turn, patients' ability to manage their problems increase and this led to improving patient's QoL. These results were in accordance with **Elsayed & Mesbah, (2018)** who stated that there were highly positive association among studied subjects' total knowledge, self-care practices and total Lupus Patient Reported Outcomes (PRO) score post intervention. Moreover, the study finding was supported with **Mostafa & Abd-Elrehem (2017)**, who added that more than two thirds of the patients included in their study had satisfactory awareness level regarding SLE which reflected on improving self-care practice and quality of life post implementation of self-management guidelines with highly statistical significance.

These findings also were compatible with **Williams et al., (2021)** who clarified that self-management interventions that incorporate both social support and health education had a positive effect in improving health outcome through reduced pain, improved function and delayed disability among patients with lupus. Additionally, these findings were in the same line with **Mohamady et al., (2022)** whose study about "Effect of Self-Care management on Health Outcomes and Symptoms for Females with Systemic Lupus Erythematosus, Tanta" founded that who found that the application of the self-care model not only achieved a high quality of life independently but also enhanced reductions in SLE flares which were triggered by the factor of physical stress. While in contrast with **Sari et al., (2022)** who conducted a study in Widya Mandala Catholic University and found that self-care practices were uncorrelated with health related quality of life and health outcomes in lupus patients.

Conclusion

In the light of the present study results: The continuous care model implementation was efficient to improve patients' knowledge, self-care practices and quality of life regarding systemic lupus erythematosus. So, the research aim and hypotheses were achieved.

Recommendations:

Based on the result of the current study, the following recommendations are suggested:

- Implementing continuous care model for all patients with systemic lupus erythematosus to enhance their knowledge, self-care practices and their quality of life.
- An educational booklet should be provided to all Rheumatology outpatient clinics at Benha City to be available for all newly admitted patients with SLE.
- Further studies are needed to be conducted about SLE in various settings with a larger sample size.

Study limitations:

The researchers faced some limitations in contact with SLE patients as telephones numbers were invalid or internet was not connected. Overcrowding and noise in outpatient clinics lead to interruptions during sessions.

Acknowledgments

The researchers greatly appreciated all patients and hospital personnel for their cooperation and accomplishment of the present study

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المخلص العربي

تأثير نموذج الرعاية المستمرة علي ممارسات العناية الذاتية وجودة الحياة لمرضى الذئبة الحمراء

الخلفية: الذئبة الحمراء هي مرض مناعي ذاتي مزمن يصيب العديد من أعضاء و أجهزة الجسم وتتأثر جودة حياة المرضى وقدرتهم على العمل بشكل كبير بسبب مرض الذئبة الحمراء.

الهدف: تهدف الدراسة إلى تقييم تأثير نموذج الرعاية المستمرة على ممارسات العناية الذاتية وجودة الحياة لمرضى الذئبة الحمراء.

تصميم البحث: تم استخدام تصميم شبه تجريبي لإجراء الدراسة

مكان الدراسة: أجريت الدراسة في العيادة الخارجية للروماتيزم بمستشفى بنها التعليمي

العينة: تم اختيار عينة غرضية 112 مريض مقسمين إلى مجموعتين متساويتين, مجموعة الدراسة ومجموعة المراقبة طبقاً لمعايير الاشتمال

الأدوات: تم استخدام ثلاث لجمع البيانات 1) استبانة المقابالت الشخصية 2) استبيان ممارسة العناية الذاتية. 3) اداة منظمة الصحة العالمية لجودة الحياة

النتائج: أشارت الدراسة الحالية إلى وجود تحسن كبير في المستويات الإجمالية لمعلومات مجموعة الدراسة وممارسات الرعاية الذاتية ونوعية الحياة بعد شهر وثلاثة أشهر من تطبيق نموذج الرعاية المستمرة مقارنة بمجموعة التحكم. ايضاً, وجدت بعض العوامل الأكثر تأثير في جودة حياة المرضى مجموعة الدراسة ومنها الحالة الاجتماعية والدخل الشهري وإجمالي المعلومات وإجمالي ممارسات الرعاية الذاتية بعد نموذج الرعاية (قيمة الاحتمال = 0.041, *0.049, >0.001**, >0.001**) على التوالي, هناك بعض العوامل الأكثر تأثير علي جودة الحياة بين المجموعة الضابطة من خلال الوظيفة وعدد زيارات المتابعة وإجمالي ممارسات الرعاية الذاتية (0.046**, <0.001, p=0.048*), على التوالي.

الخلاصة: أدى نموذج الرعاية المستمرة إلى تحسين معلومات مرضى الذئبة الحمراء وممارسات العناية الذاتية وجودة الحياة بكفاءة.

التوصيات: تنفيذ نموذج الرعاية المستمرة لجميع مرضى الذئبة الحمراء لتعزيز معلوماتهم وممارسات الرعاية الذاتية وجودة الحياة لديهم.