

Effectiveness of Exercises on Quality of Life in Patients with Systemic Lupus Erythematosus

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Abstract: **Introduction:** Systemic Lupus Erythematosus (SLE) is a chronic progressive autoimmune disease that produces a significant negative impact on patients' quality of life which influencing both physical and psychological well-being. Patients with SLE reported significantly worse quality of life in comparison with other chronic patients and even the general population. Because the chronic nature of SLE, quality of life is an important factor in patients' overall health and there is a need for better understanding of the impact of the illness on patients on life (Moldovan et al., 2011). There is evidence that exercise improves one's quality of life. There is evidence that exercise improves one's quality of life. However, there is a need for further research about exploring the beneficial effects of exercise on quality of life in SLE population. **Aim:** to examine the effects of exercise intervention on quality of life among patients with SLE. **Methods:** A quasi-experimental (pre-post test) design was used. The study was conducted at the Chronic Illness Clinics in Menoufia University Hospital, at Shebin El-Kom district, Menoufia Governorate. A convenient sample of 70 patients was recruited. **Tools:** A Semi Structured Demographic Sheet; Systemic Lupus Erythematosus Specific Quality of Life Questionnaire (SLESQOL);_Designed Observational Sheet to record patients' daily performance and duration of exercises per week. **Results:** there was a highly statistically significant differences between the study and the control group regarding the quality of life score post intervention (123.0±8.47),(183.88±7.26) respectively with a p value ≤ 0.001. Also, there is a relationship between Quality of Life and gender & educational level in the study group post intervention. **Conclusion:** adding exercise to patient schedule had a great effect on improving quality of life in patients with SLE. **Recommendation:** Encouraging individuals with SLE to increase their physical daily activity and increase their awareness about the psychological beneficial effects of exercise in improving quality of life.

Keywords: Quality of Life, Exercises, Nursing Intervention, Systemic Lupus Erythematosus.

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I. Introduction

Systemic Lupus Erythematosus (SLE) is a chronic progressive autoimmune disease that produces a significant negative impact on patients' quality of life which influencing both physical and psychological well-being. Depression and anxiety, poor social support and worse health-related quality of life are common symptoms of SLE. Patients with SLE reported significantly worse quality of life in comparison with other chronic patients and even the general population [1, 2, 3 & 4]. Most of the patients consider the overall impact of SLE on the quality of life as either restrictive (57%) or very restrictive (21%). The most influenced areas include career (68%), social activities (63%), and almost one third of patients indicate problems within their family and partnership. Thirty percent of patients indicate limitation in "having a child or having more children". The fact that limitations in all activities are present in more than 50% of patients is a serious finding which means that in almost all patients SLE significantly affects the possibility to lead everyday life comparable to matched healthy controls [5]. Physical activity, regardless of the type, leads to a significant improvement in quality of life, without deteriorating the activity of underlying disease. [6].

Physical activity can prevent long-term consequences of SLE such as obesity, osteoporosis and premature cardiovascular and cerebrovascular diseases risk [7]. Reducing the obesity of the stomach region will reduce the level of IL-6 and tumor necrosis factor (TNF) as well as insulin resistance which improves the immune status and the quality of life [8 & 9].

II. Significant of the Study

Systemic Lupus Erythematosus has a significant negative impact on patients' quality of life [10]. Because the chronic nature of SLE, quality of life is an important factor in patients' overall health and there is a need for better understanding of the impact of the illness on patients one' life [11]. There is evidence that exercise improves one's quality of life [12]. A greater improvement in quality of life has been reported in individuals with osteoarthritis who exercised in the form of walking, stretching, and weight training for 12 weeks, three times a week, for 40 minutes a day in comparison to the control group [13]. The psychological beneficial effect of exercise has been proved in a number of different conditions, including depression [14]; fibromyalgia [15] and chronic fatigue syndrome [16]. However, there is a need for further research about exploring the beneficial effects of exercise on quality of life in SLE population.

III. Aim of the Study

The aim of this study was to examine the effect of exercises on quality of life in patients with Systemic Lupus Erythematosus.

Definitions of Variables:

Dependent Variables:

Quality of life is theoretically defined by World Health Organization [17] as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns". It is a broad concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment.

Operational Definition of Quality of Life: in the present study, QOL is operationally defined as the obtained individuals' scores of QOL as measured by Systemic Lupus Erythematosus Specific Quality of Life Questionnaire (SLESQOL) [18].

Independent Variable:

Exercises Intervention: the designed exercises intervention was theoretically defined as "the planned repetitive physical activity structured to improve and maintain physical fitness".

Operational Definition of Exercises Intervention: In the present study, the designed exercises intervention was operationally defined as the amount of daily exercises recorded through structured observational sheet.

Research Hypotheses:

- 1- Individuals who received the exercise intervention are more likely to experience change in quality of life more than individuals who did not receive the intervention.
- 2- There is a relationship between the change in quality of life and demographic variables such as age, gender, educational level, and occupation after intervention

Methods

Research Design: A quasi experimental (pre-post test) design was used to examine the effect of exercise on quality of life in patients with Systemic Lupus Erythematosus.

Setting: The study was conducted at the Chronic Illness Clinics in the teaching Hospital of Menoufia University, at Shebin El-Kom district, Menoufia Governorate.

Sample: A convenient sample of 70 patients was recruited. These patients were approached over a one year period from the beginning of May 2016 to the end of May 2017. These patients met the following inclusion criteria: a) Adult patients (19-65yrs); b) Free from chronic diseases such as, Diabetes Mellitus and Hypertension; c) Conformed diagnosis of Systemic Lupus Erythematosus (through antinuclear antibodies (ANA) test and Erythrocyte Sedimentation Rate (ESR) more than 100 at 1st hour & d) Willing to participate in the study. Patients were excluded if they have :a) active sever myositis, nephritis, neurological involvement or cardiac or pulmonary disease excluded because performing exercises may be painful and increase fatigue level; b) Pregnant woman, they are excluded because pregnancy affects quality of life and increases fatigue level.

Sample Size Calculation: A previous study examined the effect of exercise on quality of life in patients with fibromyalgia. Findings of the study showed that 50% of patients considered themselves moderately improved by exercises compared with 10% of the control group receiving flexibility training [15]. By assuming similar treatment responses with a = 0.05 and a power of 80%, we calculated that 30 subjects would be required for each group.

Tools: In order to achieve the purpose of the study, the following instruments were used:

I-A Semi Structured Demographic Sheet: It was used to collect data about age, gender, educational level,

marital status, occupation, economic status and duration of illness. Data were collected by the investigator at the initial data collection point through face-to face interview with the patients.

II: Systemic Lupus Erythematosus Specific Quality of Life Questionnaire (SLESQOL):

It was developed by Freire, et al., [19] to assess quality-of-life (QOL) in individual with systemic lupus erythematosus (SLE). It contains 40 items, including physical functioning (6 items), activities (9 items), symptoms (8 items), treatment (4 items), mood (4 items), and self-image (9 items). The scale score ranged from 0 to 7. A summary score is derived from the sum of all responses across the domains; alternatively the authors suggested that a summary score can be obtained by taking the mean of each of the six domains. The total sum of scores ranges from 40–280, with higher values corresponding to worse quality-of-life. The reliability of SLESQOL was reported in a study of 275 patients. Internal consistency was evaluated using Cronbach's alpha and was 0.95. Test retest reliability was assessed in 51 patients with a 2 weeks interval the correlation coefficient was 0.83 for the summary of the score [20]. In the current study, the test-retest reliability of SLESQOL was tested in seven patients with a period of two weeks interval and was 0.92.

III: Designed Observational Sheet: it was developed by the researcher to record patients' daily performance and duration of exercises per week.

Ethical Considerations

The permission for conducting the study was obtained from the Faculty of Nursing and hospital director to carry out the study after explaining the purpose of the study. Oral consent was obtained from subjects who met the study inclusion criteria to participate in the study at the initial interview. Subjects were informed about the purpose, procedure, and benefits of participating in the study. The investigator explained that participation in the study is voluntary and the patient can withdraw from the study at any time without penalty. It was also emphasized that refusal to participate or to withdrawal from the study would not affect any aspect of the care they receive from the hospital. Confidentiality and anonymity of patients was assured through coding all data and put all data sheet in a closed cabinet. Questionnaires were fulfilled by the participants themselves or through personal interview and took about 20 minutes to complete. The nature of the questionnaires didn't cause any physical or emotional harm to the participants.

Pilot Study

A pilot study was conducted on 10% of the study sample (seven patients) to test the practicality and applicability of the questionnaire and detect the obstacles and the problems that might be encountered during the data collection. Also to estimate the time needed to fill in the study questionnaires. Subjects participating in the pilot study were excluded from the final analysis of the studied sample.

Data Collection Procedure

Patients who met the study inclusion criteria were interviewed individually by the researcher. Data collection process continued for one year from the beginning of May 2016 to the end of May 2017. Both groups were matched against the study inclusion criteria as much as possible in relation to age and sex. Seventy adult patients with SLE were randomly assigned into two equal groups, 35 each group. Assigning the subjects to the study and control groups took place by writing the names of the subjects on a slip of paper, placed in a container, mixed well and then drawn out one at a time until assigning the required sample. The researcher drew the names out of the container. The study group received the designed exercise intervention for three months. The control group received the routine hospital care. The rationale for the duration of the exercises intervention is based on the existing evidence that the most successful exercise programs consist of between one and a half and three hours a week of exercise for 8 to 15 weeks.

The Study Group: The study group received the designed exercise intervention including oral instruction supported by illustrated instruction booklet that consisted of:

Exercise Instruction: Participants were given the designed exercises intervention for two sessions about range of motion exercises for all joints based on the recommendation of the American College of Rheumatology (ACR) and Arthritis Foundation which suggest that people with SLE perform flexibility exercises and aerobic exercise as walking [21].

Flexibility Exercises such as range of motion exercises (ROM) by performing flexion, extension and avoid hyper extension movements to prevent joint ache. As following: Neck ROM, Shoulder ROM, Elbow ROM, Wrist ROM, Hip ROM, Knee ROM & Foot ROM.

Aerobic exercise such as walking, from 20 to 30 minutes per day three days a week and being physically active along the day and adherence to exercise intervention was assessed using the design observational sheet given to participants to record days and the total number of minutes in which recommended

designed exercises intervention achieved. Each participant was scheduled for a minimum of six follow up sessions for three consecutive months (follow up every week at the first month, every 2 weeks at the second month and third month of the intervention); follow up were undertaken through personal participant interview or through phone call as available. Each session takes about 20- 30 minutes. Participants received verbal instructions supplemented by written material that is supported by pictures as an illustrative guide for more clarification to participants.

The first time the researcher met the Participants was considered the baseline measure. Participants were interviewed in the chronic illness clinics to fill the study questionnaires. The study questionnaires included: a) semi structured interview questionnaire included the Socio-demographic data. b) Systemic Lupus Erythematosus Specific Quality of Life Questionnaire. The researcher interviewed the participants again after three months at the end of the intervention and re-administered the study questionnaires to identify the effects of exercises on quality of life in patients with SLE.

IV. Results

Characteristics of the Sample

The mean age of patients in the study and control group was 28.68 ± 7.25 and 30.48 ± 8.67 years old respectively. The majority of the groups were females, 88.6% for the study group and 91.4% for the control group, about 34.3% and 25.7% of the study and control groups were illiterate respectively while about 14.3% and 25.7% of the study and control groups had university education respectively. Only 14.3% and 11.4% of the study and control groups were employee respectively. About 57.1% and 71.4% of the study and control groups stated that the monthly income of their families is not enough respectively. Approximately 51.4% and 45.7% of the study and control groups were single respectively while about 48.6% and 51.4% of the study and control groups were married respectively. See Table (1).

Table (1) The Sociodemographic Characteristics of the Sample.

Socio-demographic characteristics	Studied Groups			
	Group I (Study) (n=35)		Group II (Control) (n=35)	
	No.	%	No.	%
Age (years):				
Mean±SD	28.68 ± 7.25		30.48 ± 8.67	
Range	19.0 – 48.0		19.0 – 47.0	
Gender:				
Male	4	11.4	3	8.6
Female	31	88.6	32	91.4
Education:				
Illiterate	12	34.3	9	25.7
Primary	10	28.6	4	11.4
Secondary	8	22.9	13	37.1
University	5	14.3	9	25.7
Occupation:				
Employee	5	14.3	4	11.4
Not employee	30	85.7	31	88.6
Income:				
Enough	15	42.9	10	28.6
Not enough	20	57.1	25	71.4
Marital status:				
Single	18	51.4	16	45.7
Married	17	48.6	18	51.4
Widowed	0	0.0	1	2.9

Table (2) Classification of Quality of Life Level of the sample

	Studied Groups				χ ²	P value
	Study Group I n(35)		Control Group II n(35)			
Pre intervention	NO	%	NO	%	1.823	0.402
Poor	19	54.3%	16	45.7%		
Fair	7	20%	12	34.3%		
Good	9	25.7%	7	20%		

Post intervention						
Poor	6	17.1%	15	42.9%	5.70	0.05 S
Fair	17	48.6%	13	37.1%		
Good	12	34.3%	7	20%		

Poor (201-280), Fair (120-200) ,Good (40-119)

Table (2): Showed that there was a statistically significant difference between the study and the control group regarding the classification of quality of life post intervention. The percentage of patients with poor quality of life decreased from 54 % in the study group pre intervention to 17 % in the study group post intervention. While, the percentage of patients with fair quality of life increased from 20% in the study group pre intervention to 48.6% post intervention. Also, the percentage of patients with good quality of life increased to 43% post intervention compared to 25.7% pre intervention.

Table (3) the Effect of Exercise on Quality of Life

Item	Studied Groups		Student's t-test	P value
	Study Group I (n=35)	Control Group II (n=35)		
	Mean ± SD	Mean ± SD		
1-Physical Functioning				
• Pre	16.60 ± 2.25	16.17 ± 2.18	0.80	0.42 NS
• Post	11.20 ± 1.85	16.14 ± 2.24	9.91	≤0.001 HS
2-Activities				
• Pre	43.34 ± 3.34	43.11 ± 3.15	0.29	0.76 NS
• Post	28.88 ± 2.15	43.02 ± 3.17	21.80	≤0.001 HS
3-Symptoms				
• Pre	42.77 ± 2.40	42.60 ± 2.78	0.27	0.78 NS
• Post	20.62 ± 3.36	42.88 ± 2.95	29.24	≤0.001 HS
4-Treatment				
• Pre	9.0 ± 0.0	9.0 ± 0.0	NA	NA
• Post	7.94 ± 3.10	9.0 ± 0.0	2.01	0.05 S
5-Mood				
• Pre	22.42 ± 0.94	22.48 ± 2.26	0.13	0.89 NS
• Post	12.65 ± 1.71	21.94 ± 2.51	18.02	≤0.001 HS
6-Self-image				
• Pre	50.85 ± 0.35	50.71 ± 1.20	0.67	0.50 NS
• Post	41.68 ± 1.82	50.88 ± 3.53	13.66	≤0.001 HS
Total Quality of Life score:				
• Pre	185.0 ± 3.76	184.08 ± 5.56	0.80	0.42 NS
• Post	123.0 ± 8.47	183.88 ± 7.26	32.26	≤0.001 HS

Table (3): Showed that there was a highly statistically significant differences between the study and the control group regarding the quality of life score post intervention (123.0 ± 8.47), (183.88 ± 7.26) respectively with a p value ≤ 0.001. There was a highly statistically significant differences post intervention comparing to pre intervention regarding all quality of life domains (physical functioning domain, activities domain, symptoms domain, treatment domain, mood domain and self-image domain) in both the study and control groups.

Figure (1): The Effect of Exercise on Quality of Life

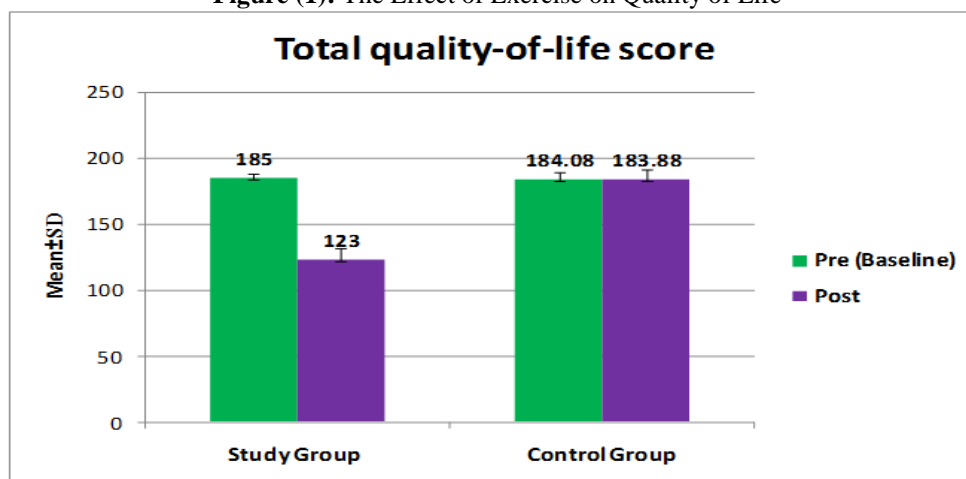


Figure 1 showed that there was a difference in the total quality of life score post intervention compared to pre intervention.

Table (4) the Relationship between Quality of Life and the Demographic Characteristics Post Intervention.

Demographic characteristics	Score of Quality of Life of the Study Group (n=35) Mean ± SD	Test significance of	P value
Age (years):	r= 0.16	Spearman's rho	0.34 NS
Gender: Male Female	130.75 ±1.25 122.0 ±8.49	t= 5.30	≤0.001 HS
Education: Illiterate Primary Secondary University	129.25 ±2.70 126.30±4.19 117.50 ±7.40 110.20±6.72	F=21.08	≤0.001 HS
Occupation: Employee Not employee	121.80±8.81 123.20±8.55	t=0.33	0.73 NS
Income: Enough Not enough	125.86±4.86 120.85±9.98	t=1.95	0.06 NS
Marital status: Single Married	122.05±9.04 124.0±7.97	t=0.67	0.50 NS

Table (4): Showed that there is a relationship between Quality of Life and gender & educational level in the study group post intervention.

V. Discussion

Systemic lupus erythematosus (SLE) is an autoimmune disease that is characterized by poor quality of life; however, little research has been conducted to determine the effect of non-pharmacological strategies, such as exercise, on improving quality of life in patients with SLE. Therefore, the purpose of the current study was to examine the effect of exercises on quality of life in patients with SLE.

The Effect of Exercises on Quality of Life

Systemic lupus erythematosus (SLE) has a negative impact on patients' quality of life. Continuous physical activity in SLE patients significantly improves their quality of life by reducing depressive reactions without negative impacts on the activity of their disease [6]. The current study hypothesized that individual who received the exercise intervention experience improvement in quality of life more than individuals who did not receive the intervention. The present study findings supported the hypothesis and revealed that there was a statistically significant improvement in the total score of quality of life post intervention. The findings of the study are similar to what was reported by Yuen & Bagley [22], who examined the exercise benefits and considerations for individuals with SLE and concluded that exercise can improve aerobic fitness and quality of

life. Also, the findings of the current study are similar to what was reported by Carvalho et al. [23] and Abrahão et al. [24] who used SF-36 to evaluate health-related quality of life and concluded that following aerobic exercise interventions physical role functioning and vitality subscales were significantly improved compared to control groups. In addition, findings of the current study are similar to what was reported by Paul [25] who examined exercising with lupus and concluded that regular exercise has been shown to significantly improve quality of life beyond just improving sleep and energy levels in people with SLE. In addition, it can help to decrease the amount of depression and anxiety, improve self-esteem, improve memory abilities, and increase one's sense of well-being. However, the findings of the study are different from what was reported by Tench et al. [26] and Boström et al. [27] who found no significant differences in any of the SF-36 subscales, except for mental health, which was significantly improved in the exercise group compared to the control group after 6 months of the study by Boström et al. [27].

Quality of Life and Socio-demographic Characteristics

Patients with SLE reported significantly worse quality of life in comparison with other chronic patients and even the general population [2 & 4]. The current study hypothesized that there is a relationship between the change in quality of life and some demographic variables such as age, gender, educational level and occupation post intervention. The present study findings supported the hypothesis and findings revealed that there was a significant relationship between quality of life, gender and educational level in the study group post intervention while there was no relationship between age, occupation and quality of life in the study group post intervention. The findings of the current study are similar to what was reported by Odhiambo, Oyoo & Amayo [28] who evaluated the quality of life in ambulatory patients with SLE attending rheumatology clinic in Kenyatta National Hospital. 67 patients with SLE were included aged from 14 years old to 71 years old. Findings revealed that women had significantly poorer scores of quality of life than men. Also, the findings of the current study are similar to what was reported by Shakeri, et al. [29] who examined the effects of demographic characteristics including gender, marital status, employment, and the income level on QOL and the study findings revealed that there was no significant effect of employment on QoL and age was not related to any domains of the health related quality of life (HRQoL) while high educational level has been shown to be associated with better QoL among people with SLE.

Limitations of the study

1. Lack of representation of males in the sample is one of the limitations of the study. Most of the participants in this study were female participants (88.6% for the study group & 91.4% for the control group). Although this is consistent with gender distribution of SLE in the general population, the findings may have underrepresented the concerns of males with SLE. Thus, the findings of the study might only be applicable among female SLE patients.
2. Another limitation of the study is using self-reported questionnaire to measure quality of life, whereas possible reactivity in completing the questionnaire in a socially desirable direction can occur.
3. The findings of the current study should be interpreted with caution because of the bias associated with using the convenient sample, whereas lack of random sampling may contribute to sample selection bias and limits the generalization of the findings.

VI. Conclusion and Recommendations

Systemic Lupus Erythematosus (SLE) has a significant negative impact on patients' quality of life which influencing both physical and psychological well-being. Also, it can be concluded that adding exercise to patient schedule had a great effect on improving quality of life in patients with SLE.

Implications for Nursing Practice

- Prepare training programs for nurses about the importance of adding exercise to patient schedule for the improvement of quality of life in patients with SLE along with the routine hospital care.
- Distribute the designed booklets about the importance of exercise at the chronic illness clinics to benefit individuals with SLE who have poor quality of life.
- Encouraging individuals with SLE to increase their physical daily activity and increase their awareness about the psychological beneficial effects of exercise in improving quality of life.

Implications for Further Research

- Extend the study period beyond three months to assess the maintenance of the positive effects of exercise on quality of life at SLE patients.
- Replication of this study is recommended with some design changes such as, using large sample size; using randomized selection to achieve appropriate representation of the population; and conducting the study in a multicenter.

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