Original Article

The Effects of an Educational Intervention on Fatigue and Activities of Daily Living in Patients with Systemic Lupus Erythematosus

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Abstract

Background: Fatigue and decreased activities of daily living (ADL) are important problems in patients with systemic lupus erythematosus (SLE) and reduce their quality of life. **Objectives:** This study was conducted to examine the effect of fatigue and activity management education (FAME) program on fatigue severity and ADL in patients with SLE. **Methods:** A quasi-experimental study was conducted on 40 patients with SLE. The patients were selected consecutively and randomly allocated into an intervention (n = 20) and a control group (n = 20). The control group was treated as usual. However, in addition to the usual treatment, the intervention group received the FAME program. Data collection was done before and 8 weeks after the intervention using the Swedish Occupational Fatigue Inventory-20 (SOFI-20) questionnaire, the daily physical activity questionnaire, and a demographic characteristics form. Descriptive statistics, independent- and paired-samples t tests, and analysis of covariance were used to analyze the data. **Results:** The two groups were homogenous in terms of demographic characteristics ($P > 0.05$) unless their job ($P = 0.002$). The mean baseline fatigue and ADL scores were significantly different between the two groups ($P < 0.0001$). Hence, analysis of covariance was used to control the confounding effect of the aforementioned variable. Then, significant differences were found between the two groups respecting the mean fatigue ($P < 0.0001$) and mean ADL ($P = 0.009$) after the intervention. **Conclusion:** Considering the effectiveness of the FAME program in reducing fatigue and increasing ADL in patients with SLE, nurses are recommended to use similar programs in the care for these patients and help them improve their own fatigue and ADL.

Keywords: *Activities of daily living, fatigue, management, systemic lupus erythematosus*

Introduction

Systemic lupus erythematosus (SLE) is an inherited autoimmune and inflammatory disease.[1,2] The global prevalence of the disease is 20–150 per 100,000 people, and African Americans, Hispanics, and Asians are at higher risk for the disease.[3,4] According to a study by the Iranian Rheumatology Research Center, the prevalence of SLE is estimated at 40 per 100,000 people In Iran.[5] This chronic disease, by involving vital organs of the body, has a detrimental effect on a person's physical health, and causes pain, stress, sleep disorders, depression, anxiety, and redisposes the patient to other psychological

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disorders.[6,7] These disorders further reduce the patient's ability to perform daily activities, which in turn causes limitations and social problems.[7]

Fatigue is one of the most common complaints in patients with SLE.[8] Significant fatigue was reported in two-thirds of patients and severe fatigue in one-third.[9] It significantly decreases the patients' capabilities at work and daily living and is associated with increased health-care costs.[10] Fatigue is strongly associated with depression and anxiety,[11] shrinks people's emotional and cognitive performances, negatively affects social and family life, and decreases the quality of life (QOL).[10] Fatigue is also associated with increased dependence and decreased ability in performing the activities of daily living (ADL).[12,13] Evidence has shown that chronic fatigue is associated with decreased physical activity,[14] which in turn predisposes people to serious conditions such as cardiovascular diseases, type 2 diabetes, breast and colon cancers.[15]

Fatigue interventions are mainly focused on self-management strategies and can be generally categorized into pharmacological and non-pharmacological approaches.[16] Due to the potential side effects and high costs of medication therapies,[17] nonpharmacological strategies are preferred by many patients including those with SLE.[16,17] Physical activity and participation in planned exercises such as cycling, walking, swimming, climbing, yoga, dancing, and aerobics are among the nonpharmacological methods commonly used to manage fatigue in patients with SLE.[8,18] However, patients should be appropriately prepared for exercise activities. Preparation programs should not only provide important information and skills to the individual patients but should also help them cope with the conditions created by the disease.[19]

Fatigue and activity management education (FAME) is a program that focuses on the management of fatigue, pain, nutrition, stress, exercise, and joint protection. With the active participation of patients, this program tries to transfer the disease management from the care providers to patients themselves as much as possible.[20] Patients play a pivotal role in this program; all care and treatment activities focus on the patient, and the goal is to maximize the patient's independence and job performance,[21] self-determination, health, and lifestyle promotion based on the individual's abilities, and improving the QOL.[22] In a study of FAME in patients with SLE, although the severity of fatigue did not significantly reduce, however, patients experienced less depression and better psychological wellbeing. They also achieved higher awareness and understanding of fatigue, and identified self-management strategies to preserve their energy and prevent fatigue in daily life and work-related activities.[23] Although studies on the effects of FAME programs have shown its beneficial effects on fatigue and ADL in patients with SLE,[16,17,23] however, such studies are limited, do not consider all aspects of people's lives, and are mostly focused on exercise activities. Hence, This study aimed to examine the effects of an FAME program on fatigue and ADL of patients with SLE.

Methods

Study design and participants

A quasi-experimental study was conducted on patients with SLE referred to Golestan Hospital and the office of a rheumatologist in Ahvaz, Iran. Data collection began in October 2020 and continued until June 2021. The researcher referred to the rheumatology clinic and rheumatology ward of Golestan Hospital (The only rheumatology clinic and ward in Khuzestan province) and the office of the rheumatologist, found eligible patients, briefed them on the study aims and process, and invited them to participate in the study. Inclusion criteria include; a medical diagnosis of SLE, and the ability to answer the study questionnaires. Failure to answer the questionnaire completely and absence in more than one training session were considered as exclusion criteria.

The sample size was estimated using the findings of an earlier study.[24] Then, considering the values of $P1 = 0.183$, $P2 = 0.817$, $\alpha = 0.01$, and $\beta = 0.1$, and predicting a possible dropout of 20%, the sample size in each group was calculated as 20. Then, 40 patients with inclusion criteria were consecutively selected and were allocated into the intervention (n = 20) and control (n = 20) groups via a block randomization method with blocks of four (i.e., 10 blocks of 4). Each block consisted of two samples of the intervention group and two samples of the control group that the order of these four samples was random. Random allocation was performed using WinPepi 11.4 software.

Data collection instruments

A four-part instrument was used to collect the study data including a demographic characteristics form, a needs assessment questionnaire, the Swedish Occupational Fatigue Inventory-20 (SOFI-20), and the Danish physical activity questionnaire (DPAQ). The demographic characteristics form included items on the patients' age, sex, education level, employment status, marital status, and the duration of the disease. The needs assessment questionnaire was made by the researcher through literature review and its content validity was confirmed by 10 professors of Ahvaz Jundishapur University of Medical Sciences. The content validity index and content validity ratio of the need assessment questionnaire were calculated as 0.71 and 0.74, respectively. The questionnaire contained 20 items on the nature of the disease, diet, activity and

rest, stress management and pain. Yes and no options were used to answer.

The SOFI-20 (Swedish Occupational Fatigue Inventory, 1997) is a 20-item multidimensional scale for assessing the quality and severity of perceived fatigue and can measure the psychological and physical aspects of fatigue including lack of energy, physical exertion, physical discomfort, lack of motivation, and sleepiness. Persian version of the scale has three main factors showing the physical, functional, and perceptual symptoms of fatigue. All items are scored on a scale from zero (not had such feelings at all) to 6 (had such feelings to a very high degree) the overall score range between 0-120. The Persian version of SOFI-20 showed appropriate validity and the Cronbach α of the three factors ranges between 0.899 and 0.940.[25]

The DPAQ (Danish Physical Activity Questionnaire) consists of eight items to assess the ADL according to the energy needed to perform them based on the metabolic equivalent (MET). The activities are listed top-down in nine levels (from need to rest and sleep with intensity of 0.9 to activity with intensity more than the previous cases with intensity >6 in terms of meters) and include "sleep and rest (0.9)," "sitting, watching television, and listening music (1)," "working while sitting such as working at a computer or desk (1.5)," "standing and doing household chores such as washing dishes and cooking," "walking, light cleaning, sweeping floors, slow dancing (3)," "cycling and brisk walking (4)," "carrying light objects upstairs (5)," "health club exercise and shoveling, running and racing (6)," and "activity with intensity more than the previous cases" (>6).[26] The validity of this questionnaire was examined and confirmed by Aligol *et al*.[27] and its reliability coefficient was 0.87.

Intervention

The control group only received the usual treatments for SLE. However, in addition to the usual treatments, the intervention group received the FAME program through a combination of lectures, group discussions, and question and answering methods. At baseline, a need assessment form was used to assess the patients' knowledge and awareness of the FAME program and to adjust the educational program based on their needs. Patients in the intervention group were divided into five subgroups of four and were asked to participate in the FAME sessions along with one of their family members. In each subgroup, FAME consisted of four 60-min sessions which were held in four consecutive weeks. All training sessions were held in a classroom in the rheumatology unit of the aforementioned hospital which was equipped with a computer and a projector to present PowerPoint presentations and videos. A nurse who was experienced in caring for patients with SLE facilitated all the training sessions. At the end of each session, educational pamphlets related to the session's topics were provided to the patients. The FAME sessions covered topics such as fatigue management, pain management, exercise, joint protection, stress management, and nutrition. The outline of the educational sessions is presented in Table 1. All patients answered the study questionnaires before the intervention started and 8 weeks after the end of the intervention.

Ethical consideration

This study was conducted according to the guidelines laid down in the Declaration of Helsinki and all procedures involving research study participants were approved by the ethics committee of Ahvaz Jundishapur University

Table 1: Outline of the educational sessions

Session number	Title	Content	Presenter
1	The nature of SLE	The pathology of SLE and fatigue, nature, causes, and consequences of fatigue in SLE, the effects of fatigue on daily living activities; and the structure of the FAME program.	The researcher
2	Diet in SLE	The effects of diet on SLE and fatigue, proper diet, benefits of a proper diet in inhibiting the inflammation and reducing the symptoms of autoimmune disorders. The role of a low-salt and low-sugar diet, calcium, and vitamin D supplements in preventing high blood pressure in patients receiving corticosteroids. Practical advice, group discussion, and question and answer about following the prescribed diet.	A nutritionist
3	Activity and exercise	Exercise and appropriate activities in SLE and its effects on patients. Benefits of walking, swimming, cycling and other aerobic activities and outdoor sports, range of motion, and joint protection. Practical advice, group discussion, and question and answering about follow the prescribed diet.	A physiotherapist
4	Stress and pain management methods	The nature and effects of stress, stress prevention relaxation techniques, emotion regulation strategies; cognitive, interpersonal and spiritual strategies to manage stress. Causes of pain in SLE, pharmacological and non-pharmacological methods of pain management in SLE. Practical advice, group discussion, and question and answer about following the prescribed diet.	A psychologist The researcher

of Medical Sciences Approval code: IR.AJUMS. REC.1398.820. All patients were also assured of the confidentiality of their personal data, the safety of the intervention, voluntary nature of participation, the right to withdraw at any time point, and all signed a written informed consent before starting data collection.

Data analysis

Data were analyzed using the Statistical Package for the Social Sciences (SPSS) software program, version 16 (SPSS Inc., Chicago, III., USA). Descriptive methods such as frequency, percentage, mean and standard were used to describe the characteristics of the study participants. The chi-square and Fisher's exact tests were used to compare the two groups in terms of nominal and categorical variables. Moreover, the independent and the paired-samples *t* tests (or their nonparametric equivalents) were used, respectively, for between- and within-group comparisons in terms of the mean scores of fatigue and ADL. Analysis of covariance was used for the job confounding variable and baseline data on fatigue and daily activities. The level of significance was set at <0.05.

Results

At the beginning of the study, 40 samples were included in the study and continued to participate until the end of the study [Figure 1]. As presented in Table 2, the two groups were homogenous in terms of their demographic characteristics ($P > 0.05$) except for their job ($P = 0.002$). Therefore, analysis of covariance was used to control the confounding effect of job ($P < 0.001$).

Table 3 also shows that the mean baseline fatigue scores were significantly different between the two groups

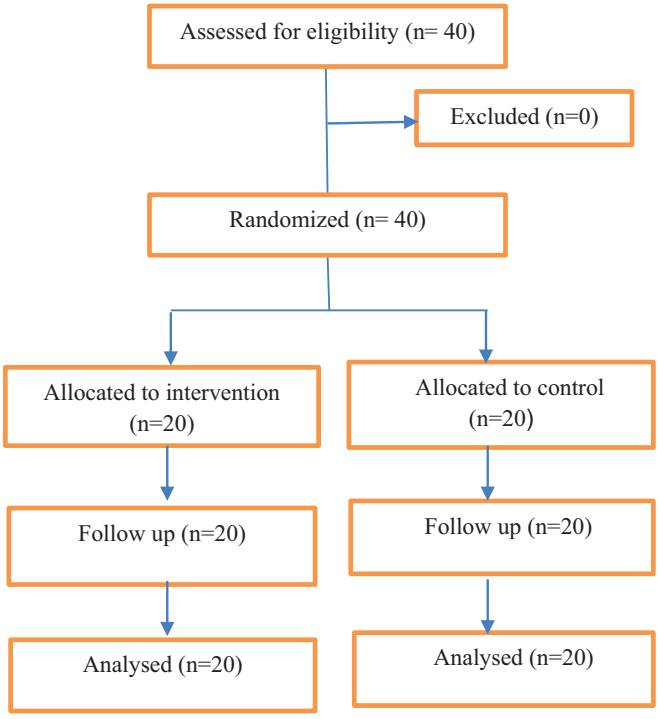

Figure 1: CONSORT flow diagram

Table 2: Comparison of the demographic characteristics of the participants in the intervention and the control groups

Variables	Control (*n* = 20) *n* (%)	Intervention (*n* = 20) *n* (%)	*P* Value
Age, years (mean ± SD)	36.65 ± 4.87	35.10 ± 5.16	0.33[a]
Disease duration, years (mean ± SD)	2.06 ± 1.33	2.21 ± 1.33	0.72[a]
Sex			0.30[b]
Female	17 (85)	19 (95)	
Male	3 (15)	1 (5)	
Marital status			0.05[b]
Married	15 (75)	9 (45)	
Single	5(25)	11(55)	
Place of residence			0.50[b]
The capital of the province	16 (80)	17 (85)	
Other cities	4 (20)	3 (15)	
Job			0.002[b]
Unemployed	0	4 (20)	
Official worker	3 (15)	7 (35)	
Homemaker	16 (80.4)	9 (45)	
Worker	1 (5)	0	
Education level			0.40[b]
Under diploma	3 (15)	2 (10)	
High-school diploma	11 (55)	11 (55)	
Bachelor's degree	6 (30)	7 (35)	

[a]Independent t test
[b]Chi-square test

Table 3: Comparison of the mean fatigue scores of the two groups before and after the intervention[a]

Variable	Control	Intervention	*P* Value[c]
Fatigue			
Before the intervention	54.15 ± 12.46	68.85 ± 9.64	<0.0001
After the intervention	53.40 ± 12.06	38.25 ± 8.44	<0.0001
P-value[b]	0.09	<0.0001	

[a]Data presented as mean ± SD

[b]Paired *t* test

[c]Analysis of covariance

Table 4: Comparison of the mean scores of activities of daily living in the two groups before and after the intervention[a]

Variable	Control	Intervention	*P* Value[c]
Activities of daily living			
Before the intervention	73.07 ± 36.63	32.75 ± 12.55	<0.0001
After the intervention	73.23 ± 36.50	47.82 ± 18.10	0.009
P Value[b]	0.03	<0.0001	

[a]Data presented as mean ± SD

[b]Paired *t* test

[c]Analysis of covariance

($P < 0.0001$). However, after using analysis of covariance for controlling the aforementioned variable, a statistically significant difference was observed between the mean fatigue scores of the two groups at the end of the study ($P < 0.0001$). In other words, the mean fatigue of patients in the intervention group was significantly lower than the control group at the end of the eighth week. The paired *t*-test also showed that the intervention could significantly decrease the mean fatigue score in the intervention group when compared with the baseline values ($P < 0.0001$). However, the mean fatigue score did not significantly change in the control group ($P = 0.09$).

Table 4 also shows that the mean baseline ADL scores were significantly different between the two groups ($P < 0.0001$). However, after using analysis of covariance for controlling the aforementioned variable, a statistically significant difference was observed between the mean ADL scores of the two groups at the end of the study ($P < 0.009$). In other words, the mean ADL of patients in the intervention group was significantly higher than the control group at the end of the eighth week. The paired *t*-test also showed that the intervention could significantly increase the mean ADL score in the intervention group when compared with the baseline values ($P < 0.0001$). However, the mean ADL score did not significantly change in the control group ($P = 0.03$).

Discussion

This study showed that the FAME program could decrease the mean fatigue intensity and increase the mean ADL in the intervention group. In an earlier study of the effect of FAME in patients with SLE, although the severity of fatigue did not significantly decrease, patients possessed higher awareness and understanding of fatigue management, energy management strategies, and experienced less depression and better mental health. Nonetheless, that study had a short-time intervention and a small sample size; therefore, further studies with longer interventions were recommended.[23]

Studies on the effects of FAME are limited; however, some studies examined the effects of complementary therapies on fatigue in patients with SLE. A study by Arriens *et al.*[28] examined the effects of fish and olive oils on fatigue and QOL in people with SLE and reported that the intervention did not significantly affect the fatigue severity and QOL. However, another study has reported that Cholecalciferol supplementation for 24 weeks was effective in reducing disease activity and improving fatigue in patients with juvenile-onset SLE.[29] A systematic review also reported that a low-calorie and a low-protein diet rich in fiber, unsaturated fatty acids, vitamins, minerals, and polyphenols with sufficient macronutrients and micronutrients can reduce inflammation, regulate immune functions, and decrease the activity of SLE.[30] Mertz *et al.*[9] have reported that fatigue in SLE is closely associated with anxiety and depression, and, therefore, requires careful assessment, care, psychological counseling, and medication intervention. Fangtam *et al.*[31] have also reviewed non-pharmacological therapies for SLE and concluded that physical exercise and psychological interventions can complement the traditional medical therapies for improving fatigue, depression, pain, and QOL in patients with SLE. Although further high-quality randomized controlled trials with longer follow-up periods are yet needed in this area. In a study of pain management strategies in children with SLE, Nabors *et al.*[32] highlighted

the importance of peer support and cognitive-behavioral therapies (CBTs) as the psychological interventions that might help reduce pain, fatigue, and isolation and increase the resilience and QOL of these patients. CBT also showed beneficial effects in reducing fatigue in patients with multiple sclerosis.[33] and cancer.[34]

Keramiotou *et al*.[35] have also examined the effect of upper limb exercise in patients with SLE and reported that the exercise program could significantly improve function, pain, daily activities, and QOL of these patients. A review study has also found that physical exercise is not only safe for patients with SLE but also improves their fitness and reduces fatigue.[36]

In general, few clinical trials have been performed on the treatment of fatigue in patients with SLE. Treating fatigue is difficult based on a limited number of studies that have reported the effectiveness of exercise, cognitive and behavioral therapies, and some self-management programs. It is not clear how exercise can improve fatigue. Also, the effect of dietary changes and herbs on fatigue in patients with SLE is not fully understood. There are claims that some herbs, vitamins, and minerals are effective in reducing fatigue in chronic diseases. But these claims have not been confirmed by high-quality clinical trials. Therefore, as reported by Tarazi *et al*.,[37] more research is needed to find an effective treatment for fatigue in patients with SLE.

As sampling was performed during the COVID-19 pandemic period, hospitalization of patients with lupus in rheumatology wards was reduced. Therefore, access to the samples was difficult for the researcher and patients' willingness to participate in the study was reduced due to the likelihood of developing COVID-19 disease. These conditions, in addition to the patients "mental state, could affect the patients" response to the questionnaire items. Despite the random assignment of samples to two groups, the baseline scores of fatigue and ADL in the two groups of intervention and control were significant, which could be due to the limited sample size.

Conclusion

Considering the effectiveness of the FAME program in reducing fatigue and increasing ADL in patients with SLE, nurses are recommended to use similar programs in the care for these patients and help them alleviate their fatigue and improve their own ADL. Also, nursing managers and those in charge of nursing education should train nurses and nursing students about the FAME program and empower them in educating patients to better manage their own fatigue and ADL. It is also recommended that more studies with larger sample sizes be performed on other disabling complications in patients with SLE.

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Conflicts of interest

There are no conflicts of interest.

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