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Original Article

Nursing Section

Education-based Self-management Intervention on Awareness among Patients with Systemic Lupus Erythematosus at Tertiary Care Hospital, Chennai, India

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ABSTRACT

Introduction: Education-based self-management intervention that incorporates both social support and health education have reduced pain, improved function and delayed disability among patients with lupus.

Aim: To assess the effect of education-based self-management intervention on awareness among patients with Systemic Lupus Erythematosus (SLE) at tertiary care hospital.

Materials and Methods: The quantitative experimental study one group pretest post-test design using purposive sampling technique was conducted on 55 patients, who were all diagnosed with SLE in Rheumatology Outpatient Department, Tertiary Care Hospital, Chennai, Tamil Nadu, India. The patients received the intervention "education-based self-management" which comprised of audio recorded powerpoint teaching on various aspects of SLE like definition, risk factors, signs and symptoms diagnostic investigations, treatment, complications and self-care measures. The investigator taught a group of 4-5 patients for 30-40 minutes using the presentation, followed by which they were provided a booklet on self-management guidelines. The pre and post-test self-management awareness determined through reliable and valid self-structured questionnaire (SLE awareness questionnaire) and their values were analysed through inferential and descriptive statistics.

Results: The SLE was reported to be highest among the age group of 21-35 years (72.7%), with higher incidence in females 96.4% than male 3.6%. Majority (n=44) 80% of the patients were founds to have inadequate level of awareness in the pretest. During the post-test on 15th and 30th day, the awareness among the patients was found to be adequate with the score of 38.2% and 94.5%, respectively. There was a significant difference noted in level of awareness between pretest and post-test on 15th day at p-value=0.04 and between pretest and post-test on 30th day at p-value=0.01.

Conclusion: The education-based self-management intervention is effective in improving the awareness levels among patients with SLE and it can also be effective for patients to manage their symptoms.

Keywords: Autoimmune disease, Knowledge, Self-care measures, Teaching programme

INTRODUCTION

The Systemic Lupus Erythematosus (SLE) or lupus is a chronic autoimmune disorder that involves multiple organ systems with a relapsing and remitting course [1]. The prevalence of SLE is 6.5 to 178.0 per 100,000 population globally [2] and in Asia is ranging from 30 to 50/100,000 population [3]. In India, the reported prevalence of SLE is 14 to 60 per 100,000 [4].

Lupus strikes mostly women of childbearing age. Most people with lupus develop the disease between the ages of 15-44. About 90% of people living with lupus are women [5]. The clinical symptoms of SLE vary among affected individuals are unpredictable with periods of remission and flares. A flare is defined as "a measurable increase in disease activity in one or more organ systems involving new or worse clinical signs and symptoms and/or laboratory measurements [6] and the signs and symptoms can involve many organs and systems, that include the skin, joints, kidneys, lungs, central nervous system, and blood forming (haematopoietic) system [7].

The SLE is not curable, however, symptomatic treatment helps to control disease progression and inhibit further complications related to organ damage. The treatment comprises of glucocorticoids and immune suppressants [8,9]. Apart from the medical treatment the patients can manage their disease through adequate self-care, knowledge, and skills which are all the important key factors for patients to reduce readmission rates, complications and to improve the quality of life [10].

The SLE complications can be prevented through self management. It is important to teach patient the warning signs of a flare. Further the patient with SLE need to acquire self-care knowledge and skills, and must find appropriate ways to manage surrounding environments and to maintain optimal health [11,12].

In India, a study assessed the level of awareness and knowledge on SLE among the general population and was found that the majority of participants had insufficient knowledge of its status as a rare disease that occurs in the population [13]. In Riyadh, Saudi Arabia, a study among the primary healthcare patients to assess their SLE awareness and knowledge found that most of the participants were unaware of SLE. This indicates the participants had poor knowledge about the disease [14].

Due to the low level of awareness among patients with SLE, we should take measures to improve their knowledge and reduce their symptom burden. Therefore, in order to increase awareness in self-management of lupus patients in India, this research was carried out. The main aim of the study was to evaluate the effect of education-based self-management intervention on awareness among patients with SLE at a tertiary care hospital, Chennai, India.

MATERIALS AND METHODS

This quantitative experimental study with one group pretest and post-test design was carried out at Rheumatology, Sri Ramachandra Institute of Higher Education and Research Chennai, Tamil Nadu, India, from February 2019 to July 2019. The study was conducted

after obtaining clearance from the Institutional Ethical Committee (Study Approval No. CSP/19/MAR/76/147).

Inclusion criteria: Patients of both genders, who were diagnosed with SLE, aged above 20 years and who were able to read and understand Tamil and/or English were included in the study.

Exclusion criteria: The SLE patients who were not willing to participate in the study were excluded.

Sample size calculation: The sample size was 55 SLE patients as estimated by power analysis assuming the mean difference (self-concept) before and after intervention of 1.2 and the standard deviation of 3.4 and 1.9, respectively. The sample size was calculated with the power of 90% with α=5 based on a previous study [15].

The formal written permission was obtained from the Principal, Faculty of nursing, Nursing Superintendent, Medical Superintendent and Head of the Department (HOD) of Rheumatology Department, at Tertiary Care Hospital. A sample of 55 patients with SLE were selected using the purposive sampling technique based on inclusion and exclusion criteria. The purpose of the study and their right to participate or withdraw from the study was explained to the patients prior and written informed consent was obtained.

Education on self-management consisted of three phases:

1. Preparation phase
2. Implementation phase
3. Evaluation phase

Preparation Phase

The researcher prepared the education-based self-management intervention content based on the Lupus Foundation of India guidelines (2018) [16]. The teaching content was exclusively represented regarding SLE-definition, risk factors, signs and symptoms, diagnostic investigations, treatment, complications and self-care measures. Based on the content, the researcher developed SLE awareness assessment questionnaire and prepared audio recorded powerpoint presentation and information booklet. The SLE awareness assessment questionnaire consisted of two parts. **Part:1-** demographic variables, which includes; age, gender, marital status, education, occupation, residence, dietary pattern and habits of patients with SLE, and **Part:2-** clinical variables that includes; family history of SLE, duration of illness, co-morbid conditions, intake of medication prescribed for SLE, alternative complementary therapy and frequency of medical follow-up. The questionnaire had 30 questions with multiple choices. One point was given to each right answer. The maximum score was 30. The audio-recorded powerpoint presentation and the information booklet were developed in two languages such as Tamil and English.

Implementation Phase

Baseline data on demographic variables were collected using interview technique and dependent variable were collected through self-administered questionnaire. Other clinical variables from the patient's case sheet were also recorded before the procedure. Pretest assessment on awareness for SLE was done by using SLE Awareness Assessment Questionnaire. Patients were assessed as per the grading system [Table/Fig-1] [17]. The intervention sessions were provided using a laptop to a group of 4-5 patients for 30-40 minutes, followed by which they were provided an information booklet on self-management guidelines. After the intervention session, the investigator has clarified patients' doubts and reinforced to changing of their lifestyle patterns.

Grade/Percentage	Description
(23-30) >75%	Adequate knowledge
(16-22) 51 to 75%	Moderately adequate knowledge
(0-15) ≤50%	Inadequate knowledge

[Table/Fig-1]: SLE awareness assessment questionnaire grading.

Evaluation Phase

After the intervention, the post-test assessment was done using the same questionnaire on 15th and 30th day. Patients were re-assessed as per the grading system [Table/Fig-1].

STATISTICAL ANALYSIS

Data analysis was performed using Statistical Package for the Social Sciences (SPSS 20.0) version for windows. Descriptive statistics (frequency, percentage, mean and standard deviation) was obtained. Inferential statistics Chi-square test was used. Chi-square test was performed to determine the effectiveness of education-based self-management intervention on awareness among patients with SLE and also association was checked between the awareness and selected background variables. The p-value <0.05 was considered as statistically significant.

RESULTS

The study had 55 participants. The demographic data is shown in [Table/Fig-2]. Out of 55 participants, 40 (72.7%) of them belonged to 21-35 years and most of them {53 (96.4%)} were females. Majority 31 (56.4%) of the participants were living in rural area and {54 (98.2%)} of the patients had no habit of smoking and alcohol consumption whereas only 1 (1.8%) had the habit of alcoholism.

Demographic variables	Frequency (n)	Percentage (%)
Age (in Years)		
21-35	40	72.7
36-50	13	23.6
51-65	2	3.6
Gender		
Male	2	3.6
Female	53	96.4
Marital status		
Married	38	69.1
Single	17	30.9
Education		
Non formal education	6	10.9
Primary	3	5.5
Secondary	14	25.5
Higher secondary	9	16.4
Diploma	4	7.3
Graduate	19	34.5
Occupation		
Professional	1	1.8
Clerical	5	9.1
Skilled	8	14.5
Semi-skilled	2	3.6
Unskilled	1	1.8
Unemployed	38	69.1
Residence		
Urban	24	43.6
Rural	31	56.4
Dietary pattern		
Vegetarian	4	7.3
Mixed	51	92.7
Deleterious habits		
No	54	98.2
Yes	1	1.8

[Table/Fig-2]: Frequency and percentage distribution of sample based on demographic variables (N=55).

The percentage distribution of clinical variables is shown in [Table/Fig-3]. Majority {52 (94.5%)} patients did not have a family history of SLE whereas 20 (36.4%) had co-morbid conditions like diabetes, hypertension and hypothyroidism. Majority of the patients 24 (43.6%) followed their medical review once in 15 days.

Clinical variables	Frequency (N)	Percentage (%)
Family history		
Yes	3	5.5
No	52	94.5
Duration of disease (Years)		
≤1	27	49.1
≤2	8	14.5
≤3	7	12.7
≤4	1	1.8
≤5	3	5.5
>5	9	16.4
Co-morbidity conditions		
No	35	63.6
Yes	20	36.4
Medications		
Never	2	3.6
Whenever symptoms arises	3	5.5
Regular	50	90.9
Alternative treatment		
Homeopathy	2	3.6
Nil	53	96.4
Medical follow-up		
15 days	24	43.6
One month	23	41.8
Three months	8	14.5

[Table/Fig-3]: Frequency and percentage distribution of sample based on clinical variables (N=55).

Before intervention, majority 35 (63.63%) participants were answered the term of SLE as "I don't know" and they believed that it is a rare condition [Table/Fig-4]. About 26 (42.27%) of them believed that SLE was a hereditary disease and 30 (54.54%) of them believed that increased physical activity is a triggering factor of SLE.

Before intervention, majority 21 (38.18%) participants believed that involvement of lupus in kidney leads to increased blood sugar level [Table/Fig-5]. Regarding diagnosis of SLE, 28 (50.90%) participants believed that SLE has been diagnosed/confirmed with a single test Complete Blood Count (CBC). Twenty four (43.63%) of them believed that the active stage of SLE were confirmed by Erythrocyte Sedimentation Rate (ESR) count.

Before intervention, 51 (92.72%) participants knew their needs and where they want to get consultation and opinion [Table/Fig-6]. Regarding nutritional status, 32 (58.18%) of them knew about vitamin D and calcium supplements can improve their nutritional status and 47 (85.45%) of them knew about the sunscreen cream was protecting their skin from the sun rays. Concerning treatment and prevention of SLE, 24 (43.6%) participants believed that SLE is a curable disease.

Assessment of pretest and post-test level of awareness has been mentioned in [Table/Fig-7]. Table shows that there was a significant difference between pretest and post-test on 15th and 30th day awareness scores interpreting effective self-management intervention on awareness. Percentage distribution of pre and post-test awareness showed that majority (80%) of participants had an inadequate level of awareness, and 20% had a moderate in the pretest. After the intervention on the 15th day, majority (61.8%) had a moderate level of awareness, and on the 30th day, majority (94.5%)

Que. No.	Items (SLE awareness assessment questionnaire)	Pretest N (%)	Post-test on 15th day N (%)	Post-test on 30th day N (%)
1.	**Lupus is considered to be a disease of**			
	a. Heart	0	0	0
	b. Kidney	7 (12.72)	1 (1.81)	2 (3.63)
	c. Autoimmune	13 (23.63)	49 (89.09)	53 (96.36)
	d. I don't know	35 (63.63)	5 (9.09)	0
2.	**Exact cause of the lupus factor is**			
	a. Hereditary	26 (42.27)	15 (27.27)	10 (18.18)
	b. Local exposure to infection	0	0	0
	c. Cause is not known	17 (30.90)	31 (56.36)	40 (72.72)
	d. I don't know	12 (21.81)	9 (16.36)	5 (9.09)
3.	**Incidence of SLE is commonly seen in the age group of**			
	a. Above 45 years	02 (3.63)	0	0
	b. 15-44 years	27 (49.09)	54 (98.18)	55 (100)
	c. 10-14 years	04 (7.27)	0	0
	d. I don't know	22 (40)	1 (1.81)	0
4.	**Gender that is commonly affected by SLE is**			
	a. Male	7 (12.72)	1 (1.81)	0
	b. Female	44 (80)	54 (98.18)	55 (100)
	c. Transgender	0	0	0
	d. I don't know	4 (7.27)	0	0
5.	**Risk factor of SLE in postmenopausal women due to decreased hormone level**			
	a. Oestrogen	4 (7.27)	24 (43.63)	43 (78.18)
	b. Progesterone	9 (16.36)	2 (3.63)	3 (5.45)
	c. Serotonin	3 (5.45)	2 (3.63)	1 (1.81)
	d. I don't know	39 (70.90)	27 (49.09)	8 (14.54)
6.	**Changes that take place in the immune system of a person with SLE is**			
	a. Formation of antibodies against the body's cells	30 (54.54)	15 (27.27)	05 (9.09)
	b. Doesn't make enough antibodies to fight of illness	21 (38.18)	35 (63.63)	50 (90.90)
	c. Doesn't make any antibodies at all	1 (1.81)	0	0
	d. I don't know	3 (5.45)	5 (9.09)	0
7.	**Common symptoms of SLE is**			
	a. Fever	30 (54.54)	34 (61.81)	45 (81.81)
	b. Diarrhoea	4 (7.27)	1 (1.81)	3 (5.45)
	c. Vomiting	7 (12.72)	4 (7.27)	7 (12.72)
	d. I don't know	14 (25.45)	16 (29.09)	0
8.	**In SLE butterfly rashes are seen**			
	a. Chest or back	3 (5.45)	1 (1.81)	1 (1.81)
	b. Across the nose and cheeks	23 (41.81)	47 (85.45)	54 (98.18)
	c. Across the pelvis	6 (10.90)	0	0
	d. I don't know	23 (41.81)	7 (12.72)	0
9.	**Lupus flare may be triggered by**			
	a. Increased physical activity	30 (54.54)	19 (34.54)	07 (12.72)
	b. Lack of sleep	14 (25.45)	26 (47.27)	48 (87.27)
	c. Consumption of heavy diet	01 (1.81)	02 (3.63)	0
	d. I don't know	10 (18.18)	08 (14.54)	0
10.	**Organs that are affected by SLE is**			
	a. Skin, liver, stomach	13 (23.63)	10 (18.18)	12 (21.81)
	b. Stomach, kidney, heart	09 (16.36)	11 (20)	10 (18.18)
	c. Heart, lung, kidney	26 (47.27)	29 (52.72)	33 (60)
	d. I don't know	07 (12.72)	05 (9.09)	0

[Table/Fig-4]: Frequency and percentage distribution of pre and post-test answers of the questionnaire.

Que. No.	Items (SLE awareness assessment questionnaire)	Pretest	Post-test on 15th day	Post-test on 30th day
		N (%)	N (%)	N (%)
11.	**Memory loss associated with lupus is named as**			
	a. Lupus brain	14 (25.45)	03 (5.45)	04 (7.27)
	b. Lupus flash	19 (34.54)	06 (10.90)	03 (5.45)
	c. Lupus fog	13 (23.63)	41 (74.54)	47 (85.45)
	d. I don't know	09 (16.36)	05 (9.09)	0
12.	**Involvement of kidney in lupus may lead to**			
	a. Increase in blood sugar	21 (38.18)	15 (27.27)	18 (32.72)
	b. Increase in blood pressure	11 (20)	24 (43.63)	37 (67.27)
	c. Increased fat deposition	03 (5.45)	01 (1.81)	0
	d. I don't know	20 (36.36)	15 (27.27)	0
13.	**Major complications of lupus is**			
	a. Hearing loss	15 (27.27)	06 (10.90)	09 (16.36)
	b. Inflammation of the kidneys	11 (20)	40 (72.72)	44 (80)
	c. Lung cancer	03 (5.45)	01 (1.81)	0
	d. I don't know	26 (47.27)	08 (14.54)	02 (3.63)
14.	**Complication in pregnancy**			
	a. Preterm/Low birth weight baby	10 (18.18)	26 (47.27)	40 (72.72)
	b. Loss of pregnancy	24 (43.63)	20 (36.36)	14 (25.45)
	c. Hydrocephalous baby	02 (3.63)	0	0
	d. I don't know	19 (34.54)	09 (16.36)	01 (1.81)
15.	**Major complications of decreased platelet count is**			
	a. Unwanted bleeding	11 (20)	32 (58.18)	51 (92.72)
	b. Vomiting	05 (9.09)	06 (10.90)	04 (7.27)
	c. Diarrhoea	07 (12.72)	01 (1.81)	0
	d. I don't know	32 (58.18)	16 (29.09)	0
16.	**SLE's effect on blood vessels causes**			
	a. Blood clot	25 (45.45)	18 (32.72)	15 (27.27)
	b. Vasculitis	06 (10.90)	22 (40)	33 (60)
	c. Cellulitis	01 (1.81)	0	0
	d. I don't know	23 (41.81)	15 (27.27)	07 (12.72)
17.	**Major complications of the SLE in the cardiovascular system is**			
	a. Swelling of the heart	11 (20)	39 (70.90)	49 (89.09)
	b. Rheumatic fever	21 (38.18)	08 (14.54)	05 (9.09)
	c. Valvular disorder	06 (10.90)	02 (3.63)	0
	d. I don't know	17 (30.90)	06 (10.90)	01 (1.81)
18.	**Lupus is in active stage when there is decrease in----**			
	a. ESR count	24 (43.63)	17 (30.90)	15 (27.27)
	b. C3, C4 count	07 (12.72)	27 (49.09)	45 (81.81)
	c. WBC count	11 (20)	08 (14.54)	0
	d. I don't know	13 (23.63)	03 (5.45)	0
19.	**Routine lab investigations for confirmation of SLE is**			
	a. ESR, CBC, urine	16 (29.09)	38 (69.09)	51 (92.72)
	b. LFT, CBC, urine	13 (23.63)	02 (3.63)	0
	c. CBC, ESR, SGOT	07 (12.72)	04 (7.27)	03 (5.45)
	d. I don't know	19 (34.54)	11 (20)	01 (1.81)
20.	**95% percentage of SLE diagnosis is confirmed by**			
	a. Urine test	05 (9.09)	01 (1.81)	0
	b. ANA test	21 (38.18)	43 (78.18)	50 (90.90)
	c. CBC test	28 (50.90)	10 (18.18)	05 (9.09)
	d. I don't know	01 (1.81)	0	0

[Table/Fig-5]: Frequency and percentage distribution of pre and post-test answers of the questionnaire.
ESR: Erythrocyte sedimentation rate; C3: Complement 3; C4: Complement 4; WBC: White blood cell; CBC: Complete blood count; SGOT: Serum glutamicoxaloacetic transaminase; ANA test: Antinuclear antibody test

Que. No.	Items (SLE awareness assessment questionnaire)	Pretest	Post-test on 15th day	Post-test on 30th day
		N (%)	N (%)	N (%)
21.	**SLE patients need to consult and get opinion from**			
	a. Oncologist	0	0	0
	b. Podiatrist	0	0	0
	c. Rheumatologist	51 (92.72)	54 (98.18)	55 (100)
	d. I don't know	04 (7.27)	01 (1.81)	0
22.	**Dietary supplement that improves the nutritional status of the SLE patient is**			
	a. Vit D and Calcium	32 (58.18)	50 (90.90)	55 (100)
	b. Vit D and vit A	04 (7.27)	03 (5.45)	0
	c. Vit C and vit E	01 (1.81)	02 (3.63)	0
	d. I don't know	18 (32.72)	0	0
23.	**Complication of SLE can be prevented by**			
	a. Prompt assessment	0	01 (1.81)	0
	b. Early diagnosis	10 (18.18)	07 (12.72)	08 (14.54)
	c. Regular follow-up and treatment	30 (54.54)	31 (56.36)	44 (80)
	d. I don't know	15 (27.27)	16 (29.09)	03 (5.45)
24.	**Management of SLE is based on this concept**			
	a. Curative	24 (43.63)	16 (29.09)	09 (16.36)
	b. Symptomatic	16 (29.09)	30 (54.54)	45 (81.81)
	c. Preventive	03 (5.45)	02 (3.63)	01 (1.81)
	d. I don't know	12 (21.81)	07 (12.72)	0
25.	**SLE patients need to protect their skin from**			
	a. Radiation	07 (12.72)	01 (1.81)	0
	b. X-ray	0	0	0
	c. Sun	47 (85.45)	54 (98.18)	55 (100)
	d. I don't know	01 (1.81)	0	0
26.	**Diet that is preferable for patient with SLE**			
	a. Fast foods	0	0	0
	b. Fruits and vegetables	45 (81.81)	53 (96.36)	55 (100)
	c. Increased amount of meat	03 (5.45)	02 (3.63)	0
	d. I don't know	07 (12.72)	0	0
27.	**The topical application that can be recommended for the SLE patients**			
	a. Sunscreen cream	47 (85.45)	54 (98.18)	54 (98.18)
	b. Ointment	0	01 (1.81)	01 (1.81)
	c. Transdermal patch	0	0	0
	d. I don't know	08 (14.54)	0	0
28.	**Joint pain in SLE can be managed by**			
	a. Warm application	16 (29.09)	10 (18.18)	07 (12.72)
	b. Cold application	08 (14.54)	38 (69.09)	43 (78.18)
	c. Mixed warm and cold applications	28 (50.90)	07 (12.72)	05 (9.09)
	d. I don't know	03 (5.45)	0 (0)	0 (0)
29.	**Life style modification in SLE includes**			
	a. Yoga, regular activity, balanced diet	33 (60)	51 (92.72)	55 (100)
	b. Tai chi, minimal activity, high carbohydrate diet	11 (20)	02 (3.63)	0
	c. Guided imagery, regular activity, high fat diet	03 (5.45)	02 (3.63)	0
	d. I don't know	08 (14.54)	0	0
30.	**Prognosis of lupus is based on**			
	a. Neuron involvement	07 (12.72)	04 (7.27)	05 (9.09)
	b. Organ involvement	17 (30.90)	40 (72.72)	48 (87.27)
	c. Tissue involvement	15 (27.27)	10 (18.18)	02 (3.63)
	d. I don't know	16 (29.09)	01 (1.81)	0

[Table/Fig-6]: Frequency and percentage distribution of pre and post-test answers of the questionnaire.

Level of awareness	Pretest		Post-test				Chi-square and p-value	
			15th day		30th day			
	n	%	n	%	N	%	15th day	30th day
Adequate	0	0	21	38.2	52	94.5	1.69 p=0.04*	0.79 p=0.01**
Moderately adequate	11	20.0	33	60.0	3	5.5		
Inadequate	44	80.0	1	1.8	0	0		

[Table/Fig-7]: Effectiveness of education-based self-management intervention on level of awareness among patients with SLE.
*Significant; **Highly significant, p<0.05 was considered as statistically significant

of them had adequate level of awareness. The calculated Chi-square value on the 15th and 30th days was 1.69, 0.79 and the p-value was 0.04, and 0.01, respectively.

Association of Awareness score among SLE patients with selected demographic and clinical variables is shown in [Table/Fig-8,9]. Chi-square test reveals that there was a significant assosciation found between the residence at the level of p<0.05 with the level of pretest awareness. However, no significant association was found between the pretest level awareness and the selected clinical variables.

Demographic variables	Level of awareness		Chi-square and p-value
	Adequate	Moderately adequate	
	N (%)	N (%)	
Age (in years)			
21-35	38 (73.1)	2 (66.7)	0.25 p=0.89
36-50	12 (23.1)	1 (33.3)	
51-65	2 (3.8)	0	
Gender			
Male	1 (1.9)	1 (33.3)	7.98 p=0.10
Female	51 (98.1)	2 (66.7)	
Residence			
Urban	21 (40.4)	3 (100)	4.09 p=0.04*
Rural	31 (59.6)	0	
Dietary pattern			
Vegetarian	4 (7.7)	0	0.24 p=0.61
Mixed	48 (92.3)	3 (100)	
Deleterious habits			
No	52 (100)	2 (66.7)	17.65 p=0.06
Yes	0	1 (33.3)	

[Table/Fig-8]: Association between the awareness and selected demographic variables.
p<0.05 was considered as statistically significant; *highly significant

Clinical variables	Level of awareness		Chi-square and p-value
	Adequate	Moderately adequate	
	N (%)	N (%)	
Family history			
Yes	3 (5.8)	0	0.18 p=0.84
No	49 (94.2)	3 (100)	
Duration of disease (years)			
≤1 year	26 (50.0)	1 (33.3)	2.12 p=0.83
≤2 years	7 (13.5)	1 (33.3)	
≤3 years	7 (13.5)	0	
≤4 years	1 (1.9)	0	
≤5 years	3 (5.8)	0	
>5 years	8 (15.4)	1 (33.3)	
Co-morbidity condition			
No	33 (63.5)	2 (66.7)	0.01 p=0.70
Yes	19 (36.5)	1 (33.3)	
Medications			
Never	2 (3.8)	0	0.12 p=0.89
Whenever symptoms arises	3 (5.8)	0	
Regular	47 (90.4)	3 (100)	
Alternative treatment			
Homeopathy	2 (3.8)	0	0.12 p=0.72
Nil	50 (96.2)	3 (100)	
Medical follow-up once in			
15 days	23 (44.2)	1 (33.3)	1.00 p=0.64
One Month	21 (40.4)	2 (66.7)	
Three Months	8 (15.4)	0	

[Table/Fig-9]: Association between the awareness and selected clinical variables.

DISCUSSION

The aim of the study was to assess the effect of education-based self-management intervention on awareness among patients with SLE at a tertiary care hospital. The overall awareness in the present study, among the 55 SLE patients, 80% had inadequate level and 20% had moderate level awareness pretest scores. However, in the post-test, scores were improved at an adequate level on the 15th and 30th days (38.2% and 94.5%), respectively. Hence, it was statistically interpreted that post-test knowledge score was higher than the pretest knowledge score at p-value (0.05 and 0.001). The above finding were supported by Elsayed DM and Mesbah SK, where they observed that before education-based intervention, 55% of the participants had poor knowledge, 45% had average knowledge and none of them had good knowledge regarding SLE. After the intervention 95% had good knowledge and 5% had average knowledge [18].

In India, at Chennai, a cross-sectional study was conducted among 116 general public respondents; 62.9% of the respondents knew about SLE and 37.1% of participants did not have any idea about it. The study revealed that most of the people had an awareness of SLE, and majority of them have a basic knowledge about SLE [13].

Another similar study was conducted by Abd-elrehem TA and Mostafa HA, where they found that the overall mean and standard deviation of level of awareness on SLE in pre and post implementation of self-management guidelines was 10.7±3.5 and 15.8±5.6 respectively. There was a statistical significant difference between pre and post mean scores of the total level of awareness at (p>0.05) [19].

Another similar study was conducted at four PHC centers in Riyadh among 400 participants, the results were congruent to our results; 64.7% of the participant were unaware of SLE, while 35.3% were aware [14].

There is no doubt that building awareness of lupus is essential to improve the early diagnosis and treatment of this unpredictable and misunderstood disease and ensure that people with lupus are aware of the support and resources available to help them manage the disease [20]. According to the general awareness items of SLE, the present study found that 63.63% of the participants don't know about the term of SLE. Regarding diagnosis and treatment, majority (50.90%) of participants believed that SLE has been diagnosed/confirmed with a single test and 43.6% of participants believed that SLE is a curable disease.

A study was conducted at the King Faisal University among the 161 participants, the results were congruent to our results, majority 60.9% did not have a clear idea regarding diagnostic, treatment, and complications of SLE. Regarding diagnosis and treatment, 91% believed that SLE was diagnosed with a single test and 65.8% agreed that it was a treatable one [21]. Another study was conducted at the King Saud University among 630 female students, the results were congruent with current study, majority 60% of participants did not previously heard the term of SLE [22].

Self-management is very essential to manage SLE. Concerning self-care measures, the present study found that 85.45% of the patients were knowledgeable regarding photoprotection method (application of sunscreen). A similar study was conducted among 222 patients from Dermatology clinics of University Kebangsaan Malaysia Medical Centre, 88.7% of the patients were knowledgeable regarding photoprotection methods and 89.2% were informed and advised on photoprotection at the time of diagnosis [23].

Most of the participants in the present study were unaware of SLE. This indicates poor knowledge about the disease. According to the association between knowledge and demographic variables, present study found that the adequate awareness level was found among rural participants than urban participants (59.6% vs 40.4%) is statistically significant ($p<0.05$). There were no statistically significant association between the awareness and selected clinical variables of patients with SLE (p-value >0.05). The findings of this study were in contrast to the study conducted at Egypt which showed that urban people had the highest knowledge mean scores compared to rural and slum peoples (34.90 vs 34.01 vs 25.81) ($p<0.001$) [24].

Future studies are recommended which should include a cross-sectional study to identify the risk factors of SLE. Further research also can includes a comparative studies among patients with SLE and other chronic diseases and an experimental study on coping strategies and symptom management of SLE. It might help to identify the risk factors and increase coping level to managing the disease activity.

Limitation(s)

The major limitation of the present study is that it was a single hospital-based study and therefore, it may not be possible to generalise the results.

CONCLUSION(S)

The present study found that education-based self-management intervention can be one of the best options for creating awareness among patients with SLE. The study concluded that almost 80% of the patients in pretest had inadequate knowledge whereas after the Education-based self-management intervention, 94.5% had gained adequate knowledge. The participants gained adequate level of awareness through education-based self-management intervention and it will help patients in management of their symptoms independently.

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