

Self-Care Management Program: Effect on Awareness of Adolescents Suffering from Systemic Lupus Erythematosus

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Abstract

Background: Systemic lupus erythematosus is an autoimmune and inflammatory disease with diverse multisystem involvement. It is imperative for adolescents to strengthen their education in order to have adequate self-care. **Aim:** This study aimed to evaluate the effect of self-care management program on awareness of adolescents suffering from systemic lupus erythematosus. **Design:** This study applied a quasi-experimental design. **Setting:** The study was undertaken at Inpatient Pediatric Department, Rheumatology outpatient clinics of Beni-Suef University Hospitals. **Sample:** A convenience sample of fifty adolescents. **Data collection tools:** Three instruments were utilized. **I:** A Structured Interviewing Questionnaire incorporating three sections: personal characteristics, medical data and knowledge assessment of studied adolescents **II:** Adolescents' reported practices checklist **III:** Adolescents' attitude likert scale. **Results:** Following application of the self-care management program, majority of the adolescents displayed satisfactory knowledge, competent practice, a positive attitude. A highly notable significance was exhibited between pre and post self-care management program regarding all variables. **Conclusion:** The self-care management program positively affects awareness of adolescents with systemic lupus erythematosus. **Recommendation:** On-going implementation of specialized self-care training programs in systemic lupus erythematosus to enrich adolescents' awareness.

Keywords: Self-Care Management Program, Awareness, Adolescents, Systemic Lupus Erythematosus.

Introduction

Systemic lupus erythematosus (SLE) is an inflammatory and autoimmune condition characterized by different multisystem involvement and a chronic course with unpredictable flares. Although SLE can potentially affect every organ system, it most commonly influences the skin, joints, central nervous system, blood cells, and kidneys. Childhood-onset SLE, which occurs before the age of 18, represents 10-20% of all cases and is known to be more severe than adult-onset SLE, demonstrating a more aggressive onset and many disease flares (Pennesi & Benvenuto, 2023).

The exact cause of SLE remains unknown, but several risk factors have been identified. Genetic influence plays a major role in SLE, with a high incidence observed among family members. Environmental factors, such as sun exposure and sunburn, also donate to the

occurrence of SLE. Hormones are implicated in its etiology, and infectious agents may trigger immune hyperactivity. Additionally, lupus can be made by certain medications, including procainamide, hydralazine, and anti-seizure drugs (Hockenberry and Wilson, 2019).

Clinical features and organ contribution in SLE can vary based on age, gender, and race. Typically, children with SLE present with more severe disease at onset, suffering higher rates of organ involvement and a more aggressive clinical features compared to adults with SLE. Initially, 40-90% of children exhibit constitutional symptoms such as fever, fatigue, or weight loss. Renal involvement is seen in 20-82%, musculoskeletal symptoms in 20-74%, malar rash in 22-74%, lymphadenopathy in 15-45%, and visceromegaly in 15-74% (Valenzuela-Almada, 2023).

The initial SLE symptoms frequently observed include prolonged fever and general malaise, often accompanied by multisystem involvement. Adolescents frequently report a history of fatigue, rash, joint pain, and fever. Additionally, various acute manifestations may be observed such as memory loss, psychosis, hemoptysis, transverse myelitis, lower extremity edema, painful mouth sores, and headaches (Fanouriakis, Tziolos, Bertias, & Boumpas, 2021).

The initial laboratory testing should include a complete blood count (CBC) along with platelet and reticulocyte counts, and a comprehensive chemistry evaluation to assess electrolytes, plus liver, and kidney function, urine analysis, and measurement of acute phase reactants such as erythrocyte sedimentation rate (ESR) or C-reactive protein (CRP). Investigative tests should include antinuclear antibody (ANA), anti-double-stranded DNA, anti-Smith antibody, lupus anticoagulant, and antiphospholipid antibody panel (Lam, Abu Brown, & Sharma, 2023).

Educating adolescents about avoiding triggers for disease flares, such as exposure to sunlight, certain drug treatments, stress, and illness is essential. It's also important to inform the affected adolescents and their family about the potential side effects of SLE medications. For instance, corticosteroids can lead to cushingoid appearance, weight gain, hypertension, and a reduced immune response to infections. Nonsteroidal anti-inflammatory drugs (NSAIDs) can cause gastric distress. Antimalarial drugs carry a risk of retinopathy and blindness. Additionally, sulfa drugs should be avoided as they can increase photosensitivity. Ensuring that both the child and family are well-informed about these aspects can greatly aid in the management of the condition (Hockenberry & Wilson, 2019).

Adolescents with SLE need specific dietary instructions: a low-salt diet for hypertension and nephritis, low-fat foods

for dyslipidemia, and calcium and vitamin D-rich diets due to the increased risk of osteoporosis from corticosteroids. Parents must also understand the importance of applying sunscreen to avoid rashes caused by photosensitivity and protecting the child from cold weather by using warm clothing like socks and gloves during winter. Educating caregivers on infection prevention is crucial, emphasizing the significance of hand washing and implementing infection control measures at home. Prophylactic antibiotics may be necessary for dental and surgical procedures to prevent infections. Additionally, it's vital to stress the importance of vaccinations, including influenza, pneumococcal, and meningococcal vaccines, to protect the child's health (Kyle & Carman, 2017).

Significance of the study:

Systemic lupus erythematosus (SLE) is a severe and life-threatening illness that affects various body systems, leading to severe complications in the kidneys, heart, central nervous system, blood vessels, joints, and skin. As a chronic illness, SLE requires comprehensive health education as a vital component of its management. Effective health teaching includes instructing caregivers on how to navigate daily life with the disease, ensuring they are equipped to handle the various challenges that come with managing such a complex condition. This education is essential for improving the quality of life for both patients and their families (Burnham, Cecere, Ukaigwe, & Knight, 2021).

It's indeed essential to study and analyze the knowledge and practices of adolescents with SLE in Egypt, particularly considering the significant number of cases reported by Statistical Hospital in Pediatric affiliated to Ain Shams University as there were 150 cases between 5-18 years old with SLE (follow up) (Unpublished Statistical Records at Ain Shams University Hospital, 2020). Therefore, it is crucial to study and analyze

adolescents' awareness regarding SLE that affect different aspects of their life and health status.

Aim of the study

This study aimed to evaluate the effect of self-care management program on awareness of adolescents suffering from systemic lupus erythematosus, through the following:

1-Assess knowledge for adolescent with SLE.

2-Assess reported practices for adolescent suffering from SLE.

3-Design and implement program to train adolescents suffering from SLE.

4-Evaluate the effect of training program on adolescents' knowledge, practice and attitude regarding SLE.

Research hypotheses

To achieve the aim of the current study, the following research hypotheses will be postulated:

Hypothesis one: following self-care management program, adolescents' knowledge will be notably higher than it was before the program.

Hypothesis two: following self-care management program, adolescents' practice will be notably higher than it was before the program.

Hypothesis three: following self-care management program, adolescents' attitude will be notably higher than it was before the program.

Operational definition:

Awareness indicates the degree to which individuals have knowledge about a particular issue, exhibit positive attitudes towards it, and engage in practices that reflect this knowledge and attitude (World Health Organization, 2008).

Subjects and Method

Design: This study employed a pre, post, one-group quasi-experimental design.

Setting: The research was conducted at the Inpatient Pediatric Department and the Rheumatology outpatient clinics of Beni-Suef University Hospitals. Located in

Beni-Suef city, Beni-Suef University Hospital is the only facility in the governorate that provides care for children with SLE and serves all districts. The pediatric department, situated on the fourth floor, consists of three rooms: the first with 10 beds, the second with 6 beds, and the third also with 6 beds. The Rheumatology outpatient clinics are located on the second floor of the outpatient clinic buildings within Beni-Suef University Hospitals.

Research Subject:

A convenience sample of 50 adolescents with SLE, who attended the aforementioned settings during the study period, were included. These participants were willing to take part in the study and had not previously attended any educational program about SLE. They were selected based on the following criteria:

Inclusion of criteria:

- Adolescents with SLE, aged 10 years and older.
- Adolescents who are alert and able to communicate.
- Adolescents willing to participate in the study.

Exclusion criteria:

- Adolescents with other chronic conditions.
- Adolescents with any psychological disorders.

Tools of Data Collection:

Data was gathered by using the following three tools:

Tool (I): A Structured Interviewing Questionnaire:

It was designed by the researchers following a review of related literature. It was written in clear Arabic language and consists of three parts:

Part I: Personal characteristic of the studied adolescents such as age, gender, education, and ranking.

Part II: Medical data of studied adolescents such as age of the child at diagnosis, method of diagnosing lupus, number and causes of previous

hospitalization, duration of disease, duration of follow up, child weight and height. The researchers collected medical data of studied adolescents from the medical record.

Part III: Adolescents' knowledge assessment:

It was adapted from Abdel Aziz, Ismail, Sabaq, and Abdel-Salam (2022) to assess adolescents' knowledge regarding SLE. It was used twice, both before and after the implementation of the educational program, and was formatted as multiple-choice questions that included the following:

- Ten multiple choice questions (MCQs) assessing adolescents' knowledge regarding SLE: Definition, most vulnerable group, causes, risk factors, types, clinical manifestations, investigations, complications, barriers which prevent the child to take medications regularly and treatment of systemic lupus.
- Twelve MCQs assessing adolescents' knowledge regarding medications: Role of steroid in treatment of systemic lupus, side effects of steroids, measures to prevent side effects from steroid problems, method of withdrawing steroid dose from the child's body, complications that occur if steroid stopped suddenly, role of NSAIDs in treatment of lupus, side effects of NSAIDs, measures to prevent side effects of NSAIDs, role of immunosuppressant drug in treatment of lupus, side effects of immunosuppressant drug, role of antimalarial drug in treatment of lupus and side effects of antimalarial drug.
- Three MCQs assessing adolescents' knowledge about diet with SLE: Dietary program that must be followed for adolescents with SLE, types of foods that the child should avoid and problem associated with non-compliance to dietary program.
- Four MCQs related to role of adolescents regarding SLE: Adolescent's role in protecting from sunlight, a adolescent's

role in preventing infection, a adolescent's role in prevent hair loss and a adolescent's role to adapt with SLE

- One question regarding source of a adolescent's knowledge about SLE.

Adolescents' knowledge was scored as following:

Each answer was divided into three score levels: a score of 3 for a complete and/or correct answer, 2 for an incomplete or partially correct answer, and 1 for an incorrect or "don't know" answer. The total knowledge scores ranged from (30- 90) points. In this respect the level of adolescents' knowledge were categorized as the following: An unsatisfactory level of knowledge ($< 60\%$) was ranged from (30 >54) points while satisfactory level of knowledge ($\geq 60\%$) was ranged from (54 to 90) points.

Tool (II): adolescents' reported practices checklist:

It was adopted from Bowden and Greenberg (2018) to evaluate the adolescents' reported practices regarding SLE care. It was used twice, both before and after educational program implementation. It contained of 61 items grouped under eight domains that included care given during fever (9 items), care given during vomiting (8 items), care given during swelling of extremities (8 items), care given during pain (6 items), care given during stomatitis (8 items), skin care (7 items), oral drug administration (7 items) and topical drug administration (8 items).

Adolescents' reported practices were scored as following:

The scoring system for each step was divided into two score levels, which are: done was scored as (2) and not done scored as (1). The total scores were ranged from (30 to 122) points. Accordingly, the level of a adolescents' reported practices were categorized as the following, incompetent level of practices ($< 60\%$) was ranged from (30 >72) points and competent level of practices ($\geq 60\%$) was ranged from (72 to 122) points.

Tool (III): Adolescents' attitude likert scale:

It was adopted from Burckhardt and Bjelle, (1996) to assess the adolescents attitude regarding SLE. It was used twice, both before and after educational program implementation. It composed of 15 statements with 5 point Likert scale varying from 1 strongly disagree to 5 strongly agree.

adolescents' attitude was scored as the following:

The adolescents response was classified into five point likert scale, strongly disagree (1), disagree (2), neutral (3), agree (4), strongly agree (5) for 6 of the statements (1, 4, 7, 10, 12 and 14). Where scoring was reversed for 9 of the statements (2, 3, 5, 6, 8, 9, 11, 13 and 15) as the following strongly disagree (5), disagree (4), neutral (3), agree (2), strongly agree (1). Total scores were ranged from (0- 75) points, so the level of adolescents' attitude were categorized as the following, negative attitude (< 60 %) was ranged from (0 > 45) points and positive attitude ($\geq 60\%$) was ranged from (45 to 75) points.

Validity and reliability

The data collection tools were assessed for their content validity by a panel of three pediatric nursing experts, who were selected to evaluate the clarity, relevance, comprehensiveness, understanding and applicability of the tools. The opinion was elicited regarding the layout, format and sequence of the questions and all of their remarks were taken into account and the tools were regarded as a valid from the experts' point of view. Additionally, Cronbach's alpha was used to assess the reliability of the instrument is. The alpha test was (0.801) for structured interviewing questionnaire, (0.917) for a dolescents' reported practices and (0.81) for adolescents' attitude likert scale. These results indicate a high level of reliability for the study tools.

Ethical consideration

The research proposal was approved by the Research Ethics Committee of the Faculty of Medicine at Beni-Suef University (Approval No: 02012024). Additionally, the participating hospital granted official permission for the study. Each adolescent provided verbal consent, and their confidentiality and anonymity were ensured. Participants were informed that they could choose not to participate or withdraw from the study at any stage without consequence.

Fieldwork:

This study was conducted over a six months period, from the beginning of January 2023 to the end of June 2024. Completing the questionnaire took about 40- 50 minutes. The researchers visited the aforementioned settings twice a week on Tuesday and Wednesday from 9:00 a.m. to 2:00 p.m.

Pilot-test

A Pilot study was conducted to evaluate the applicability and clearness of the used tools and spot any barriers and difficulties during data collection. It was done on 10% of the total sample; (5) adolescents who have SLE were excluded from the study to reduce potential sample bias. Based on the analysis of the pilot study, necessary modifications were made, and the final version of the tools was developed.

Educational intervention

The actual study was split into four stages:

1st stage: Assessment

It aimed at assessing adolescents' knowledge, reported practice, and attitude. This was conducted through interviews using the aforementioned questionnaire. The researchers conducted interviews with adolescents at the study settings. To facilitate the data collection process, the purpose and nature of the study were clearly explained to the adolescents. The time required for tools lasted around 40-50 minutes. This stage was extended for one month.

2nd stage: Planning

In developing the educational program, the goals, priorities, and expected outcomes were established based on the needs identified during the assessment phase for adolescents with SLE. Educational materials, including printed resources and PowerPoint presentations, were created for the program. The teaching strategies incorporated a mix of theory and practical lectures, case studies, self-directed learning, discussions, and sharing real-world experiences. The development of these educational materials took one month to complete.

3rd stage: Implementation

The 50 adolescents in the study were divided into five groups, each consisting of ten adolescents. The implementation stage was completed through eight sessions: four theoretical sessions and four practical sessions, conducted over a period of two days per week, with two sessions held each day. The duration of each session ranging from 30 to 60 minutes. This stage took three months to finish this step. These sessions were replicated for every group. The sessions were applied face-to-face in the lecture.

4th stage: Evaluation

Once the educational intervention was finished, evaluation was immediately performed in a post-test similar to the pretest questionnaire format. This stage took one month.

Statistical analysis

The recorded data were analyzed using the statistical package for social sciences (SPSS), version (28). Quantitative data were indicated as mean \pm standard deviation (SD). Qualitative data were measured using frequencies and percentages. The following statistical tests were done:

- The Chi-square test was used to compare between qualitative data .
- Pearson's correlation coefficient (r) test was employed to evaluate the degree of association between two sets of variables.
- Cronbach's Alpha: Reliability statistics was used to assessed using Cronbach's Alpha test

The confidence interval was set to 95% and the margin of error accepted was set to 5%. So, the p-value was regarded significant as the following:

- P-value \leq 0.001 was categorized highly significant.
- P-value \leq 0.05 was categorized significant.
- P-value $>$ 0.05 was categorized insignificant.

Results

Table (1): Distribution of the studied adolescents according to their personal characteristic (n=50).

Personal characteristic	No.	%
Age/ years		
10-<12	18	36.0
12-<14	12	24.0
≥ 14	20	40.0
Mean ±SD	12.60±1.895	
Gender		
Male	19	38.0
Female	31	62.0
Educational level		
Illiterates	3	6.0
Read and write	4	8.0
Primary school	18	36.0
Preparatory school	9	18.0
Secondary school	16	32.0
Ranking of the child		
First	12	24.0
Second	13	26.0
Third	21	42.0
Fourth	4	8.0

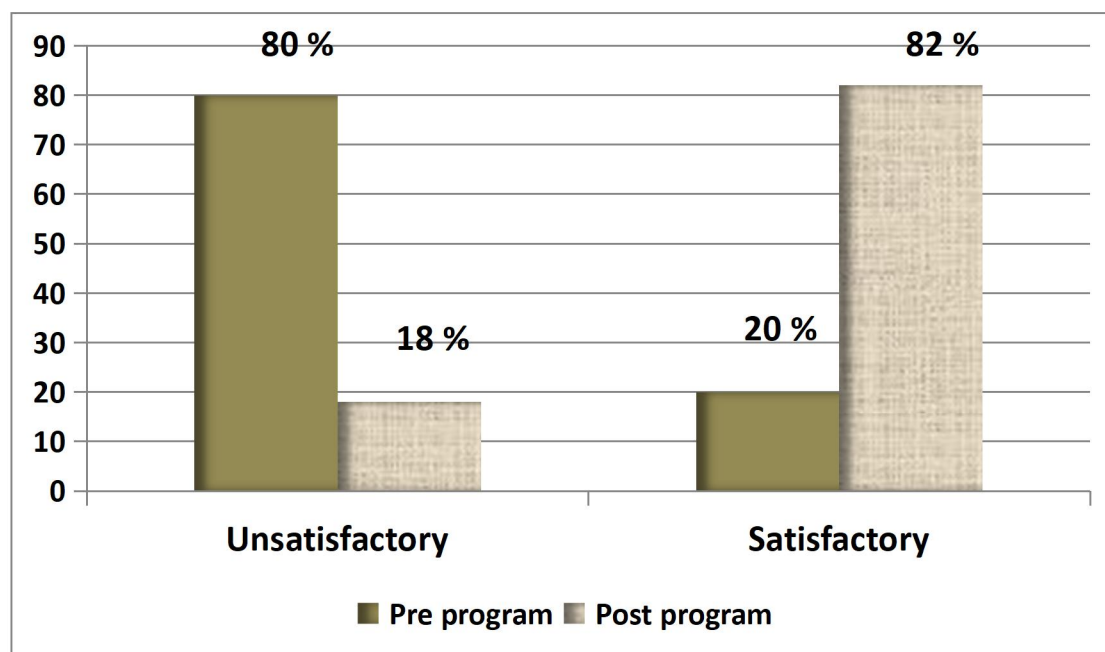
Table (2): Distribution of the studied adolescents according to their medical history (n=50).

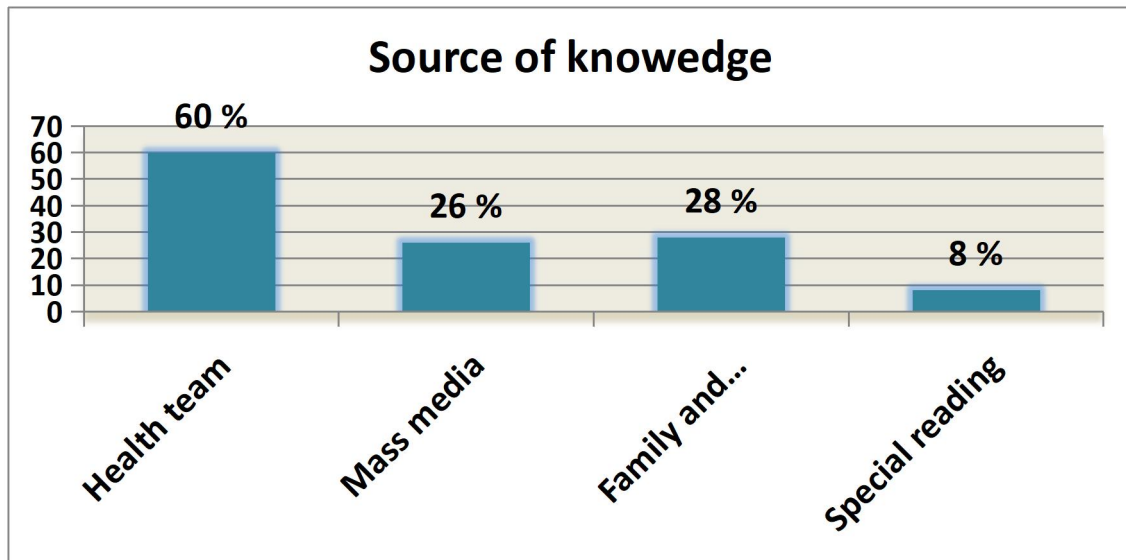
Medical history	No.	%
Age of the child at diagnosis/ years		
1-<6	12	24.0
6-<12	16	32.0
12-<18	22	44.0
Method of diagnosing SLE		
Routine examination	41	82.0
Clinical manifestations	9	18.0
Number of pervious hospitalization		
Once	8	16.0
Twice	12	24.0
Three	7	14.0
More than three	23	46.0
Causes of pervious hospitalization		
Complication of nervous system	2	4.0
Complication of respiratory system	8	16.0
Complication of digestive system	6	12.0
Complication of urinary system	11	22.0
Complication of bone and joint	8	16.0
Complication of hematological system	6	12.0
Complication of skin	6	12.0
Complication of cardiovascular system	3	6.0
Duration of the disease		
<6 month	14	28.0
6<12month	18	36.0
12<24 month	10	20.0
>24month	8	16.0
Duration of follow up		
Every month	28	56.0
Every 3 month	11	22.0
Every 6 month	7	14.0
Irregular follow up	4	8.0
Child weight		
Normal weight	8	16.0
Underweight	17	34.0
Overweight	25	50.0
Child height		
Normal height	15	30.0
Less than normal	31	62.0
More than normal	4	8.0

Table (3): Distribution of the studied adolescents regarding their knowledge about systemic lupus erythematosus pre and post self-care management program.

Items	Pre				Post				Chi-square	
	Unsatisfactory		Satisfactory		Unsatisfactory		Satisfactory		X ²	p-value
	No.	%	No.	%	No.	%	No.	%		
Systemic lupus erythematosus	38	76.0	12	24.0	7	14.0	43	86.0	25.775	0.000**
Medications of SLE	39	78.0	11	22.0	9	18.0	41	82.0	38.9140	0.000**
Dietary program for SLE adolescents	42	84.0	8	16.0	7	14.0	43	86.0	42.733	0.000**
Adolescents' role	41	82.0	9	18.0	8	16.0	42	84.0	6.607	0.026*

Chi-square test, ** highly statistically significance $p \leq 0.001$, * statistically significance $p \leq 0.05$

**Figure (1):** Distribution of the studied adolescents regarding their total level of knowledge about systemic lupus erythematosus pre and post self-care management program.



*Percentage not mutually exclusive

Figure (2): Distribution of the studied adolescents regarding their source of knowledge.

Table (4): Distribution of the studied adolescents regarding their reported practices toward systemic lupus erythematosus pre and post self-care management program (n=50).

Items	Pre				Post				Chi-square	
	Incompetent		Competent		Incompetent		Competent		X ²	p-value
	No.	%	No.	%	No.	%	No.	%		
Fever	31	62.0	19	38.0	6	12.0	44	88.0	11.124	0.002*
Vomiting	32	64.0	18	36.0	8	16.0	42	84.0	6.287	0.019*
Swelling of extremities	33	66.0	17	34.0	8	16.0	42	84.0	18.487	0.000**
Pain	32	64.0	18	36.0	7	14.0	43	86.0	14.470	0.000**
Stomatitis	35	70.0	15	30.0	9	18.0	41	82.0	18.125	0.000**
Skin care	32	64.0	18	36.0	6	12.0	44	88.0	12.121	0.001**
Oral medication	36	72.0	14	28.0	7	14.0	43	86.0	13.449	0.001**
Topical medication	34	68.0	16	32.0	9	18.0	41	82.0	16.324	0.000**
Total	32	64.0	18	36.0	7	14.0	43	86.0	14.470	0.000**

Chi-square test, ** highly statistically significance $p \leq 0.001$, * statistically significance $p \leq 0.05$

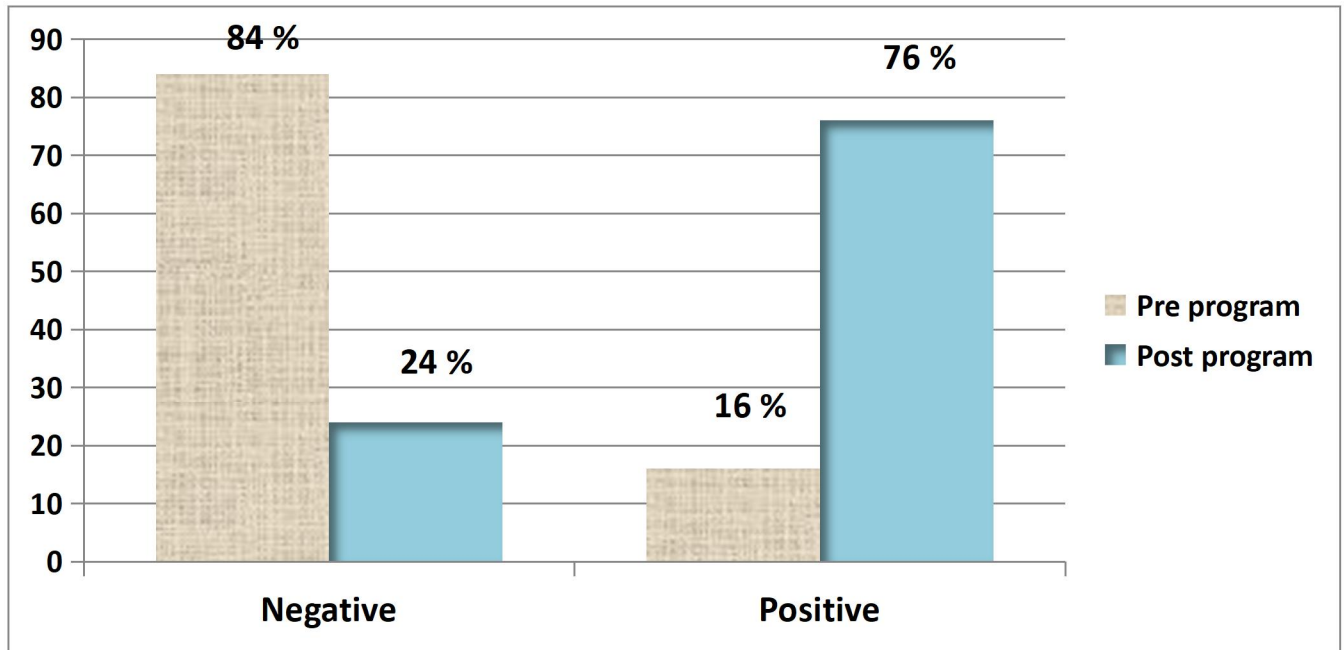


Figure (3): Percentage distribution of the studied adolescents' total attitude regarding systemic lupus erythematosus pre and post self-care management program.

Table (5): Statistically relation between total knowledge and personal characteristics among the studied adolescents pre and post self-care management program (n=50).

Items	Pre				Chi-square		Post				Chi-square	
	Unsatisfactory (n=40)		Satisfactory (n=10)		X ²	p-value	Unsatisfactory (n=9)		Satisfactory (n=41)		X ²	p-value
	No.	%	No.	%			No.	%	No.	%		
Age/ years												
10-<12	18	45.0	0	0.0	18.750	0.000**	0	0.0	18	43.9	16.463	0.000**
12-<14	12	30.0	0	0.0			0	0.0	12	29.3		
≥ 14	10	25.0	10	100.0			9	100.0	11	26.8		
Gender												
Male	13	32.5	6	60.0	2.568	0.109	6	66.7	13	31.7	3.828	0.059
Female	27	67.5	4	40.0			3	33.3	28	68.3		
Educational level												
Illiterates	3	7.5	0	0.0	5.425	0.246	0	0.0	3	7.3	4.645	0.326
Read and write	3	7.5	1	10.0			1	11.1	3	7.3		
Primary school	17	42.5	1	10.0			1	11.1	17	41.5		
Preparatory school	6	15.0	3	30.0			3	33.3	6	14.6		
Secondary school	11	27.5	5	50.0			4	44.4	12	29.3		
Ranking of the child												
First	10	25.0	2	20.0	4.716	0.194	2	22.2	10	24.4	4.039	0.257
Second	29	22.5	4	40.0			3	33.3	10	24.4		
Third	19	47.5	2	20.0			2	22.2	19	46.3		
Fourth	2	5.0	2	20.0			2	22.2	2	4.9		

Chi-square test, * * highly statistically significance $p \leq 0.001$, * statistically significance $p \leq 0.05$, No statistically significance $p > 0.05$

Table (6): Statistically relation between total reported practices and personal characteristics among the studied adolescents pre and post self-care management program (n=50).

Items	Pre				Chi-square		Post				Chi-square	
	Incompetent (n=32)		Competent (n=18)		X ²	p-value	Incompetent (n=7)		Competent (n=43)		X ²	p-value
	No.	%	No.	%			No.	%	No.	%		
Age/ years												
10-<12	18	56.3	0	0.0	42.188	0.000**	0	0.0	18	41.9	12.209	0.002*
12-<14	12	37.5	0	0.0			0	0.0	12	27.9		
≥ 14	2	6.3	18	100.0			7	100.0	13	30.2		
Gender												
Male	9	28.1	10	55.6	3.679	0.054	5	71.4	14	32.6	3.861	0.063
Female	23	71.9	8	44.4			2	28.6	29	67.4		
Educational level												
Illiterates	3	9.4	0	0.0	19.980	0.001**	0	0.0	3	7.0	4.780	0.311
Read and write	3	9.4	1	5.6			1	14.3	3	7.0		
Primary school	17	53.1	1	5.6			1	14.3	17	39.5		
Preparatory school	5	15.6	4	22.2			3	42.9	6	14.0		
Secondary school	4	12.5	12	66.7			2	28.6	14	32.6		
Ranking of the child												
First	6	18.8	6	33.3	2.018	0.569	2	28.6	10	23.3	0.843	0.839
Second	9	28.1	4	22.2			2	28.6	11	25.6		
Third	15	46.9	6	33.3			2	28.6	19	44.2		
Fourth	2	6.3	2	11.1			1	14.3	9	7.0		

Chi-square test, ** highly statistically significance $p \leq 0.001$, * statistically significance $p \leq 0.05$, No statistically significance $p > 0.05$

Table (7): Statistically relation between total attitude and personal characteristics among the studied adolescents pre and post self-care management program (n=50).

Items	Pre				Chi-square		Post				Chi-square	
	Negative (n=42)		Positive (n=8)		X ²	p-value	Negative (n=12)		Positive (n=38)		X ²	p-value
	No.	%	No.	%			No.	%	No.	%		
Age/ years												
10-<12	18	42.9	0	0.0	14.286	0.001*	1	8.3	17	44.7	17.684	0.000*
12-<14	12	28.6	0	0.0			0	0.0	12	31.6		
≥ 14	12	28.6	8	100.0			11	91.7	9	23.7		
Gender												
Male	13	31.0	6	75.0	5.534	0.027*	8	66.7	11	28.9	5.507	0.023*
Female	29	69.0	2	25.0			4	33.3	27	71.1		
Educational level												
Illiterates	3	7.1	0	0.0	5.202	0.267	0	0.0	3	7.9	7.816	0.099
Read and write	3	7.1	1	12.5			2	16.7	2	5.3		
Primary school	17	40.5	1	12.5			1	8.3	17	44.7		
Preparatory school	8	19.0	1	12.5			3	25.0	6	15.8		
Secondary school	11	26.2	5	62.5			6	50.0	10	26.3		
Ranking of the child												
First	9	21.4	3	37.5	1.623	0.654	3	25.0	9	23.7	2.902	0.407
Second	11	26.2	2	25.0			4	33.3	9	23.7		
Third	19	45.2	2	25.0			3	25.0	18	47.4		
Fourth	3	7.1	1	12.5			2	16.7	2	5.3		

Chi-square test, ** highly statistically significance $p \leq 0.001$, * statistically significance $p \leq 0.05$, No statistically significance $p > 0.05$

Table (8): Correlation between total knowledge, reported practices and attitude among the studied adolescents pre and post self-care management program.

Variables		Pre- program			Post-program		
		Knowledge	Reported practices	Attitude	Knowledge	Reported practices	Attitude
Knowledge	r	-	0.667	0.736	-	0.861	0.834
	p- value	-	0.000**	0.000**	-	0.000**	0.000**
Reported practices	r	0.667	-	0.582	0.861	-	0.718
	p- value	0.000**	-	0.000**	0.000**	-	0.000**
Attitude	r	0.736	0.582	-	0.834	0.718	-
	p- value	0.000**	0.000**	-	0.000**	0.000**	-

Pearson Correlation Coefficient, ** Highly statistically significance $p \leq 0.001$

Table (1) reveals that, with an average age of 12.60 ± 1.895 , two-fifths (40%) of the adolescents studied were older than 14 years. Among the studied adolescents, nearly two-thirds (62%) were female. Beyond that, over one-third (36%, 42 % respectively) of the adolescents studied were in primary school and classified as third in sequence among their siblings.

Table (2) exhibited that 44% of the study's adolescents were diagnosed between the ages of 12 and 18 years. Eighty-two percent were uncovered by routine examination. Concerning prior hospital stays, 46% had over three hospital times. Urinary complications comprised more than one-fifth (22%) of the reasons behind these hospital stays. In relation to the duration of SLE, 36% revealed a six to less than twelve months period of having the condition. Beyond this, over fifty percent (56%) of the adolescents reported attending monthly periodic follow-ups. Additionally to this point, nearly two-thirds of the adolescents were shorter than average in height, and half were overweight.

Systemic lupus erythematosus, SLE medication, and dietary programs for adolescents with SLE are among the topics for which **Table 3** demonstrates a highly notable improvement in post-program knowledge regarding SLE, medications used, and SLE dietary program when compared with prior to program knowledge ($P = 0.000$). Furthermore, post-program knowledge regarding adolescents' role increased significantly ($P = 0.026$).

Figure 1 exhibits that 80% of the adolescents studied had unsatisfactory knowledge pre-program, whereas 82% demonstrated satisfactory knowledge after the self-care program. With a p-value of 0.000, the improvement in post-test scores over pre-program scores was highly statistically significant.

Figure 2 portrays that 60% of the studied adolescents obtained their

information about SLE from healthcare professionals team.

Table 4 summarizes that 64% of the adolescents exhibited incompetent practices before the program, while 86% displayed competent practices after the intervention. The enhancement in post program results compared to pre-program was highly significant, with a p-value of 0.000

Figure 3 indicates that 84% of the adolescents had a negative attitude toward SLE prior to the SLE self-care management program, whereas 76% showed a positive attitude following the program. With a p-value of 0.000, the change in post-test scores compared to pre-program scores was highly significant.

Table 5 shows a highly significant relation between adolescents' knowledge and age in pre-program and post-program, with $P = 0.000$.

Table 6 demonstrates that, with $P = 0.000$ and 0.002 respectively, the relationship between reported practice and age was highly significant before the program and remained significant after. Additionally, a highly significant relationship ($P = 0.001$) between pre-program educational level and reported practice was pointed out.

Table 7 reveals a highly significant relation between adolescents' attitude and age in pre-program and post-program, with $P = 0.001$, and 0.000 respectively. A significant relation was found between attitude and gender in pre-program and post-program, with $P = 0.027$ and 0.023 accordingly.

Table (8) reveals a highly statistically notable positive correlation between adolescents' knowledge and both practice and attitude in both pre-program and post program at $P = 0.000$. Regarding correlation between reported practice and attitude it was positively highly significant in pre and post self-care program at $P = 0.000$.

Discussion

Multiple organs and tissues may be severely affected by SLE, a chronic multisystemic disease marked by recurrent episodes of exacerbation and remission. The condition usually affects the nervous system, kidneys, joints, and skin. It entails the production of autoantibodies, which aid in the formation of immune complexes. When these complexes build up in blood vessels, they trigger intense inflammatory reactions that may harm different organ systems (Accapezzato et al., 2023). This study's aim was to evaluate self-care management program: effect on awareness of adolescents suffering from SLE.

Two-fifths of the adolescents examined in this study were older than 14 years old. According to Battran, Abd El Monem, & Ismail's (2022) and Hossny, Youssef, Radwan, and Al-Ashkar (2022) studies, the children's ages ranged from 12 to 18. According to the researchers, this might be because puberty and hormonal changes precipitate SLE to peak in adolescence.

Regarding gender, around two-thirds of the studied adolescents were female according to the present study. This current study's result match those of Faheim, Hegazy, Ismail, and Mohammed (2023), who showed that the predominant gender among the studied children was female. According to the researchers, this finding supported the scientific review that found that females are at a greater risk of developing SLE than males because female hormones play a significant role in enhancing susceptibility to the disease.

The current findings revealed that over one-third of the participants were in primary school, which contrasts significantly with Elsayed and Mesbah (2018), who observed that more than half of their patients had achieved secondary education. This difference may stem from several factors, including differences in sample populations, or regional educational opportunities. Moreover, this discrepancy emphasizes the importance of

considering multiple perspectives when evaluating the educational backgrounds of patients to gain a more comprehensive understanding of the factors influencing their educational attainment.

As evidenced in the current results, more than one-third of adolescents were classified as third in sequence among their siblings. This exactly aligns with the results of Faheim et al. (2023). This consistency suggests a recurring pattern that might have implications for family dynamics and the impact of birth order on adolescents' health education and overall well-being.

The present study findings represented more than half of the adolescents attending monthly periodic follow-up. The result mentioned is in line with the study done by Costagliola, Mosca, Migliorini, and Consolini (2018), which revealed that the majority of the studied children did follow up consistently every month. Taking into account the unpredictable nature of SLE, with recurrent periods of remission and flare-ups, regular follow-up is a necessity to prevent manage complications and to quickly address any changes in the condition. However, this finding stands in contrast to the results of Elsayed and Mesbah (2018), who reported that nearly one-third of their patients sought follow-ups biannually. This discrepancy highlights the variability in follow-up practices and suggests that more frequent follow-ups might be more common or recommended.

The study conducted also revealed that half of the adolescents were overweight. The results of Souza et al. (2021), which showed that over half of the study participants were overweight or obese, are consistent with this finding. This alignment highlights the pervasive issue of weight management in adolescents with SLE, likely influenced by factors such as corticosteroid treatment, reduced physical activity due to fatigue or joint pain, and possible dietary changes.

Addressing these contributing factors plus tailored interventions is essential for improving overall health outcomes in this population.

On investigating height of studied adolescents, less than two-thirds of the adolescents were shorter than average in height. This finding is in stark contrast with results of Battran et al. (2022) who discovered that nearly three-quarters of children were of normal height. This striking discrepancy might indicate differences in the sample populations or the impact of various genetic or environmental variables.

Regarding the disease duration, over one-third of the studied adolescents reported having it for six to twelve months. This contrasts with findings by Battran et al. (2022), who reported that almost all their study participants had been living with the disease for one year or more. This variation might reflect differences in sample characteristics or healthcare access.

Concerning source of adolescents' knowledge, the current study showed that three fifths of them gained their knowledge from health team. This result contradicts with the result of Sedrak, Mohamad, Abo El-Noor, and Abd-Elall (2020) reporting friends plus mass media were the sources of information about SLE. Also, Radhwi et al. (2023) found that the most source of literacy about SLE reported was the Internet. This difference between our study and other studies might indicate improvements in healthcare communication strategies, emphasizing the role of health teams in providing reliable information.

The current study demonstrated a notable significant improvement in adolescents' knowledge about SLE after the program compared to their pre-program understanding. This agrees with results of Elsayed and Mesbah (2018). These results stress the effectiveness of structured educational programs in enhancing awareness regarding SLE among adolescents. The success of the

program highlights the necessity for targeted educational efforts continuously to ensure that adolescents are well-informed about their condition, ultimately aiding in achieving better health outcomes and more empowered patient communities.

Moreover, this result was substantiated by Mohamed and Kamel (2018) who found that the education program produced a highly significant improvement of SLE patients' overall knowledge. This result highlights the program succeeding in improving knowledge regarding SLE.

The study revealed that the highest percentage of adolescents initially exhibited incompetent SLE practices, but following the self-care program, most of them displayed competent SLE practices. This remarkable improvement, highlighted by the highly significant post-test scores compared to pre-program scores, underscores the effectiveness of the self-care program in enhancing adolescents' practical management skills for SLE.

The study highlighted that before the intervention, the majority of the adolescents had a negative attitude towards SLE. Following the self-care management program, this shifted significantly, with most of them exhibiting a positive attitude. The statistical significance of this change, showcases the profound impact of the educational program in not only improving knowledge but also in preserving a more optimistic and mitigating approach towards managing their condition.

The study emphasized a highly significant relationship between knowledge and age both before and after the program. Older adolescents initially displayed more satisfactory knowledge about SLE. However, after the program, it was the 10 ≤ 12 year-old adolescents who exhibited greater understanding. This indicates that the educational intervention was particularly effective for younger adolescents, significantly boosting their SLE knowledge and narrowing the knowledge gap between different age

groups. This conclusion is corroborated by Abdel Aziz et al. (2022), who discovered a marked statistical relation between overall knowledge level and age in pre and post the program implementation.

Furthermore, the current study highlighted a highly significant relationship between reported SLE practice and age before the program, which remained significant after. Older adolescents demonstrated more competent practices prior to the self-care program, whereas post-program, it was the 10≤12 year-old adolescents who showed greater competency in their practices. This shift implies that younger adolescents benefited greatly from the self-care program which enhanced their practical skills and bridged the gap in practice competency across different age groups.

The current pre-program findings demonstrated a highly notable association between educational level and reported SLE practices. This current result is matched with Mohamed, (2021), who pointed out a highly statistically significant difference between education and total SLE practices level. This consistency highlights the critical influence of educational attainment on the effective self-care management and SLE awareness, stressing the need for targeted educational interventions to improve patient outcomes.

The current results demonstrated a highly notable relationship between SLE attitudes and age, both before and after the program. This indicates that age may play a crucial role in shaping how adolescents perceive and manage their condition, with attitudes towards SLE potentially becoming more positive as they grow older. Consistently, Alkalash et al. (2024) reported that attitude scores were significantly associated with age. This consistency underscores the importance of considering age-specific strategies when designing self-care management programs to ensure they are effective and resonating with adolescents at different developmental stages.

The current study uncovered a significant relation between attitude and gender both before and after the self-care program. Males showed more positive attitudes in the pre-program phase, whereas females exhibited more positive attitudes following the program's implementation. This shift suggests that the self-care program may have been particularly effective in addressing the specific needs and concerns of female adolescents, leading to a notable improvement in their attitudes towards managing SLE.

The present study uncovers a strong positive correlation between knowledge and practice. The essential role of knowledge in influencing and improving practical behaviors is highlighted by this finding. It suggests that individuals who possess more information are better equipped to implement that knowledge effectively in practical settings. The current study agrees with Elsayed and Mesbah (2018), who reported a highly positive association among participants' total knowledge, and their self-care practices. This alignment reflects the critical role of self-care programs in enhancing both the understanding and practical application of self-care among adolescents with SLE.

On another note, the current study demonstrated a highly notable positive correlation between reported SLE practices and attitudes both before and after the self-care management program. This suggests that as adolescents improve their SLE practical management, their attitudes towards self-care also become more positive. Accordingly, a more positive attitude can strengthen their commitment to effective practices. This symbiotic relationship highlights the importance of addressing both practical and psychological aspects in self-care management programs to foster comprehensive, sustainable self-care behaviors in adolescents managing SLE.

The alignment of findings across various studies indicates that self-care programs play a vital role in the management of SLE. These programs equip SLE patients with essential knowledge, skills, and attitudes necessary for a better comprehension of their condition and effective coping strategies. The results reflect the need for continuous development and implementation of such educational efforts to enhance adolescents' understanding and improve disease management outcomes.

The current study presents the remarkable effect of the self-care program on adolescents' knowledge, practices, and attitudes towards SLE. The significant improvement in knowledge and the shift towards competent practices and positive attitude after the self-care program emphasize its effectiveness in equipping these young individuals with essential self-care skills and a more positive outlook towards SLE. This comprehensive improvement underscores the importance of self-care management programs in empowering adolescents to manage their health conditions more effectively.

Conclusion:

The self-care management program positively affects awareness of adolescents with SLE explained that before the intervention, most of the adolescents had unsatisfactory knowledge, incompetent reported practices, and negative attitudes towards SLE. Following the program implementation, there were statistically notable improvements in all assessed outcomes. A strong positive relationship was found between SLE knowledge and both practices and attitudes, evident in both pre-intervention and post-intervention assessments, with a significance level of $P= 0.000$. Additionally, the relationship between reported practices and attitudes was also found to be highly significant, with $P= 0.000$.

Recommendations:

- On-going implementation of specialized self-care training

programs in systemic lupus erythematosus to enrich adolescents' awareness.

- Nursing personnel should offer ongoing health education to SLE patients regarding their condition and self-care practices, utilizing informational booklets as a resource.
- Replicating the research in diverse regions to yield consistent findings.
- Future studies to investigate how self-care protocols impact the health outcomes of adolescents diagnosed with SLE.

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