

## Effect of Nursing Educational Guidelines on Knowledge and Practices of Mothers having Children with Systemic Lupus Erythematosus

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### Abstract

**Background:** Children with systemic lupus erythematosus (SLE) are suffering from a lot of health problems that can be overcome by nursing educational guidelines that focused on the improvement of mothers' knowledge level and their practices. **This study aimed** to evaluate the effect of nursing educational guidelines on knowledge and practices of mothers having children with systemic lupus erythematosus. **Research design:** A quasi-experimental research design was utilized in this study with one group pre-posttest. **Sample:** This study was carried out on 80 mothers having children with systemic lupus erythematosus. **Setting:** The study was conducted at the Inpatient Pediatric Department, Rheumatology unit, and Rheumatology following-up outpatient clinics of Beni-Suef and Zagazig University Hospital. **Tools:** Two tools were used: A self-administered questionnaire and an observational checklist (pre/post and follow-up tests). **Results:** There were statistically significant differences between total scores of knowledge and practices level pre, post, and at following up phases of implementing educational guidelines ( $P=0.001$ ) and there were statistically negligible relation between knowledge and practices and children's ages and occupational levels. **Conclusion:** It can be concluded that there was a highly statistically significant difference between total scores of knowledge and practices level pre, post, and at following up phases of guidelines implementation. **Recommendation:** There is a need for mothers' and public awareness to educate people about SLE, its clinical manifestations, diagnosis, treatment, and complications; although it is not a contagious disease that requires isolation, it may be fatal if neglected.

**Keywords:** Nursing Educational Guidelines, Knowledge and Practices, Mothers, Children & Systemic Lupus Erythematosus.

### Introduction

Systemic lupus erythematosus (SLE) is a chronic inflammatory autoimmune disease that occurs when the immune system assaults the tissues of the body and its organs (*Sedrak et al., 2020*). Systemic lupus is defined by the development of the antibody-antigen complex that occurs in the circulation and accumulates in the cell and organs. A variety of signs and symptoms arise due to damage to tissue by complement, neutrophils, and lymphocytes (*Wel et al., 2018*). Systemic lupus erythematosus can affect the body's various organs, including the skin, joints, brain, blood cells, kidneys, lungs, and heart that Systemic means. Lupus refers to the butterfly rash on the child's face, which is similar to the whitish outline marking on the middle of wolves' faces (*Mohamed et al., 2022*). It means the rash is reddish to purplish in color. Consequently, four types of lupus can be identified: SLE, neonatal

lupus, drug-induced lupus, and cutaneous lupus erythematosus. However, lupus erythematosus is the most common classification (*Bin-Haikel & Al-Tulaihi, 2018*). It affects approximately 5% of the population in the Western world; in lupus, the group most prone to the illness is Native Americans, who are then followed by African-Americans, Hispanics, Chinese, and Filipinos. African Americans and Hispanics tend to be more severely affected by the disease (*Olesinska & Saletra, 2018*).

The clinical manifestations of SLE depend on the affected organ. Malar or butterfly rash is the most common sign of lupus characterized by maculopapular rash, which symmetrical macules, erythematous, elevated lesion, and pruritic and can be diagnosed by clinical manifestations and results of laboratory tests, also requires careful history taking and physical examination with laboratory testing (*Mohamed et al., 2022*).

Presently, no established standard treatment methods are available, and the preferred treatment is the long-term administration of glucocorticoids or a combination of multiple immune inhibitors (*Huang et al., 2016*). Corticosteroids have been the basis of lupus treatment; it's advantageous in most lupus manifestations. It is used as an effectual anti-inflammatory and immune-suppressive medication. It reduces the swelling, hotness, tenderness, and pain that are connected with inflammation by decreasing immune system response (*Danchenko, 2015*).

Nurses have a vital role in recognizing the need for mothers and their children with SLE education because their education is an important but complex issue. The significant nursing role in the SLE management process is especially during periods of disease exacerbation. Because the nurse helps mothers and their children to cope with the disease in their daily living, teaches how to deal with lupus symptoms, prevents periods of SLE exacerbation, and provides health education concerning lifestyle changes. The nurse provides the necessary help and emotional support to the mothers and their children, undertaking educational actions affiliated with lifestyle and rehabilitation to improve their quality of life (*Ogórek-Tećza and Pych, 2018*). Lifestyle modifications and other children care, such as offering advice on a balanced diet, adequate exercise and rest, and the use of heat or cold therapy (depending on joint symptoms), all aid to manage disease activity and other roles of the nurses as performing urinalysis and close monitoring during any complications and screening for diabetes, avoiding overexposure to sunlight, stress management, and a diet low in saturated fats are also very important (*Williams et al., 2017; Nada et al., 2018; Mohamady et al., 2022*).

### Significance of the study

Children with lupus correspond traumatic stress for their mothers, especially in rural areas where there are limited health care and dangerous complications such as lupus nephritis, hematologic anomalies, photosensitivity, neuropsychiatric and mucocutaneous pathology that causes morbidity and mortality in systemic lupus (*Harry et al., 2019*). Besides the lack of mothers' knowledge and practices in handling

their children and expenses finance to manage their children with SLE. In Egypt, the data and statistics center of Cairo University Hospital reported that approximately 85 cases monthly were admitted to the rheumatology department with different clinical manifestations (*Mostafa & Abd-Elrehem, 2017*). The incidence rate of SLE at Ain-Shams University Hospital in Egypt is 10866 cases yearly according to the statistics center of Ain-Shams University Hospital (*Mohamed et al., 2019*). The total number of patients who were admitted to Assiut University Hospital at 2018 was approximately 400 cases to the medical and rheumatology department (*Sedrak et al., 2020*).

### The aim of the study was:

To evaluate the effect of nursing educational guidelines on knowledge and practices of mothers having children with systemic lupus erythematosus

### Research Hypothesis:

1. The mothers' knowledge will be significantly improved after the implementation of nursing educational guidelines than before.
2. The mothers' practices will be significantly enhanced after the implementation of nursing educational guidelines than before.

### Subject and Methods

#### Research design:

A quasi-experimental research design was utilized in order to achieve the purpose of the study. This design was used to compare studied groups and measure the degree of change occurring as a result of treatments or interventions.

**Settings:** The present study was carried out at the Inpatient Pediatric Department, Rheumatology unit, and Rheumatology following-up outpatient clinics of Beni-Suef and Zagazig University Hospitals. Beni-Suef University Hospital is the only hospital for children with systemic lupus erythematosus in Beni suef Governorate and locates in Bani suef city and serves all districts such as (Beni-Suef, Al Wasta, Nasser, Al Fashn, Ehnsia and BPA districts). Also, Zagazig University Hospital is the only hospital for children with systemic lupus erythematosus in Sharqia Governorate and

locates in Zagazig city and serves all districts such as (Minia Al-Qamah, Abu Kabir, Kafr Saqr Al-Hussainiyah districts).

**Subjects:** All available mothers and their children (convenience sample) with systemic lupus erythematosus who attended the previously mentioned settings at the study time (80 mothers) are willing to participate in the study and didn't attend any educational program about systemic lupus erythematosus before.

### III. Tools of data collection: Two tools were utilized in this study:

#### Tool I: A self-administered questionnaire:

Developed by the researchers after reviewing the related literature (*Mohamed et al., 2022 & Sedrak et al., 2020*). It was used to assess the following parts:

**Part (A): Characteristics of mothers,** such as; age, educational qualification, occupational status, consanguinity, and sources of information.

**Part (B): Characteristics of the children,** such as; age, sex, educational level, and child order in the family.

**Part (C): Common health problems** accompanying a child with Systemic Lupus Erythematosus such as discoid rash, malar rash, oral ulcers, hematological disorders, weight loss, photosensitivity, activity intolerance, painful joint, anxiety, and immunological disorders.

**Part (D): Mothers' knowledge questionnaire:** It was used to assess mothers' knowledge about systemic lupus erythematosus in their children (pre, post, and at follow-up tests) of educational guidelines implementation. It assesses the main concepts in systemic lupus erythematosus, which included 10 open-ended questions about the definition, incidence, types, causes, clinical manifestation of SLE, diagnostic tests, and factors affecting in SLE, medical treatment, complications and nursing care of child having SLE. This questionnaire was distributed in the same form three times (pre, post one month of guidelines implementation and at three months follow-up) for the same group of mothers. The questionnaire Alpha Cronbach's reliability test equals 0.85.

**Scoring system:** Knowledge contents were divided into 10 questions and each question was

allocated to three score levels: 3 were scored for complete and/or correct answer, while the incomplete correct answer was scored 2, and don't know or the wrong answer was scored (1). The total score was classified after summing up into either satisfactory level (from 70% and more) or unsatisfactory level (less than 70%) from the total score (30).

**II. A reported practices checklists (pre/post and follow-up tests). Adopted from; (El-Sayed and Mesbah (2018) and Abd El-Latif et al., (2018).** It was filled in by the researchers to evaluate mothers' reported practices in relation to children with systemic lupus erythematosus as nutritional assessment, sun rays, vaccination, pain relieving, sports, medications, emotional support, follow-up, personal hygiene, skin rash care, skin massage and yoga exercise.

**Scoring system:** Each step was appointed to two score levels, which are: done was scored (2) and not done scored (1). The total score was summed up and classified into either competent (70% and more) or incompetent (less than 70 %) from the total score as the following: Nutritional assessment (5 point) and total score = 10; sun rays (4 point) and total score = 8; vaccination (5 point) and total score = 10; sports (5 point) and total score = 10; medication course (5 point) and total score = 10; emotional support (4 point) and total score = 8; follow up (5 point) and total score = 10; pain-relieving (7 steps) and total score = 14; personal hygiene (10 point) and total score = 20; skin rash care (4 point) and total score = 8; and skin massage & yoga exercise (14 steps) from total score = 28. The checklist's Alpha Cronbach's reliability test equals 0.87. The practice total score equals 136.

#### Validity and reliability of the study tools:

Content validity was ascertained by a group of experts (5) including 3 in Pediatric Nursing, 1 Pediatric Medicine, and 1 Rheumatology physician. Their opinions were stimulated regarding the tool's data format layout, consistency, and scoring system. The tool's information was checked for competency, accuracy, and relevancy. Every point of the tools' reliability was completed. The reliability test was established by using Cronbach's alpha to assess internal consistency construct validity. Cronbach's alpha  $r = 0.87$  and  $0.85$ .

**Administrative design:**

The administrators of the study settings gave their official consent for the study to be conducted. It was accepted that, the purpose, character, significance, and anticipated results of the study were clearly explained. It was accepted that the purpose, character, significance, and anticipated results of the study were clearly explained.

**Pilot study:**

A pilot study was conducted on 10% of the total study subjects to test the clarity and practicability of the tools, and suitability of the setting. Those who participated in the pilot study were later included in the study as there were no modifications to the tools.

**Ethical considerations:**

All relevant ethical aspects were considered in conducting the research. Ethical approval was obtained from the Ethics and Clinical Research Committee, Faculty of Nursing, Zagazig University.

The director of the previous setting gave his consent for the study to be conducted. The study's purpose and mothers rights to participate or not in the study, as permitted by research ethics, were explained to all mothers who decided to participate and met the inclusion criteria. They subsequently agreed to take part in the study.

**Fieldwork:**

This study was conducted over a twelve months period, from the beginning of May 2020 to the end of April 2021. The self-administered questionnaire took an average of 45 minutes to complete, while the reported practices checklists which was filled out by the researchers, took an average of 45 minutes. The researchers visited the previously mentioned locations twice a week on Monday and Tuesday from 9:00 a.m. to 2:00 p.m.

**Educational guidelines phases:**

This guideline was conducted in five consecutive phases, assessing, developing, implementing, evaluating and following-up as following:

**Assessment phase:**

A pre-educational guidelines assessment was performed using the self-administered

questionnaire for data collection from the previously mentioned settings. This phase aimed to assess mothers' knowledge and their reported practices regarding their children with systemic lupus erythematosus

**Preparatory phase:**

- Educational guidelines were developed based on actual mothers' needs assessment about systemic lupus erythematosus in their children.
- In accordance with the relevant literature and mothers' educational levels, the researchers wrote the guidelines' content in simple Arabic Language.
- Both theoretical and practical sessions were used to present the guidelines. Small groups (10) mothers were assigned to the subjects, and all mothers participated in subsequent sessions. Each group had six sessions (3 theories and 3 practices). Additionally, each mother received brief instructions before orientation regarding the purpose, contents, and anticipated results.

**First:** The theoretical sessions included the following topics: definition, types, causes, clinical manifestations, diagnostic tests, preventive measures, medical and surgical treatment, complications, and nursing care of systemic lupus erythematosus in children and were delivered in 3 sessions, each lasting for 45 minutes..

**Second:** Lectures and discussions took place first, then the practical part, which was divided into three sessions (each lasting for 45 minutes), covered the following topics.: nutritional assessment, sun rays, vaccination, pain relieving, sports, medication, emotional support, follow up, personal hygiene, skin rash care, skin massage, and yoga exercise through role playing, a simulator, actual objects, conversations, and brain storming, as well as demonstration and re-demonstration. The researchers effectively communicated their findings through PowerPoint presentations and posters. After the guidelines were implemented, mothers were given a handout with the guidelines on it as a reference.

**Program construction:**

- In accordance with relevant literature and mothers' educational level, the researchers

wrote the guidelines' content in simple Arabic form.

- Both theoretical and practical guidelines were used to provide the educational guidelines. Small groups (10 mothers) were used as the subjects, and sessions were repeated to include all mothers. Six sessions were attended by each group (3 theories and 3 practices). Additionally, each mother received instructions before being given the guidelines.
- Evaluate the effect of educational guidelines on the studied mothers using the pre-designed tools:
  - Posttest was done after one month of implementing the guidelines.
  - Following up tests were done three months later by using the same tools

### Implementations the guidelines:

Implementations of the nursing educational guidelines were carried out in the previously mentioned settings. An orientation of the educational guidelines and their aim were introduced at the start of the first session. Groups of mothers were formed, each group containing 8 mothers. Each session began with an overview of the information presented in the previous sessions and the goals of the current session, taking into account the use of simple language to meet the level of education of the mothers. The programme concluded with a feedback of its information and mother input. The educational guidelines were implemented over the course of six sessions, with each session lasting between 30 and 45 minutes depending on the needs of mothers and the nature of the group. The theoretical element of the strategic guidelines was presented over the course of two lectures and conversations, and was then followed by two sessions of demonstration and re-demonstration using role playing, a simulator, actual items, discussions, and brainstorming. The researchers effectively communicated their findings through PowerPoint presentations and posters. After the guidelines were implemented, mothers were given a handout with the guidelines on it as a reference.

### Evaluation phase:

The evaluation phase involved comparing changes in mothers' knowledge and practices regarding nursing educational guidelines for children with systemic lupus erythematosus following the post (after one month) implementation of the guidelines and at following-up three months later.

### Statistical Design:

The data collected were organized, sorted, tabulated, and analyzed using the Statistical Package for Social Sciences (SPSS), version (22). They were presented in tables and charts by numbers, percentages, means, standard deviations, t-test, and Chi-square (X<sup>2</sup>) test. The level of significance was considered  $p < 0.0001$ .

### Results

**Table (1)** showed that, 43.75% of the studied mothers were in the age grouping 30 < 40 years with a mean age  $36.68 \pm 6.88$  years old. Concerning educational level, 50% of the studied mothers had secondary education. In addition, it was found that, 62.5% of studied mothers weren't working and 68.75% of them had negative consanguinity.

**Table (2)** revealed that, 50% of the studied children aged  $\geq 14$  years and 81.25% of them are females. Regarding the educational level, 37.5% of the children are in preparatory school. While, 37.5 % of the studied children were ranked as a third child in their families.

**Figure (1)** illustrated the sources, where mothers get their information about Systemic Lupus Erythematosus, where other families having children with SLE represented 35%, followed by health care team 30%, then friends 22% and the least sources of mothers' information were mass media (13%).

**Table (3):** Showed percentage distribution of children with Systemic Lupus Erythematosus regarding the total scores of the common health problems. It was found that there were statistically significant differences between children's health problems before and at following up (after three months) from program implementation. Also, there were statistically and highly statistically significant improvements amongst Children with Systemic Lupus Erythematosus after one month of

nursing educational guidelines in some of common health problems than in pre-education ( $P<0.05$ ).

**Table (4):** Interpreted the percentage distributions of mothers according to their knowledge about SLE in children throughout the nursing educational guidelines phases. There were highly statistically significant improvements in mothers' knowledge immediately post and at following up phases of nursing educational guidelines implementation as regards all knowledge items about SLE in children than before guidelines implementations.

**Figure (2):** Stated the total knowledge scores of the studied mothers about systemic lupus erythematosus in children throughout the nursing educational guidelines phases, the majority of mothers (90%) had an unsatisfactory level of knowledge; however, most of them (88%) showed an improvement post interventions. Additionally, the same figure showed that, the majority of studied mothers (80%) had satisfactory levels in all their knowledge scores in the following-up phase after guidelines implementation.

**Table (5):** Illustrated that there was highly statistically significance improvements in mothers' reported practices immediately post and at following up phases of guidelines implementation as regards all items of their reported practices about Systemic Lupus Erythematosus in their children.

**Figure (3)** Showed that, the majority of the studied sample (85%) had incompetent practices before the implementation of the guidelines, which improved where also 85% have competent practices immediately post the guidelines implementation. The same figure also demonstrated that, in the following up of guidelines implementation, the majority of the studied sample (70%) scored competently overall their practices items.

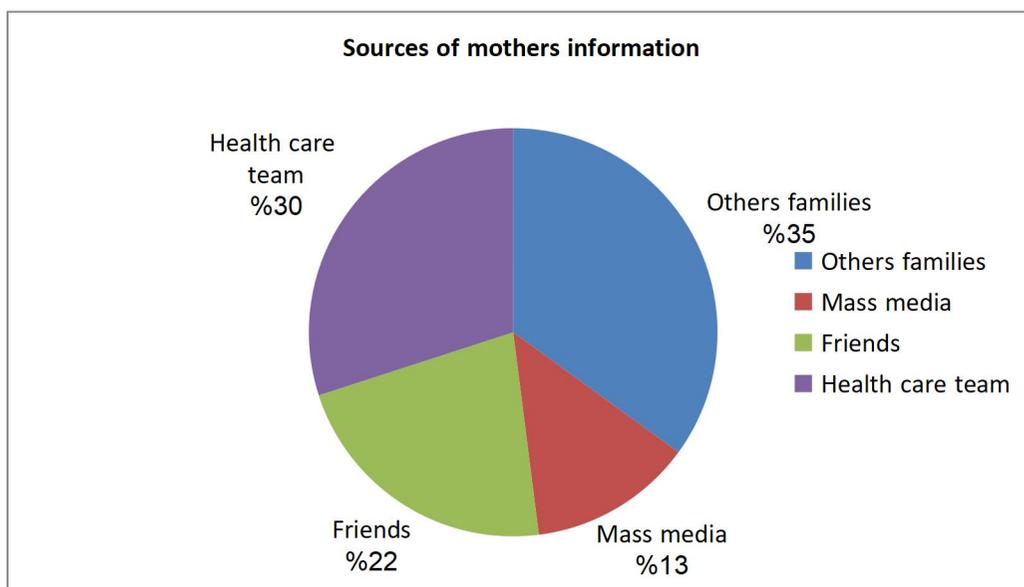
**Table (6):** Exhibited positive correlations between knowledge scores and educational level that are statistically significant at both the pre-and following-up phases of the guidelines implementation ( $P<0.001$ ). However, this table showed that there were statistically insignificant correlations between knowledge and practices and children's age and occupational level at pre guidelines implementation phases.

**Table (1):** Frequency Distribution of Studied Mothers Regarding Their Characteristics (n=80).

Demographic data	N	%
<b>Age group</b>		
20-<30yrs	20	20.0
30-<40yrs	35	43.75
≥40yrs	25	31.25
Mean±SD	36.68± 6.88	
<b>Level of education</b>		
Illiterate and primary education	15	18.75
Secondary education	40	50.0
University education	25	31.25
<b>Occupational level</b>		
Work	30	37.5
Not work	50	62.5
<b>Consanguinity</b>		
Yes	25	31.25
No	55	68.75

**Table (2):** Frequency Distribution of the Studied Children Regarding Their Characteristics (n=80)

Demographic data	N	%
<b>Child age:</b>		
10< 12 years	15	18.75
12< 14 years	25	31.25
≥ 14 years	40	50.0
<b>Mean ±SD</b>	13.27± 1.70	
<b>Gender:</b>		
Male	15	18.75
Female	65	81.25
<b>Child education:</b>		
Illiterate	10	12.5
Primary School	15	18.75
Preparatory School	30	37.5
Secondary school	25	31.25
<b>Ranking:</b>		
First child	20	25.0
Second child	25	31.25
Third child	30	37.5
Fourth child	5	6.25



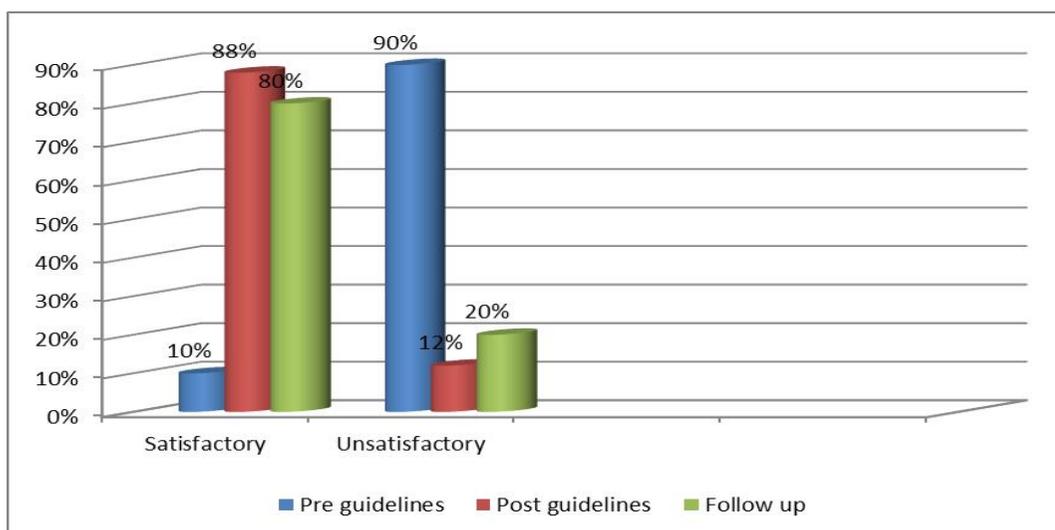
**Fig (1):** Distributions of Mothers according to their Sources of Information about Systemic Lupus Erythematosus in their Children (n=80).

**Table (3):** Percentage Distributions of Children with Systemic Lupus Erythematosus regarding their Total Scores of the Common Health Problems (n=80).

Problems	Pre-education		Follow up		P-value
	Present	Not present	Present	Not present	
	%	%	%	%	
Discoid rash	35.0	65.0	15.0	85.0	.459
Malar rash	80.0	20.0	30.0	70.0	.459
Oral ulcer	20.0	80.0	10.0	90.0	.000**
Hematological disorder	85.0	15.0	40.0	60.0	.160
Weight loss	52.0	48.0	35.0	65.0	1.000
Photo-sensitivity	43.0	57.0	25.0	75.0	.000**
Activity intolerance	27.0	73.0	11.0	89.0	.000**
Painful joint	65.0	35.0	48.0	52.0	.000**
Anxiety	80.0	20.0	65.0	35.0	.021 *
Immunological disorder	85.0	15.0	70.0	30.0	.000**

**Table (4):** Distributions of Mothers Knowledge about Systemic Lupus Erythematosus in their Children throughout the Nursing Educational Guidelines Phases (n=80).

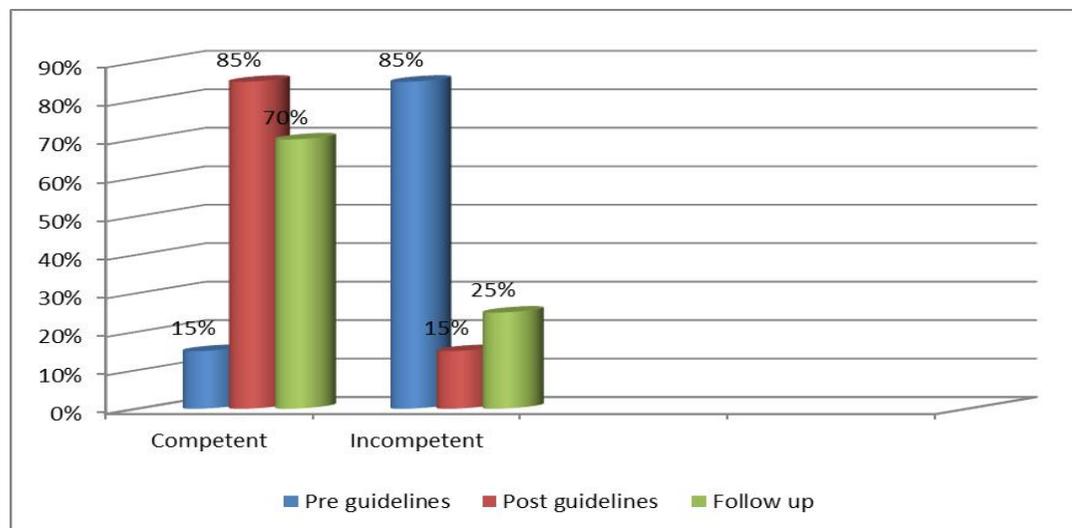
Mothers Knowledge	Pre- guidelines		Post- guidelines		Follow up	
	Satisfactory	Unsatisfactory	Satisfactory	Unsatisfactory	Satisfactory	Unsatisfactory
	%	%	%	%	%	%
Definition of SLE	15.0	85.0	88.0	12.0	85.0	15.0
Named of SLE	5.0	95.0	95.0	5.0	92.0	8.0
Incidence	37.0	63.0	96.0	4.0	95.0	5.0
Causes	25.0	75.0	88.0	12.0	85.0	15.0
Types	30.0	70.0	85.0	15.0	80.0	20.0
Clinical manifestations	40.0	60.0	88.0	12.0	85.0	15.0
Factors increase the disease activity	20.0	80.0	88.0	12.0	85.0	15.0
Diagnostic tests	10.0	90.0	90.0	10.0	85.0	15.0
Complication	40.0	60.0	88.0	12.0	85.0	15.0
Medical treatment	10.0	90.0	90.0	10.0	85.0	15.0
Nursing care	30.0	70.0	95.0	5.0	92.0	8.0
<b>T-test</b>	$X^2_1 = 17.4$ pre-guidelines versus post- guidelines					P – value <0.001**
<b>P value</b>	$X^2_2 = 24.5$ pre-guidelines versus follow- up					
	$X^2_3 = 14.8$ post-guidelines versus follow- up					



**Figure (2):** Total Knowledge Scores of the Studied Mothers about Systemic Lupus Erythematosus in Children throughout the Nursing Educational Guidelines Phases (n = 80).

**Table (5):** Mothers' Reported Practices regarding Systemic Lupus Erythematosus in their Children throughout the Guidelines Phases (n = 80).

Mothers Reported Practices	Pre- guidelines		Post- guidelines		Follow-up		
	Competent	Incompetent	Competent	Incompetent	Competent	Incompetent	
	%	%	%	%	%	%	
Nutrition	15.0	85.0	82.0	18.0	80.0	20.0	
Pain reliving	60.0	40.0	96.0	4.0	94.0	6.0	
Sunrays	11.0	89.0	75.0	25.0	75.0	25.0	
Vaccination	75.0	25.0	96.0	4.0	96.0	4.0	
Personal hygiene	40.0	60.0	95.0	5.0	90.0	10.0	
Sports and yoga exercise	10.0	90.0	90.0	10.0	85.0	15.0	
Treatment course (Cortisone)	8.0	92.0	85.0	15.0	82.0	18.0	
Follow up with doctor	28.0	72.0	94.0	6.0	92.0	8.0	
Emotional support	15.0	85.0	82.0	18.0	80.0	20.0	
Skin rash care	28.0	72.0	94.0	6.0	92.0	8.0	
<b>T-test</b>	X <sup>2</sup> <sub>1</sub> =28.4 pre- guidelines versus post- guidelines					P-value	
<b>P value</b>	X <sup>2</sup> <sub>2</sub> = 50.9 pre - guidelines versus follow- up					<0.001**	
	X <sup>2</sup> <sub>3</sub> = 24.2 post - guidelines versus follow- up						



**Figure (3):** Percentage Distributions of Total Practices Scores of the Studied Mothers about SLE in their Children throughout the Guidelines Phases (n = 80).

**Table (6):** Correlations Coefficient between Mothers' Total Knowledge and Practices Scores about Their Children SLE at (Pre, Post & Follow-Up) Phases with Children's Characteristics (n=80).

Characteristics		Age		Educational level		Occupational level	
Variables	Guidelines phases	r	P	r	P	r	P
		Knowledge	Pre guidelines	0.82	> 0.05	0.252	0.001
Post guidelines	0.554		0.001	0.142	> 0.05	0.136	> 0.05
Follow up	0.463		0.001	0.322	0.001	0.62	> 0.05
Practices	Pre guidelines	0.32	>0.05	0.52	> 0.05	0.31	> 0.05
	Post guidelines	0.446	0.001	0.412	0.001	0.54	> 0.05
	Follow up	0.228	0.001	0.266	0.001	0.35	> 0.05

\* Statistically insignificant (P> 0.05)

\*\* Highly statistical significant correlations (P< 0.001)

## Discussion

Systemic lupus erythematosus (SLE) is an episodic, multi-system, autoimmune disease characterized by widespread inflammation of blood vessels and connective tissue. There is no cure for lupus, but medical interventions and lifestyle changes can help control it. The severity of SLE can range from mild to life-threatening. Patients with lupus who get proper medical care, preventive care, and education can significantly improve function and quality of life (*Brown et al., 2012*). The aim of this study was to evaluate the effect of nursing educational guidelines on the knowledge and practices of mothers having children with systemic lupus erythematosus.

Regarding mothers' knowledge about Systemic Lupus Erythematosus, the present study showed that the most common sources of their information were other families, followed by the health care team, then their friends, and the least sources were mass media. This result contradicted the result of *Sedrak et al., (2020)* who studied the Effect of Nursing Education on Knowledge and Self Care for Patients with Systemic Lupus Erythematosus and found that friends and mass media were the sources of mothers' education about SLE. This result may be related to a failure of mass media in medical and nursing fields so; there are Medical ignorance and a lack of awareness about the disease and its treatment in our country.

Concerning the total scores of the common health problems in children with Systemic Lupus. The current study presented that there were statistically significant differences between children's health problems before and at follow-up (after three months) from program implementation. This result may be related to that the program succeeding in improving the practices of mothers regarding their children's common health problems. In the same line, *Atia et al., (2018)* who studied the Effect of Health Education Intervention on Mothers' Performance of their Children Suffering from Systemic Lupus Erythematosus and revealed that there were highly significant improvements in health status as weight loss; photosensitivity, and anxiety relieve post program application.

Also, this result is supported by *Jaime-Herndon et al., (2016)* who found that Lupus can be mild, causing skin rashes and joint aches. The disease can also be very active; if it spreads to vital organs it can do a lot of damage. To help keep the disease from flaring up child will probably be taking some type of medication for years to overcome its complications, and also need to see doctors regularly for checkups. But by helping children do these things and adopt good health habits for life (avoiding sun exposure, eating well, exercising), you'll ensure the best possible outlook for the future.

As regards mothers' knowledge about Systemic Lupus Erythematosus in their children throughout the guidelines phases, the present study results portrayed that, there were highly statistically significant improvements in mothers' knowledge immediately post and at following up phases of guidelines implementations as regards all knowledge items about Systemic Lupus Erythematosus in their children than before guidelines implementations. This study finding was supported by *Sahebalzamani et al., (2017)* who mentioned that continuous education significantly improved patients' knowledge level and awareness of their disease. This study finding was supported by *Mohamed & Kamel (2018)* who found that the health education-based intervention had a significant effect on the improvement of SLE patients' knowledge. However, after the application of the designed nursing education the patients had a highly significant improvement. This result may be related to the program succeeding in improving mothers' knowledge regarding their children with SLE.

On assessing mothers' total knowledge about SLE, the present study showed that the majority of mothers had unsatisfactory levels of knowledge before the implementation of the guidelines, which improved for most of them immediately after post guidelines implementation. Also, the majority of the studied mothers had a satisfactory level in their total knowledge scores in the following up phases of guidelines implementation, with highly statistically significant differences ( $P < .0001$ ). This study goes on the same line as *Sedrak et al., (2020)* who revealed that there

was a highly statistically significant difference in SLE patient knowledge in the pre-post-test (after one month and three months) for the study sample. This result supports the study hypothesis which suggested that the knowledge level of the studied mothers after the implementation of nursing education guidelines improved than pre-education.

The present study points out that there were highly statistically significance improvements in mothers' reported practices immediately post and at following up phases of guidelines implementation as regards all practices items about Systemic Lupus Erythematosus in their children. This might be due to lack of mothers' awareness about nature of the disease and mothers' knowledge that is important to help in the care practices and management of chronic disease to prevent complications. That's go in the same direction with *Mostafa and Abd-Elrehem, (2017)* who found that more than half of studied mothers had unsatisfactory level of practices about SLE in the pre- program.

On assessing the studied mothers' total practices scores; most of the studied mothers had an incompetent level of practices before guidelines implementation, which improved for most of them to have competent scores in their practices immediately after post and in the following up phases of guidelines implementation with highly statistically significant differences. This finding is likely due to a combination of improved recognition of SLE and a better approach to the therapy. Furthermore, this finding is incongruent with *Abdel Aziz et al., (2022)* who studied Assessment of Mothers' Knowledge and Practices towards Systemic Lupus Erythematosus in their Children and revealed that the mothers' total practices scores were competent despite their poor knowledge scores.

As regards Correlations between mothers' total knowledge and practices about their children's SLE at (pre, post & follow-up) phases and their children's demographic characteristics. The study results showed that there were statistically significant positive correlations between knowledge scores and educational level at the pre and follows up phases of guidelines implementation

( $P < 0.001$ ). Additionally, there were statistically insignificant correlations between knowledge and practices and children's age and occupational level at the pre-guidelines implementation phases. This result is in agreement with *John and Sons (2017)* who mentioned that the main causes of morbidity and mortality from SLE are now either treatment-related or mothers' lack of knowledge rather than the disease itself. Also, supported by *Sedrak et al., (2020)* who found that there were positive correlations between total knowledge and self-care of patients with SLE. This result may be related to a lack of training programs for mothers of children with SLE about the nature of the disease, consequences, common health problems, and management.

### Conclusion

Based on the result of the current study, it can be concluded that there was a highly statistically significant differences between total scores of knowledge and practices levels pre, post-test, and at following up phases of nursing guidelines implementation. Also, mothers' knowledge significantly improved and mothers' practices significantly enhanced after the implementation of nursing educational guidelines than before.

### Recommendations

In the light of the findings of the current study the following recommendations were suggested:

1. There is a need of mothers and public awareness to educate people about SLE, its clinical manifestations, diagnosis, treatment, and complications; although it is not a contagious disease that requires isolation, it may be fatal if neglected.
2. Dissemination of research booklet at the Rheumatology department to the mothers having children with SLE and continuous health education about the disease and care.
3. Replicate the study at different areas to generate the study results.
4. Future research is proposed to explore the effect of self-care protocols on outcomes of children with SLE.

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**References**

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- Abdel Aziz FS., Ismail SS., Sabaq AG. & Abdel-Salam AA. (2022):** Assessment of Mothers' Knowledge and practices towards Systemic Lupus Erythematosus, *Journal of Nursing Science - Benha University JNSBU*, ISSN 2682 – 3934, 3 (1) 178.
- AbdEl-Latifa E., HassanaZ. & Gomaa A. (2018):** Effect of Systemic Lupus on Patient's Self-Esteem and Quality of Life, *Egyptian Nursing Journal*, 15 (3):156–161.
- Atia MN., Bahgat RS. & Sharshor SM. (2018):** Effect of Health Education Intervention on Mothers' Performance of Their Children Suffering From Systemic Lupus Erythematosus. *International Journal of Novel Research in Healthcare and Nursing* 5(1): 214-226. Available at: [www.noveltyjournals.com](http://www.noveltyjournals.com).
- Bin-Haikel KA. & Al-Tulaihi B. (2018):** Awareness of Systemic Lupus Erythematosus among Primary Health Care Patients in Riyadh, Saudi Arabia. *Open Access Maced J Med Sci*. 6(12): 2386-2392. Available at: <https://doi.org/10.3889/oamjms>.
- Brown, R., Shaftman, S., Tilley, B., Anthony, K., Kral, M., Maxson, B., & Nietert, P. (2012):** The health education for lupus patients study, A randomized controlled cognitive behavioral intervention targeting psychosocial adjustment and quality of life in adolescent females with systemic lupus erythematosus. *American Journal of Medical Science*, 344(4): 274-282.
- Danchenko N. (2015):** Enhancing diagnosis and management of systemic lupus erythematosus, PhD thesis, University of Pittsburgh School of medicine, Pittsburgh, 12-15.
- El-Sayed DM. & Mesbah SK. (2018):** Effect of Health Education based Intervention on Self-Care among Systemic Lupus Erythematosus Clients. *American Journal of Nursing Research*, 6 (3): 105-112. doi: 10.12691/ajnr-6-3-4.
- Harry O., Crosby LE., Smith AW. & Favier L. (2019):** Self-Management and Adherence in Childhood-Onset Systemic Lupus Erythematosus: What Are We Missing? *HHS Public Access Lupus*. 28(5): 642–650. doi:10.1177/0961203319839478.
- Huang X., Magder L. & Petri M. (2016):** Predictors of incident seizure in systemic lupus erythematosus. *J Rheumatol*, 43(3):565-57.
- Jaime Herndon M, Brenda B. & Spriggs, M. (2016):** Systemic lupus erythematosus—Patient Education For patient education information, the Arthritis Center, as well as. Also the American College of Rheumatology's patient fact sheets for SLE, Systemic Lupus Erythematosus in Children and Teens, and Anti phospholipids Syndrome.
- John W & Sons L. (2017):** Systemic Lupus Erythematosus. Part D: Autoimmune Disease; *Annals of the New York academy of sciences Journals*. 56(1): 114–120.
- Mohamady SH., Srour OA. & Saad NS. (2022):** Effect of Self- Care management on Health Outcomes and Symptoms for Females with Systemic Lupus Erythematosus. *Tanta Scientific Nursing Journal*, 25(2) (Suppl).
- Mohamed D. and Kamel S. (2018):** Effect of Health Education based Intervention on Self-care among Systemic Lupus Erythematosus Clients." *American Journal of Nursing Research*, 6(3):105-112.
- Mohamed, S., Fahmy, N., Mohamed, S., Morshedy, N. (2019).** Assessment of quality of life among women with systemic lupus erythematosus. *Egyptian Journal of Health Care*, 10(4): 82-95.
- Mohamed FS., Ismail SS., Sabaq AG. & Abdel-Salam AA. (2022):** Assessment of Mothers' Knowledge towards Systemic Lupus Erythematosus. *Journal of Nursing Science - Benha University ISSN 2682 – 3934*, 3(1).

- Mostafa H. & Abd-Elrehem T. (2017):** Self-Management Guidelines, Effect on Awareness of Patients with Systemic Lupus Erythematosus, Egypt, IOSR Journal of Nursing and Health Science; 6 (6):15-23.
- Nada MA., Bahgat RS., Sharshor SM. (2018):** Effect of Health Education Intervention on Mothers' Performance of Their Children Suffering from Systemic Lupus Erythematosus .International Journal of Novel Research in Healthcare and Nursing, 5(1): 214-226. Available at: [www.noveltyjournals.com](http://www.noveltyjournals.com).
- Ogórek-Tęcza B. & Pych A. (2018):** Nursing Care of a Patient with Systemic Lupus Erythematosus. Problemy Pielęgniarstwa, 26 (4): 312–316.
- Olesinska M. & Saletra A. (2018):** Quality Of Life in Systemic Lupus Erythematosus and its Measurement Reumatologia journal, 56(1): 38-47.
- Sahebalzamani M., Farahani H., Jamarani T., Faezi T., Moradi K., & Paragomi P., (2017):** Effects of a Continuous Care Model on Patients' Knowledge and Health-Related Quality of Life in Systemic Lupus Erythematosus. Rehabil Nurs., 42(6): 9-18
- Sedrak MW., Mohamad ZA., Abo El-Noor El. & Abd-Elall HA. (2020):** Effect of Nursing Education on Knowledge and Self Care for Patients with Systemic Lupus Erythematosus. Assiut Scientific Nursing Journal, 8(23): 113-121. Available at: <http://asnjournals.ekb.eg> [http:// www.arabimpactfactor.com](http://www.arabimpactfactor.com)
- Wel L., Feng C., Xiali H., Yan W., Xiaokun H. & Shuzen Z. (2018):** Application of the ICF Checklist in the Chinese Systemic Lupus Erthemematosus Patients: Across-Sectional Study. Actamedica Mediterranean, 34, 1281.
- Williams E., Egede L., Faith T. & Oates J. (2017):** Effective Self-Management Interventions for Patients with Lupus: Potential Impact of Peer Mentoring. The American Journal of the Medical Sciences; 353(6): 580-592.