

Assessment of Mother's Knowledge and Practices Regarding their Children with Systemic Lupus Erythematosus

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Abstract:

Background: Systemic lupus erythematosus is a long-term autoimmune disease characterized by multiple organs damage resulting in potentially life-threatening complications. **Aim:** This study was aimed to assess mother's knowledge and practices regarding their children with systemic lupus erythematosus. **Research design:** A descriptive research design was utilized in this study. **Setting:** This study conducted at Allergy and Immunity Out-Patient Clinic in Pediatric Hospital affiliated to Ain Shams University Hospitals. **Subjects:** A purposive sample composed of 120 mothers accompanying their children with systematic lupus erythematosus. **Tools of data collection:** Two tools were used; a structured interviewing questionnaire and structured observational checklists to gather data about systemic lupus erythematosus from mothers and their children. **Results:** More than two thirds (68.3%) of the studied mothers had unsatisfactory knowledge about systemic lupus erythematosus, while most (82.5%) of them had incomplete reported practices level. Also, there was a statistically significant differences between mother's total knowledge level and their educational level with $p < 0.05$ and there was a highly statistically significant difference between mother's total practices and their educational level with $p < 0.001$. **Conclusion:** The majority of the studied mothers had unsatisfactory knowledge and incomplete practices regarding systemic lupus erythematosus. **Recommendations:** Continuous educational program for mothers having children with systemic lupus erythematosus to increase their knowledge and practices regarding care of their children.

Key words: Children, Mother's knowledge, Practices, Systemic lupus erythematosus.

**Introduction:**

Systemic Lupus Erythematosus (SLE) is a severe and devastating multisystem autoimmune and inflammatory disease that can affect any organ system and cause significant damage, disability, and death. Also, it's more aggressive with higher disease activity and medication burden that contribute to the increased children morbidity and mortality associated with the disease (*Tang et al., 2021*).

The worldwide prevalence of pediatric SLE ranges from 1.89 to 34.1 per 100,000 children every year and from 20 to 150 children per 100,000 in the United States and more common in females than male with ratio of 12:1 with average age of onset between 10 and 14 years and rarely to occur before the age of 5 years. Also, the prevalence is higher among Asian, African American, African Caribbean, and Hispanic American children compared with white children (*Li et al., 2020 and Barber et al., 2021*).

The exact cause of SLE is unclear, but certain risk factors have been identified as genetic predisposition, environmental factors, hormonal, and some drug interactions; that lead to immune system dysfunction with antibody formation and immune complex deposition. This immune system dysregulation causes organ damage, contributing to the variable manifestations, and relapsing-remitting course of the disease (*Barcia-Sixto & Isenberg, 2020*).

The heterogeneous clinical manifestations of SLE ranging from mild cutaneous disease and extended to organ failure. However, the common initial manifestations include low grade fever, extreme fatigue, loss of appetite, weight loss or gain, pain or swelling in the joints, and myalgia and the other symptoms depend on the part affected as oral ulcers, arthritis and problems in skin, lung, heart, kidney, gastrointestinal, Central Nervous System (CNS), blood cells, and immunological abnormalities (*Kiriakidou & Ching, 2020*).

Consequently, SLE is complicated and challenging disease in diagnosis and treatment. So, Systemic Lupus International Collaborating Clinics (SLICC) in 2012, create classification criteria that focusing on clinical manifestations and antibody profiles specific to SLE, if four of the diagnostic criteria including at least one clinical



and one immunologic criteria, have been satisfied to confirmed diagnosis of SLE (*Aringer & Petri, 2020*).

However, treatment options are limited in control the inflammation and decrease organ damage but continuing researches in the pathogenesis of SLE can led to new discoveries and making more medications available to treat this difficult disease. Also, there are found standard types of medication for SLE including Non-Steroidal Anti-Inflammatory Drugs (NSAIDs), corticosteroids, anti-malarial, and immunosuppressant drugs (*Liossis & Staveri, 2021*).

On the same line, the nurse has a pivotal role toward instruct caregivers to have a voice and play an active role in all aspects of their children life through helping them to identify needs of their children, engaging in the planning and provision of care which recognizes the importance of children needs, providing both practical and emotional support, access to resources and give them guidance about proper diet, sun protection, exercise, smoking cessation, appropriate immunizations, and management of comorbid conditions, which lead them to better life and health outcomes (*Pongmarutani et al., 2018 and Tamirou et al., 2019*).

Significance of the study:

Systemic lupus erythematosus is a life threatening condition that causes a plenty number of complications which affects all body organs and associated with significant morbidity and mortality in children. Therefore, the role of the mother is necessary in ensuring their children survive and thrive (*Burnham et al., 2021*).

In Egypt, as reported by Statistical Office in Pediatric Hospital affiliated to Ain Shams University Hospitals were 150 cases between 5-18 years old with SLE (follow up) and about 3- 4 cases newly diagnosed at February, 2020 (*Unpublished Statistical Records at Ain Shams University Hospital, 2020*). Therefore, it is one of the issues that need to study, analysis and determine mother's knowledge and practices about SLE that affect different aspects of their children's life and health status.

**Aim of the Study:**

This study aimed to assess mother's knowledge and practices regarding their children with systemic lupus erythematosus.

Research Questions:

What are the level of mother's knowledge and practices toward systemic lupus erythematosus?

Subjects and methods:**Research design:**

A descriptive research design was used to achieve the aim of this study.

Setting:

The study was carried out at Allergy and Immunity Out-Patient Clinic in Pediatric Hospital affiliated to Ain Shams University Hospitals.

Subjects:

A purposive sample that composed of 120 mothers accompanying their children with systemic lupus erythematosus was admitted to the previous mentioned setting based on certain inclusion criteria as the follows:

- Available mothers having children with SLE with different level of education.
- Children with confirmed diagnosed of SLE at least 6 months from both sexes.
- Children free from any other physical or mental diseases.

Tools of data collection:

Two tools were used in the current study:

Tool (I): A Structured Interviewing Questionnaire:

This tool was designed by the researcher after reviewing the related literatures.

It was written in a simple Arabic language and included four parts as the follows:

Part (1): Personal characteristics of mothers included; age, level of education, occupation, marital status, and consanguinity between parents.

Part (2): Personal characteristics of children with systemic lupus erythematosus included; age, gender, level of education, ranking, and residence.

Part (3): Data about medical history of the studied children such as; child current weight and height (using growth chart), taking routine vaccination and

having SLE, disease duration, and the frequency of hospital admissions due to disease complications.

Part (4): Mothers' knowledge assessment:

It was developed by *Belotti (2003)* and was adapted and modified by the researcher after reviewing the related literature to assess mothers' knowledge level about SLE. It was translated into simple Arabic language to assure accuracy of this tool and the modification was done to be appropriate with the studied mothers. The quiz was included 20 multiple - choice questions related to SLE such as; definition, incidence, morbidity, mortality, pathophysiology, causes, signs and symptoms, complications, diagnostic measures, medical management, lifestyle changes, and management of general problems for children with SLE.

Scoring system:

The mothers answered were compared with model key answers; where each correct answer was given (1) grade and incorrect or unknown answer was given (0) grade. The total score of lupus awareness quiz was 20 grades (equal 100%) converted into percentage and then categorized as following; unsatisfactory level of knowledge = < 60% equal (0<8 grades), while satisfactory level of knowledge = $\geq 60\%$ equal (8 ≥ 12 grades).

Tool (II): Structured Observational Checklists:

It was adopted from *Ralph & Taylor, (2011) and Bowden & Greenberg, (2016)*, to assess mothers' reported practices for their children. It contained of (64) items for 10 procedures that included; measurement of axillary temperature (8 items), respiration (5 items), weight (6 items), height (5 items), teething brush (6 items), management of fever (8 items), vomiting (5 items), mouth and throat ulceration (5 items), extremities edema(11 items), and joint pain(5 items).

Scoring System:

The scoring system consisted of two points; done was scored (1) and not done was scored (0).The total scores are 64 score (equal 100%) for all procedures. Accordingly, the scoring system of reported mothers' practices was classified into;



incomplete practices = $< 60\%$ equal (0<38 score), while complete practices = $\geq 60\%$ equal (38 to 64 score).

Tool validity:

Tools validity was checked through a jury of three experts two (professors) of Pediatric Nursing from the Faculty of Nursing, Ain Shams University and one professor from the Faculty of Nursing, Helwan University to test the content validity of the instruments and to judge its clarity, comprehensives, relevance, simplicity, and accuracy. All of their remarks were considered. Some items were rephrased to arrive at the final version of the tools. The tools were regarded as valid from the experts' point of view.

Tools reliability:

Reliability of the tools were tested by using Cronbach's Alpha which detect excellent internal consistency of the tools was performed. Where, structured interviewing questionnaire formats = 0.795 and structured observational checklist=0.801.

Ethical considerations:

An official permission to conduct the proposed study was obtained from the Scientific Research Ethical Committee at Helwan University. Participation in the study was voluntary and subjects were given complete full information about the study and their role before signing the informed consent. The ethical considerations were included explaining the purpose and nature of the study, stating the possibility to withdraw at any time, confidentiality of the information where it was not be accessed by any other without taking permission of the participants. Ethics, values, culture and beliefs were respected.

Pilot study:

A pilot study was carried out before starting the data collection, to test the applicability, validity and time consuming to fill in the study tools. It was applied on 10% equal (12) mothers with their children suffering from SLE at previously mentioned setting. The result of the pilot study helped to make some modifications on



the tools were some questions and items omitted, added or rephrased. Mothers and their children included in the pilot study were excluded from the main study sample.

Field work:

The actual field work was carried out over a period of 6 months started from beginning of April to end of September 2021 for data collection. The researcher was available at morning shift by rotation two days weekly at the study setting from 8:00 a.m. to 2:00 p.m. The researcher explained the aim of the study for studied mothers and their children with SLE to gain their cooperation before starting interviewing and data gathering, and taken written consent from mothers to participate in the study. The researcher gave each mothers questionnaire sheet to filling it when mothers educated with clarified any misunderstanding items, while the mothers that can't read and write; the researcher filled the questionnaire through ask questions in interviewing with mothers. The average time needed for the completion of each questionnaire was approximately 30-35 minutes; that started with (Tool I) it took nearly 20-25 minutes, and (Tool II) took about 10 minutes.

Administrative Design:

After explanation of the study aim and objectives, an official permission was obtained from the Dean of Faculty of Nursing, Helwan University, and the general manager of Pediatric Hospital affiliated to Ain Shams University Hospitals asking for cooperation and permission to conduct the study.

Statistical Design:

The collected data were organized, revised, scored, tabulated and statistically analyzed using Statistical Package for Social Sciences (SPSS) version "25" and Excel (2010). The following statistical analyses were used: number, percentage, mean score (\bar{x}), standard deviation (SD), chi square (X^2) and proportion probability of error (P-value) the significance of the results were considered as follows; when $p > 0.05$: statistically insignificant difference, while $p < 0.05$: statistically significant difference and $p < 0.001$: a highly statistically significant difference.

Results:

Table (1): Regarding the studied mother's characteristics, this table showed that, more than half (55.9%) of the studied mothers were in the age group ≥ 40 years with $\bar{x} \pm SD$ was 39.62 ± 5.86 years and more than one third (38.3%) of them were secondary education, while the majority (88.3%) of them were housewives and most (93.3%) of them were married. As regard the consanguinity between parents, more than two thirds (70%) of the studied mothers had no consanguinity.

Table (2): As observed from this table, most (85% and 83.3 %) of the studied children were in the age group from $12 \leq 18$ years and females respectively. Also, less than half (45%) of them in secondary school and 63.3% were live in urban areas.

Figure (1): This figure revealed that; more than two thirds (68.3%) of the studied mothers had unsatisfactory knowledge about systemic lupus erythematosus and slightly less than one third (31.7%) of them had satisfactory knowledge level.

Figure (2): Regarding total reported practices, this figure cleared that, most (82.5%) of the studied mothers had incomplete practices level and the minority of them had complete reported practices level.

Table (3): This table clarified that; there was a statistically significant differences between total knowledge level of the studied mothers and their education, where ($p < 0.05$).

Table (4): This table showed that; there was a highly statistically significant difference between total reported practices level of the studied mothers and their education, where $p (< 0.001)$.

Table (1): Distribution of the studied mothers according to their characteristics (n=120).

Mother's Characteristics	No	%
Age / years:		
20 <30.	1	0.8
30 < 40.	52	43.3
≥ 40 .	67	55.9
$\bar{x} \pm SD = 39.62 \pm 5.86$ years		
Education:		

Can't read and write.	30	25
Reading and writing.	10	8.3
Primary school.	18	15
Secondary education.	46	38.3
High education.	16	13.4
Occupation:		
Housewife.	106	88.3
Working.	14	11.7
Marital status:		
Married.	112	93.3
Divorced.	8	6.7
Consanguinity between parents:		
Yes.	36	30
No.	84	70

Table (2): Distribution of the studied children according to their characteristics (n=120).

Children's Characteristics	No	%
Age / years:		
< 6.	2	1.7
6 < 12.	16	13.3
12 ≤ 18.	102	85
$\bar{x} \pm SD = 14.33 \pm 2.93$ years		
Gender:		
Male	20	16.7
Female.	100	83.3
Education:		
Read and write.	4	3.3
Nursery school.	2	1.7
Primary school.	16	13.3
Preparatory school.	44	36.7
Secondary school.	54	45
Child rank:		
Frist.	36	30
Second.	42	35
Third.	28	23.3
Fourth and more.	14	11.7
Residence:		
Urban.	76	63.3
Rural.	44	36.7

Figure (1): Percentage distribution of the studied mothers according to their total knowledge level about systemic lupus erythematosus (n=120).

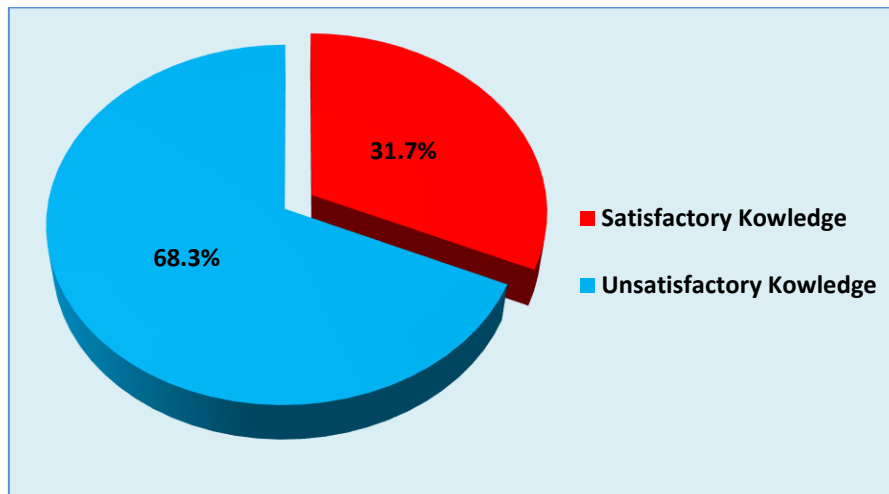


Figure (2): Percentage distribution of the studied mothers according to their total reported practices level for their children with systemic lupus erythematosus (n=120).

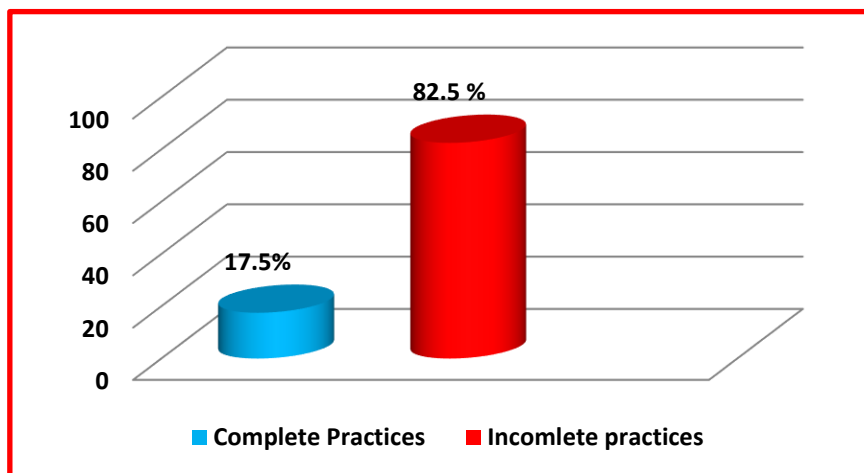


Table (3): Relation between total knowledge level of the studied mothers and their characteristics (n=120).

Mother's Characteristics	Total knowledge level			
	Satisfactory (n=38)		Un-satisfactory (n=82)	
	No	%	No	%
Age / years:				
20 <30.	0	0.0	1	1.2
30 < 40.	28	73.7	24	29.3
≥ 40.	10	26.3	57	69.5

X²: 5.021 P :0.107				
Education:				
Can't read and write.	0	0.0	30	36.5
Reading and writing.	0	0.0	10	12.2
Primary school.	0	0.0	18	22
Secondary education.	22	57.9	24	29.3
High education.	16	42.1	0	0.0
X²: 9.557 P :0.045*				
Occupation:				
Working.	28	73.7	78	95.1
Housewife.	10	26.3	4	4.9
X²: 3.2227 P: 0. 139				
Marital status:				
Married.	34	89.5	78	95.1
Divorced.	4	10.5	4	4.9
X²: 2.056 P: 0.411				

X²: Chi Square Test.

p >0.05: No significant.

*** p<0.05: Statistically significant.**

Table (4): Relation between total reported practices level of the studied mothers and their characteristics (n=120).

Mother's Characteristics	Total reported practices level			
	Complete (n=21)		Incomplete (n=99)	
	No	%	No	%
Age / years:				
20 <30.	0	0.0	1	1
30 < 40.	13	61.9	39	39.4
≥ 40.	8	38.1	59	59.6
X²:4.300 P:0.124				
Education:				
Can't read and write.	0	0.0	30	30.3
Reading and writing.	0	0.0	10	10.1
Primary school.	0	0.0	18	18.2
Secondary education.	5	23.8	41	41.4
High education.	16	76.2	0	0.0
X²: 12.99 P:0.005**				
Occupation:				
Working.	14	66.7	92	92.9
Housewife.	7	33.3	7	7.1

$X^2: 3.227$ $P:0.139$				
Marital status:				
Married.	17	81	95	95.9
Divorced.	4	19	4	4.1
$X^2: 1.800$ $P:0.450$				

X^2 : Chi Square Test. * $p < 0.05$: Statistically significant.

** $p < 0.001$: Highly significant. $p > 0.05$: No significant.

Discussion:

The children with SLE represent a traumatic stressful for their mothers especially when there are limited health care, beside the lack of mother's knowledge and skills in caring for their children. So, the mothers needs to identify more information about SLE, acquired new skills and participate in the disease management to maintain their children health (*Fava & petri, 2019*).

Regarding the studied mother's characteristics, this study finding clarified that, more than half of the studied mothers were in age group from 40 and more years. In the same line, the study of *Fortuna-Reyna et al., (2021)*, who studied psychosocial and economic impact of rheumatic diseases on caregivers of Mexican children, reported that, slightly less one third of mothers having children with juvenile systemic lupus erythematosus with age 40 years and the median from 36 - 46 years. From the researcher point of view, the mother's age was necessary in acquiring new information and experiences to increase their enthusiasm about caring of children with SLE.

Considering mother's education, this study finding showed that, less than half of the studied mothers were secondary education. On the contrary, *Mohamed, (2021)* in Egypt at Benha University, who studied the effect of educational program on improving mother's knowledge, practice and child attitudes toward systemic lupus erythematosus, found that, two fifths of the studied mothers were graduated from secondary education. From the researcher point of view, the mother's education play an important role to understanding the nature of their children disease and how to dealing with it.

In relation to mother's occupation, this study finding cleared that, more than three quarters of the studied mothers were housewives. This result goes in the same

line with *Ethica et al., (2020)* in Indonesia, who studied socialization of lupus disease awareness for housewife group of Genting Village, Ambarawa, and Central Java, stated that, all mothers of the counseling program were housewives. From the researcher point of view, the demands of treatment and frequent follow up for children with SLE may require housewives mothers to providing a suitable care for their children.

Concerning mother's marital status, this study finding showed that, almost all of the studied mothers were married. This study finding was an accordance with *ELghareeb & Mohmoud, (2022)* in Mansoura, Egypt, who studied influence of self-management instruction on outcomes of health for systemic lupus patient, reported that, more than two thirds of the studied mothers were married.

As regards consanguinity between parents, this study finding illustrated that, more than two thirds of the studied mothers had no consanguinity. This study finding supported by *Asiri et al., (2020)* in Kingdom of Saudi Arabia, who studied awareness of systemic lupus erythematosus among general population in Abha, KSA; found that, more than two thirds of the studied mothers had negative consanguinity.

Regarding the studied children's characteristics, the finding of the current study revealed that, most of the children with SLE age ranged from 12-18 years old with the mean age of 14.3 ± 2.9 years. This finding was an agreement with the study of *Hossny et al., (2022)* in Egypt, who studied impact of pediatric systemic lupus erythematosus on the health-related quality of life, reported that, the children' ages ranged between 12-18 years old with the mean age of 12.2 ± 1.9 years. From the researcher point of view, this could be due to the peak incidence of SLE in adolescence due to puberty and hormonal changes.

Concerning gender of the studied children, the finding of the present study illustrated that, the majority of them were females. This finding was paralleled with *Mohamed et al., (2018)* who studied juvenile lupus: different clinical and serological presentations compared to adult lupus in Egypt, found that, the majority of the studied sample were females and the ratio between females and males reached 36:1. From the researcher point of view, this result confirmed the scientific review about increase

incidence of SLE between female than male due the important role of female hormones in increasing vulnerability to SLE.

In relation to education of the studied children, the current study showed that, less than half of them in secondary school. This finding was in disagreement with *Mohamed et al., (2022)* in Benha, Egypt, who studied assessment of mothers' knowledge towards systemic lupus erythematosus, stated that, more than half of the studied children in preparatory school. From the researcher point of view, this could be due to the difference between two target samples.

Considering residence of the studied children, the present study illustrated that, less than two thirds of them were living in urban areas. In the same line, the study of *Gergianaki et al., (2019)* in cross-sectional analysis of the Crete in Greece, who studied is systemic lupus erythematosus different in urban versus rural living environment? Data from the Cretan lupus epidemiology and surveillance registry showed that, more than two fifths of the studied children had lived in urban area. From the researcher point of view, the incidence increase in urban area due to life style and environmental pollutants which increase the risk of SLE occurrence.

Regarding mother's total knowledge level about SLE, this study finding revealed that, more than two thirds of the studied mothers had unsatisfactory level of knowledge about SLE. This study finding is concurrent with *Mohamed, (2021)*, who found that, almost all of studied mothers had unsatisfactory level of knowledge pre - educational program implementation. From the researcher point of view might be due to lack of information provided by the nurse in Allergy and Immunity Out-Patient Clinic.

Regarding total reported practices of the studied mothers, this study cleared that, most of the studied mothers had incomplete reported practices. This result was in congruent with *Elsayed & Mesbah, (2018)* in Benha, Egypt, who studied effect of health education based intervention on self-care among systemic lupus erythematosus clients, reported that, the majority of the studied mothers had unsatisfactory reported practices preprogram. From the researcher point of view, the mothers had high desire



to educate more practices for increase their ability to caring and help their children to improve their health status.

The present study revealed that, there was a statistically significant difference between total knowledge of the studied mothers and their education. This result was supported by *Mohamed et al., (2022)*, who reported that, there was a highly statistical significant relation between total mothers' knowledge level and their education. From the researcher point of view, the acquired mother's knowledge corresponding with their educational levels that affect on talent ability to remember and improve their information.

The finding of the present study showed that, there was a highly statistically significant difference between total reported practices level of the studied mothers and their education. This finding was matched with *Mohamed, (2021)*, who found that, there was a highly statistically significant difference between total reported practices level of the studied mothers and their education. From the researcher point of view, this relation might be due to the fact that, education level had significant impact on knowledge and practices of mothers which helping them in caring of their children with SLE.

Conclusion:

More than two thirds of the studied mothers had unsatisfactory knowledge level, while the majority of them had incomplete reported practices regarding systemic lupus erythematosus. There was a statistically significant differences between mother's total knowledge level and their education with $p < 0.05$ and there was a highly statistical significant difference between mother's total reported practices and their education with $p < 0.001$.

Recommendations:

Continuous educational program for mothers having children with systemic lupus erythematosus to increase their knowledge and practices toward children caring.

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