Assessment of Mothers' Knowledge towards Systemic Lupus Erythematosus

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Abstract

Background: Systemic lupus erythematosus is a chronic, relapsing inflammatory disease that affects both cellular and humoral immunity **Aim:** This study aimed to assess mothers' knowledge towards systemic lupus erythematosus. **Research design:** A descriptive design was utilized in the current study. **Settings:** This study was conducted at pediatric medical departments in Specialized Pediatric Hospital and Health Insurance Hospital in Benha City. **Subjects:** A purposive sample of 50 mothers accompanying their children suffering from systemic lupus erythematosus. **Tools of data collection:** One tool was used: A structured interview questionnaire formats. **Results:** There was a highly statistical significant relation between total mothers knowledge level and their age, education with $P < 0.001$. **Conclusion:** Majority of studied mothers had unsatisfactory level of knowledge regarding systemic lupus erythematosus. **Recommendations:** Continuous educational programs to increase awareness of the mothers having children with systemic lupus to ensure enough knowledge and decrease functional disabilities of the children.

Keywords: Assessment, Mothers' knowledge, Systemic lupus erythematosus.

Introduction

Systemic Lupus Erythematosus (ELS) denotes to the butterfly rash on the child's face, which alike to the whitish outline marks on the centrality of wolves' faces. Erythematosus called the rash is ruddy to purplish in color **(Bowden and Greenberg, 2014).**

Systemic lupus affects approximately 5% of the population in the Western world; in lupus, Native Americans are most susceptible to the disease followed by African-Americans, Hispanics, Chinese and Filipinos. The disease tends to be more severe in the African-Americans and Hispanics **(Olesinska and Saletra, 2018).**

Systemic lupus characterized by the development of the antibody-antigen complex that presents in the circulation and accumulates in the cell and organs. The diversity of signs and symptoms arise due to damage to tissue by complement, neutrophils and lymphocytes **(Wel et al., 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 **(John et al., 2011).**

The diagnosis of systemic lupus based on clinical manifestations and results of laboratory tests, also requires careful history taking and physical examination with laboratory testing. Laboratory assessment is helpful for establishing the diagnosis and for

monitoring the disease course **(Ashwill et al., 2013).**

Corticosteroids have been the basis of lupus treatment, it's beneficial in most of the lupus manifestations. It used as effective anti-inflammatory and immune-suppressive medication. It decreases the swelling, hotness, tenderness and pain that are associated with inflammation by decreasing immune system response **(Danchenko, 2015).**

Lupus nephritis is the most dangerous complication and the first cause of morbidity and mortality in systemic lupus. It is inflammation of the kidney caused by deposition of immune complex in the kidney. Symptoms be different from child to child the first symptoms are swelling in ankle and face, foamy urine, proteinuria, hematuria and hypertension **(Paglia et al, 2017).**

The mothers' are the primary caregiver for the children with a long-lasting condition and takes responsibility for assessment and management despite the level of skill and complexity involved in the care. The benefits of home care provided by the mother include the promotion of health, development for the child and decrease the financial cost of the health services. To perform home care effectively the mother requires receiving extensive training and instructions on the child's care **(Koroma, 2012).**

Significance of the study

The children with lupus represent a traumatic stressful for their mothers especially in rural areas where there are limited health care. Beside lack of mothers' awareness to handling their children and expenses finance to manage their children with SLE **(Fava and Petri, 2019).**

In Egypt, the information and statistics center of Cairo University Hospital reported that about 85cases monthly admitted to the rheumatology department with different signs and symptoms. The prevalence 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).**

Aim of the study

The study aimed to assess mothers' knowledge towards systemic lupus erythematosus.

Research questions

What are the levels of mothers' knowledge towards Systemic Lupus Erythematosus?

Subjects and Method

Research design:

A descriptive research design was utilized for conducting this study.

Research setting:

This study was conducted at pediatric medical departments in Specialized Pediatric Hospital and Health Insurance Hospital in Benha city.

Sample:

A purposive sample of 50 mothers' accompanying their children suffering from systemic lupus erythematosus after fulfilling the following criteria:

Inclusion of criteria :

- Mothers' had children with SLE and their age ranged from 10-15years old.
- Mothers' willing to participate in the study.

Tools of data collection:

Data collection was gathered by using the following tool:-

I. A structured interviewing questionnaire:

It was designed by the researcher based on a review of the current relevant researches. It was written in a simple Arabic language and consists of four parts:

A: Characteristic of the studied mothers' such as age, level of education, occupation, residence, consanguinity and attending educational course about SLE.

B: Characteristic of the studied children such as age, gender, education, and ranking.

C: Mothers knowledge assessment :

It was designed by the researcher based on literature review (**Hockenberry, and Wilson, 2015)** to assess mothers' knowledge regarding systemic lupus erythematosus and written in the form of **multiple choice questions included the following:**

- Ten (10) multiple choice questions covering mothers' knowledge regarding systemic lupus.
- Twelve (12) multiple choice questions covering mothers knowledge regarding medications.
- Three (3) multiple choice questions related to mothers knowledge about diet for their children with SLE.
- Four (4) multiple choice questions related to role of mothers' regarding SLE.
- One (1) question about source of mothers knowledge about SLE.

Scoring system:

Studied mothers answered were compared with model key answers; where scored as correct answer had score (1), unknown or wrong answer had scored (0). Total knowledge scores ranged from (0- 30) points In this respect the level of mothers' knowledge was categorized as the following: unsatisfactory level of knowledge (< 60%) was ranged from (0 >18) points and satisfactory level of knowledge (≤ 60%) was ranged from (18 to 30) points.

Tools validity:

Tools of data collection were investigated for their content validity by panel of three experts in pediatric nursing specialty from the faculty of nursing Benha University and Beniseuf University, who are selected to test content validity of the tools and to judge its clarity, relevance, comprehensiveness, understanding and applicability. The opinion was elicited regarding the layout, format and sequence of the questions and all of their remarks were taken into consideration and the tools were regarded as a valid from the experts' point of view.

Tools reliability:

Reliability for tools was applied by the researcher for testing the internal consistency of the tools by administrating of the same tool to the same subjects under similar condition. Internal consistency reliability of all items of the tools was assessed using Cronbach's alpha coefficient. It was (0.90) for structured interviewing questionnaire formats.

Ethical considerations:

The researcher clarified aim of the study to the studied mothers' and verbal approval was prerequisite to participate in the study. Mothers' were assured that all gathered data were used in research purpose only and the study was harmless. Additionally, mothers were allowed to withdraw from the study at any time without giving the reason. Confidentiality of the gathered data and results were secured.

Pilot study:

A Pilot study was conducted to test the clearness and applicability of the study tools and to estimate the time needed for each tool, it was done on 10% of the total subjects,(5) mothers'who have children with SLE and excluded from the present study to avoid sample bias and contamination. In the light of pilot study analysis, modification was done and last form was developed.

Field work:

This phase took five months from the beginning of October 2019 to the end of February 2020.It started by interviewing with mothers and children to collect baseline data. The researcher was visited the Pediatric Medical Departments at Specialized Pediatric Hospital in Benha city and Health Insurance Hospital in Benha city three days/ weeks by rotation from 10AM and extended to 2:00 PM. At the beginning of interview; the researcher welcomed mothers' and their children, explained the purpose, duration, activity of the study and take their oral approval to participate in the study prior to data collection. The data of the children with SLE was collected from medical record and from the mothers' and it took nearly 15 minutes for each child. Then the researcher gave the studied mothers questionnaire (Tool I) for filling it to assess their knowledge, it took nearly 30- 45 minutes.

Statistical analysis:

The collected data were organized, coded, computerized, tabulated and analyzed by using the Statistical Package for Social Science (SPSS) version 21. Quantitative data were described using numbers, percentages, mean and standard deviation. Reliability of the study tools was done using Cronbach's Alpha. A significant level value was considered when $p \leq 0.05$ and a highly statistical significant was considered at $p < 0.001$.

Results

Table (1) showed that 62% of the studied mothers were in the age group 30< 40 years with a mean age 36.68± 6.88 years old. Concerning educational level, 42%of the studied mothers had secondary education. In addition, it was found that 70% of studied mothers were housewife and 64% of them had negative consanguinity. Regarding attending educational courses about SLE 94% of the studied mothers didn't attend any educational courses about SLE.

Table (2) revealed that 40% of the studied children were aged ≥14 years and 80% of them were female. Regarding the educational level 54% of the children were in preparatory school. While 36% of studied children were ranked as second children in their families.

Figure (1) showed that 90% of studied mothers had unsatisfactory level of knowledge toward systemic lupus.

Table (1): Frequency distribution of studied mothers regarding their characteristics (n=50).

Mothers characteristics	Studied Mothers (n=50)	
	No.	%
Mothers age:		
20 < 30 years	7	14.0
30< 40 years	31	**62.0**
≥ 40 years	12	24.0
Mean ±SD = 36.68± 6.88		
Mothers educational:		
Illiterate	11	22.0
Primary education	11	22.0
Secondary education	21	**42.0**
University education	7	14.0
Occupation :		
Employee	15	30.0
Housewife	35	**70.0**
Consanguinity:		
Yes	18	36.0
No	32	**64.0**
Attending educational courses about SLE		
Yes	3	6.0
No	47	**94.0**

Table (2): Frequency distribution of studied children regarding their characteristics (n=50).

Children characteristics	Studied Children (n =50)	
	No.	%
Child age:		
10< 12 years	15	30.0
12< 14 years	15	30.0
≥ 14 years	20	**40.0**
Mean ±SD = 13.27± 1.70		
Gender:		
Male	10	20.0
Female	40	**80.0**
Child education:		
Read and write	3	6.0
Primary School	20	40.0
Preparatory School	27	**54.0**
Ranking:		
First child	17	34.0
Second child	18	**36.0**
Third child	8	16.0
Fourth child	7	14.0

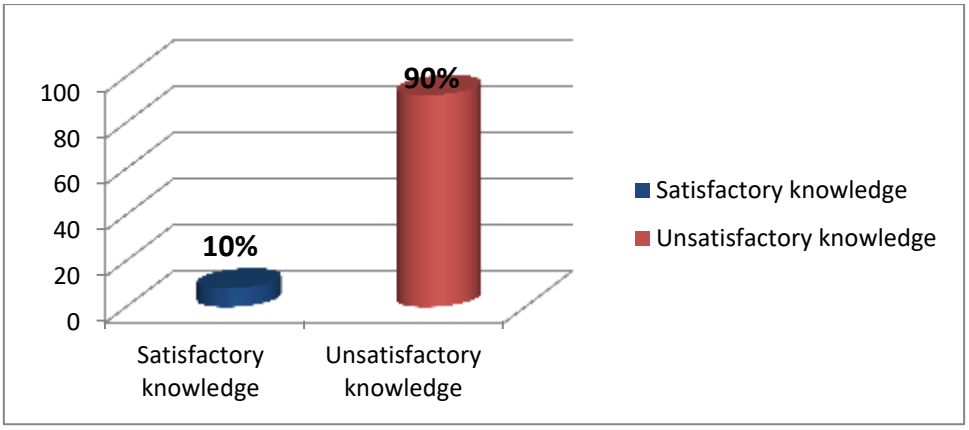

Figure (1): Frequency distribution of the studied mothers' regarding their total level of knowledge (n= 50)

Discussion

The mothers' have an effective role and responsibilities for their children with systemic lupus. Most of the children with chronic disease have cared in the home without nursing or other health services and the mother assumes the role of care coordinator for the child. It is important for the mother to become knowledgeable about child condition and treatment regimen and taking an active role in treatment planning and decision making **(Khawaja et al, 2018).**

Regarding characteristics of studied mothers' the present study showed that the majority of the studied mothers had a mean age 36.68± 6.88 years old. This could be due to age of mother was important in providing knowledge for care of the child and understanding new experiences with care and treatment. This result was paralleled with **Spore, (2012)** who found that more than two fifth of mothers the mean age were 36 years.

Related to mothers' level of education, two fifths of studied mothers were graduated from secondary education. This due to the mothers level of education could be contributing factor in help them to understand the nature of disease besides education greatly strengthens the mothers to perform their dynamic roles in caring of their children. This finding incomparable with **Ali, (2015)** who found that more than half of mothers were illiterate.

The current study result showed that more than three quarters of studied mothers were housewife. This could be due to low level of education and most of them coming from rural area. This finding disagreed with **Yousef et al. (2018)** who found that two fifth of the studied mothers were employee.

Concerning consanguinity, the present study showed that two third of studied mother's had negative consanguinity. This might be due to the fact that SLE is an autoimmune disease not hereditary disease and consanguinity not affect occurrence of disease. This result matched with **Asiri et al., (2020)** who found that more than three quarters of studied mothers had negative consanguinity.

Regarding residence, the present study showed that more than two third of studied mothers were living in rural area. This was likely owing to the mothers in rural areas usually confronted with environmental factors that had linked with the development

of lupus and their children exposure to ultraviolet and pesticides, so environmental exposures considered the strongest risk factors for the development of SLE. This result agreed with **Barbhaiya and Costenbader, (2016)** who stated that majority of the study subjects were living in rural area.

Regarding children characteristics, more than two fifth of the studied children had a mean age of 13.27± 1.70 years. This might be related to the fact that systemic lupus more common in the reproductive age as a result of hormonal changes in adolescence. This result was in the same direction with **Shoeib et al., (2018)** who found that more than three quarter of studied children ages were ≥14 years.

Related to gender of the studied children, the majority of the studied children were females. This might be due to lupus mainly a girlish disorder and hormones play a major role in the etiology of disease, girls are most exposure to estrogen hormone, while androgen hormone in boy plays as defending function in SLE. This result was in the same line with **Khawaja and Zletni, (2018)** who mention that majority of studied children were female.

On assessing mother's total knowledge about SLE, the present study showed that vast majority of studied mothers had unsatisfactory level of knowledge about SLE. This might be due to lack of mothers' awareness about nature of the disease and mothers' knowledge is important to help in the 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 knowledge about SLE in the pre- program.

Conclusion

Vast majority of studied mothers had unsatisfactory level of knowledge toward systemic lupus. There was a highly statistical significant relation between total mothers knowledge level and their age, education with $P < 0.001$.

Recommendations

Continuous educational programs to increase awareness of the mothers' having children with SLE to ensure enough knowledge and decrease functional disabilities of the children with SLE.

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تقييم معلومات الأمهات تجاه الذئبة الحمراء

فاطمة سيد عبدالعزيز- صفاء صلاح إسماعيل - أمال غريب سباق- أمل عبدالعزيز عبدالسلام

الذئبة الحمراء هو مرض مناعي التهابي مزمن يؤثر علي العديد من أجهزة الجسم وتلعب الأمهات دورًا حيويًا في علاج الأطفال المصابين بالذئبة الحمراء وتحتاج إلى جهد يومي للحفاظ على صحة الطفل. لذلك هدفت الدراسة إلي تقييم معلومات الأمهات تجاه الذئبة الحمراء. وقد أجريت هذه الدراسة داخل قسم باطنة الأطفال بمستشفي الاطفال التخصصي وبمستشفي التأمين الصحي بمدينة بنها وكانت عينة الدراسة عينة غرضية شملت ٥٠ من الأمهات المصاحبات لأطفالهن الذين يعانون من الذئبة الحمراء. حيث كشفت النتائج إن (٩٢%) من الأمهات قد حصلوا علي مستوي غير مرضي من المعلومات عن مرض الذئبة الحمراء. كما توجد فروق ذات دلالة إحصائية بين مستوي معلومات الأمهات وعمرهم ومستوي التعليم. وأوصت الدراسة بأن هناك حاجة إلي تنفيذ برامج توجيهية لزيادة وعي الأمهات اللاتي لديهن أطفال مصابون بمرض الذئبة الحمراء والمساعدة في تحسين معرفة الأمهات وتقليل الإعاقات الوظيفية للأطفال المصابين بمرض الذئبة الحمراء.