Effect of Family Empowerment Model on Quality of Life and Self-Efficacy of Mothers Toward Children with Systematic Lupus Erythematosus

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Abstract

Systemic lupus erythematosus in children is a multisystem disease with extensive organ involvement. Mothers may struggle to manage their child's health, their own emotions and had negative effect on mothers quality of life and self-efficacy. The aim of the study: Was to evaluate effect of family empowerment model on quality of life and self- efficacy of mothers toward children with systematic lupus. Research A quasi-experimental (pre/post-test) design. Setting: This study was design: conducted at Rheumatology and Immunology Department and Rheumatology and Immunology Outpatient Clinics at Benha University Hospital in Benha city. Tools of data collection: Tool (I): A structured interviewing questionnaire Sheet (pre/post): It was divided into four main parts: part (1): Personal characteristic of the studied mothers, Part (2): Characteristics of the studied children, Part (3): Medical data of studied children and Part (4): Mothers knowledge Assessment format. Tool (II): Mothers Quality of Life questionnaire: to assess mothers quality of life. Tool (III): mothers Self-efficacy Scales to assess mothers selfefficacy toward children with systematic lupus. Tool (IV):Mothers Reported Practices Sheet, regarding care of children with systemic lupus. Results: Majority of studied mothers had good level of knowledge and reported practice at post and after three months of family empowerment implementation as compared to pre family empowerment implementation.while, majority of studied mothers had good level of quality of life and high self-efficacy at post and after three months of family empowerment implementation respectively. Conclusion: Mothers' knowledge and reported practice significantly improved after the implementation of family empowerment implementation than pre family empowerment implementation. Also, mother's self-efficacy and quality of life improved in post and after three months of empowerment implementation family than pre family empowerment implementation..Recommendation: Family empowerment program should be conducted for caregiver periodically and regularly regarding systematic lupus erythematous .

Key Words: Self-Efficacy, Quality of Life, Systemic lupus Erythematosus, Family Centered Empowerment.

Introduction

Systemic lupus erythematosus (SLE) is an autoimmune disease that affects the connective tissue in various organs. It is a long-term illness that causes organ dysfunction ⁽¹⁾. Systemic lupus erythematosus can cause a wide symptoms, including; range of photosensitivity, joint pain, rash, and fatigue, as well as irreversible organ damage and death. It has been linked to most of morbidity and mortality, as well as significant negative effects on daily activities children and self perceptions of health ⁽²⁾. Other lupus symptoms are damage to a particular organ system, stiffness, skin changes, changes in renal function, the digestive system can be affected by medications used to treat lupus. Also, lupus can affect lung, heart, nervous system and retinal damage $^{(3)}$.

nature of systematic lupus The disturbs the unit of the family and leaves serious complications since children receive a major part of their treatment at home and study in usual schools. Children depend on family as active members in child care and is very effective in the process of treatment and recovery of the child ⁽⁴⁾. is clear that children need It concentration, autonomy, and selfcontrol .In addition, the lack of physical activity lead to obstacle involvement of children with chronic

disease in school and extracurricular activities creating a sense of inadequacy and humility ⁽⁵⁾.

Quality of life (QOL) is children's perception of their position in the context of the culture and value systems in which they live, and in relation to their expectations standards and interests, aims, conditioned by the environment ⁽⁶⁾. The mothers are the curcial caregivers for their children with a long-lasting disease and take responsibility for management, monitoring, , and protection beside the level of skills and complexity of the child care at home. Also, most children with chronic disease have cared at home without nursing or other health care services and the mother must assume the role as a care coordinator for their children with SLE. Therefore, so, mother requires receiving extensive training skills, knowledge, instructions about the child's care, and guidance about exercise nutrition. proper .sun protection, vaccination. and • management of comorbid conditions, which leading to better self efficacy and quality of life for mothers and improve child's health outcomes ⁽⁷⁾. Self-efficacy was refers to the ability of performing a particular function that a children expects from his/her ability to do in different situations.

Self-efficacy is the most important precondition to change behavior. Selfefficacy is one of the concepts of family-centered empowerment model. In fact, empowering the children and his familv and increasing the involvement of children in self-care reflects the emphasis on health, prevention and health education, not just focusing only on illness and its treatment ⁽⁸⁾. Awareness of parents about the disease is a vital part of child care and is essential for making appropriate decisions to support the diseased children. On the other hand, nursing interventions for children must also address the participation of their families. Family involvement in childcare is one of the key principles of the family-centered empowerment model. As a result, giving an opportunity to the children and family members by nurses might help them to become aware of their abilities required to meet the needs of children (9)

Family–Centered Care (FCC) is a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the child and in which all the family members are recognized as care recipients ^(10,11). The empowerment approach should be tailored to the caring conditions of a child with a chronic illness or disability. The family-centered

empowerment model is designed with an emphasis on the effectiveness of the family role in the dimensions of motivation, psychology as; perceived threat, performance (self-efficacy), and quality of life can simultaneously promote knowledge, skills, values, and beliefs of the children and the family and the main purpose of this model is to empower the family system to improve the child health (12). Through this model, children and their families can identify their weaknesses and have enough power to alter their current situation, which is achieved through increased information. support, and skills development. In general, family-centered empowerment can be considered an important way to improve children self-care and to involve family members intheir care . Evidence shows that educating sick children and families strengthens their their knowledge and skills. One of the most important responsibilities of a nurse is to promote the level of health and empowerment of the family. Having children with chronic illness can have adverse effects on other family members, especially mothers, and can reduce self-esteem and increase anxiety and stress ⁽¹³⁾.

Health caregivers have an important role in empowering family members to decrease tension. Meanwhile, nurses are one of the most appropriate

members of the health team for training children and their family due to their vocational and professional responsibility and ability to undertake different roles in health service systems ⁽³⁾. Also, nurse can play vital role in the process of treatment of systemic lupus erythematosus periods especially during of exacerbation of the disease. The nurse support the children to cope with the disease in their everyday lives, teaches how to deal with lupus symptoms, prevents periods of SLE exacerbations. and provide systematic education health concerning lifestyle changes. The nurse help the children and their family through giving the necessary information . provides emotional support to the children and their family, undertaking educational actions connected with lifestyle and rehabilitation improve their to ⁽¹⁴⁾. Lifestyle quality of life modifications, such as avoiding sunlight, overexposure to stress and a diet low in management saturated fats, are essential ⁽¹⁵⁾.

Significance of the Study:

Systemic lupus erythematosus has a negative effect on different aspects of a child's life, such as ; quality of life , mental health, daily activities, and heavy economic burden ⁽¹⁶⁾. The children with lupus represent a

traumatic stress for their mothers especially in rural areas where there are limited health care services, lack of mothers' awareness to handling their children and expenses finance to manage their children with SLE (17). Lupus is a significant global public problem. The estimated health incidences of the systematic lupus in worldwide is 0.28-0.9 per 100,000 children and a prevalence of 3.3-8.8 per 100,000 children, in USA the range of 0.4-2.2 per 100,000 children vearly⁽¹⁸⁾.

The estimated incidences of the systematic lupus in Egypt, is 1/100,000 population (0.24/100000 males and 1.8/100000 females). 7.4% developed pre-pubertal SLE (\leq 7 years); 73.3%, peri-pubertal; and 19.3% during early adolescence ⁽¹⁹⁾.

Aim of the Study:

The aim of this study was to evaluate the effect of family empowerment model on quality of life and selfefficacy of mothers toward children with systematic lupus.

The research hypotheses:

1. Mothers receiving family empowerment model will expect to be improved knowledge and reported practice scores in post family empowerment implementation than pre family empowerment implementation. 2. Mothers receiving family empowerment model will expect to be improved quality of life and selfefficacy score in post family empowerment implementation than pre family empowerment implementation.

Subjects and Methods

I. Technical design:

The technical design for the study includes research design, setting of the study, subject and tools for data collection.

Study Design

A quasi-experimental research design was utilized for conducting the study.

Setting:

The study was conducted at Rheumatology and Immunology Department and Rheumatology and Immunology Outpatient Clinics at Benha University Hospital in Benha city. Rheumatology and Immunology Department which located in the Seveen floor, consists of four rooms, the first room contains 4 beds, the second room contains 8 beds, the third room contains 4 beds and the fourth room contains 8 beds. Rheumatology and Immunology Outpatient Clinics which located in the First floor in Benha University Hospital.

Subjects of the Study

A purposive sample of (60) mothers accompanying their children suffering from systemic lupus erythematosus attending the above-mentioned setting after fulfilling the following.

Inclusion criteria:

- Mothers' had children with SLE and their age ranged from 8-14years old.
- Mothers' had children conscious, free from any other chronic disease and psychological problem and able to communicate.
- Mothers' willing to participate in the study.

Tools of Data Collection:

Four tools were used for data collection; it was all written in an Arabic language to suit mothers' level of understanding after reviewing related literature and involved the following.

Tool (I): A structured interviewing questionnaire Sheet (pre/post):

This tool was developed by the researchers based on the previous related literatures review and used for collection of data related children with systematic lupus. It was divided into four main parts:

Part (1): Personal characteristics of
the mothers: age, educational level,
occupation, number of family
members, consanguinity and
residence.

Part (2): Characteristic of the children

It was designed by the researchers to gather data related to children, through individual interviewing of children and their accompanying mothers such as age, gender, education, residence and ranking.

Part (3): Medical data of studied children: such as age of the child at diagnosis, onset of disease, family history of systemic lupus, duration of disease, symptoms, method of diagnosing, number of pervious hospitalization, and causes of pervious hospitalization and duration of follow up. The researchers collected medical data of studied children from the medical record.

Part (4): Mothers Knowledge Assessment Format

It was designed by the researchers based on **Hockenberry and Wilson**, (2021)⁽²⁰⁾, to assess mothers knowledge regarding systemic lupus erythematosus. It was written in the form of multiple choice questions. This part consisted of (14) multiplechoice questions as the following:-

A) Mothers knowledge regarding systematic lupus

The first section concerned with assessment of mothers knowledge related to systematic lupus. It included 8 questions: Definition of lupus, causes, predisposing factor, types, clinical manifestation, complications, investigation and management.

B) Mothers Knowledge regarding medications

The second section concerned with assessment of mothers knowledge

related to medication. It included 6 questions: Type of treatment of systematic lupus, role of corticosteroid in treatment of lupus, side effect of corticosteroid, <u>method to prevent of</u> <u>side effect from corticosteroid</u>, complication may occur from stop corticosteroid treatment and role of inflammatory drug in treatment of lupus.

Mothers knowledge was scored as following:

Studied mothers answered were compared with model key answers; where scored as complete correct answer had score (2), incomplete correct answer had score (1) and incorrect or unknown had scored (0). Total knowledge scores ranged from (0-28) points. In this respect the level of mothers knowledge was categorized as the following: poor level of knowledge (< 40%) was ranged from (0 > 9) points, average level of knowledge (<40-60%) was ranged from (9 > 18) and Good level of knowledge ($\geq 60\%$) was ranged from (19 to 28) points.

Tool (2): Mothers Quality of Life questionaire

It adapted from **Skevington**, etal., (2004) ⁽²¹⁾, to assess mothers quality of life toward children with systematic lupus. It consisted of 24 items in which their responses were evaluated using a 5-point Likert scale on four domain : physical health (6 items) psychological health (6 items) social relationships (3 items) and environment (7 items).

Scoring system Mothers Quality of Life:

The mothers response was classified into five point likert scale, strongly disagree (1), disagree (2), neutral (3), agree (4), strongly agree (5). Total scores were ranged from (0- 120) points, so the level of mothers quality of life was categorized as the good level was ranged following, from (80 - 120)points. average (60 < 80) point and poor (less than 60) point.

- Good $\ge 60\%$
- Average <40-60%
- Poor <40%

Tool (3): Mothers Self-Efficacy Scales

Was adapted from a standardized likert type rating scale by **Kankaras** (2017)⁽²²⁾, to assess mothers selfefficacy toward children with systematic lupus. It consisted of 17 items in which their responses were evaluated using a 5-point Likert scale as following (I can always manage to solve difficult problems if I try hard enough, I can solve most problems if I invest the necessary effort and I can remain calm when facing difficulties because I can rely on my coping abilities).

Scoring system Mothers Self-Efficacy Scales: The mothers response was classified into five point likert scale, strongly disagree (1), disagree (2), neutral (3), agree (4), strongly agree (5). Total scores were ranged from (0- 85) points, so the level of mothers self efficacy was categorized as the following, High self eeficacy was ranged from (45-85) points and low self efficacy (less than 45) point.

-High self-efficacy≥ 60%

-Low self-efficacy<60%

Tool (4): **Mothers** Reported Practices Sheet: It was adapted from Martin, $(2022)^{(23)}$, to assess the mothers' reported practices regarding care provided for their children with systemic lupus. It was used twice pre empowerment and after family implementation. It contained of 52 items grouped under seven domain that included nutrition (9 items), personnel hygiene (8 items), drug administration (8 items), prevention from infection (6 items), management of pain and fatigue (8 items), skin care (7 items) and hair care(6 items).

Mothers' reported practice was scored as following:

The scoring system consisted of two points: done complete and correct was scored (1), not done was scored (0). The total scores were ranged from (0 to 52) points. Accordingly, the level of mothers' reported practices was categorized as the following, poor level of practices(< 17 point), average

level of practices (< 34%) and good level of practice (34 to 52) points. The total score for all practice was classified as the following:

-Good reported practice $\geq 60\%$

-Average reported practice<40-60%

- Poor reported practice <40%

II. Operational design:

The operational design included: preparatory phase, content validity, reliability of tool, pilot study and field work.

The preparatory phase

This phase included reviewing the related literature and different studies related to systemic lupus erythematosus and theoretical knowledge of various aspects of the study, using textbooks, evidence based articles, internet, periodicals and journals to develop tools and to get acquainted with the various study aspects of the research problems.

Content validity:

Tools validity was checked through a jury of three experts (professors) of Pediatric Nursing from the Faculty of Nursing Benha University, and El-Mansoura University, to test the content validity of the instruments and to judge its clarity, comprehensives, relevance, simplicity, and accuracy.

Reliability:

Reliability for tools was applied by the researchers for testing the internal consistency of the tools .Internal consistency reliability of all items of the tools was assessed using Cronbach's alpha coefficient. This turned to be (0.72.) for children knowledge assessment sheet. Reliability of children screen health related quality of life; the value was (0.79). Reliability of children Self-Efficacy Scales, the value was (0.88).

Ethical Considerations:

Ethics approval granted from the Scientific Research Ethical Committee of Faculty of Nursing, Benha University, an official approval was obtained from directors of the Benha University Hospital. Informed consent was obtained from the studied mothers prior to data collection. The children and their mothers were informed about the purpose and the expected outcomes of the study. Also, the mothers were assured that the study was harmless to their children. their participation was voluntary and they have the right to withdraw from the study at any time without giving any reason.

Pilot study

A pilot study was carried out involving 10% of the total subjects (6) mothers who have children with systematic lupus and excluded from the present study

Field work:

Data collection for this study was carried out over a period of Five months starting from November 2022 until the end of March 2023. The researchers were available two days /week. Data was collected during the morning times from the previously mentioned setting. The researchers started to collect data through assessment, planning, implementation and evaluation phases as the following:

Assessment phase

Assessment phase involved interviews with children and their mothers' to collect baseline data. The researchers visited Benha University were Hospital in Benha city two days/ weeks by rotation from 9 AM and extended to 1.00 PM. At the beginning of interview: the researchers welcomed mothers, 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 and then the researchers asking the children and filled tool in by the researchers to assessed the mothers knowledge, it took nearly 30- 45 minutes, This period of pretest took 4 weeks starting from beginning to the end of November 2022).

Planning phase

Based on baseline data obtained from assessment phase and relevant review of literature, the family centered care empowerment model implementation

was designed by the researchers for mothers of children with systematic lupus according to the mothers needs. It was constructed, revised and modified from the related literature to improve quality of life, self-efficacy of mothers toward children with systemic lupus. The contents were prepared according to mothers' level of understanding in simple Arabic language. Selecting the teaching place study setting (teaching at the classroom). Different teaching methods were used such as: lecture. modified small group discussion, demonstration, and re-demonstration and role-play. Suitable media was used such as booklet, photos, power point presentation, educational videos, lab top, and CD to help proper understanding of the content by children and their mothers.

Design program: General objective:

The main goal of family empowerment implementation is to improve quality of life and self efficay of mothers toward children with systematic lupus erthymatous.

Specific objectives: At the end of the family empowerment implementation, the mothers will be able to:

Define systematic lupus erthymatous.,list predisposing factors , types , clinical manifestation , complication, investigation and management , type of treatment , role of corticosteroid in treatment, side effect of corticosteroid and <u>method to</u> <u>prevent it as well as possible</u> complication may occur from stop corticosteroid treatment and role of inflammatory drug in treatment of lupus.

Implementation phase:

This phase took two months from the beginning December 2022 to the end of January2023.

The implementation phase was achieved through sessions, each session started by a summary of the previous session and objective of the new one. Taking into consideration the use of Arabic language that suits the mothers' educational level Motivation and reinforcement during sessions were used to enhance motivation for the sharing in the study. Empowerment nursing intervention was designed and implemented by the researchers for mothers. The overall aim of the family empowerment intervention was to provision children their mothers' confidence. and advising about the disease. empowering against worried situations and getting with appropriate method of problem solving to increase mothers' quality of life and selfchildren with efficacy toward systemic lupus and decreases mothers strain level. Family empowerment nursing intervention contains four steps as follow:

First step: (knowledge enhancement)

To enhance knowledge of children and their mothers about lupus. The studied children were divided into 10 groups. The educational content was explained by the researchers to mothers in small group around (6 mothers) per each group. The family centered empowerment has taken 14 hours for each group 6 hours for theoretical part and 8 hours for practical part. The total numbers of sessions were 8 sessions distributed as sessions the following: (4) for theoretical part each session kept going for 30-45 minute and (4) sessions for practical part each session kept going for 45 minute.. These sessions were repeated to each group. Theoretical part as the following; the first session of the program included introduction of the family empowerment model, anatomy and immune system, physiology of definition, causes, risk factors and of systemic types lupus erythematosus. The second session clinical included manifestation. investigations, complication, contraindications that prevent child from taking medications regularly and treatment of systemic lupus. The third session included role of steroids in treatment of systemic lupus, side effect of steroids, measures followed to prevent side effects from steroids,

methods of withdrawing steroid dose the child's from body and complications happen if steroid stop The fourth suddenly. session included role of NSAD in treatment of systemic lupus, side effects of NSAD, measures followed to prevent side of effect NSAD. role of immunosuppressant drug in treatment of systemic lupus, side effects of immunosuppressant drug, role of antimalarial drug in treatment of systemic lupus and side effects of antimalarial drug. Fifth session included knowledge about nutrition and personnel hygiene. Sixth session include prevention from infection and drug adminstration. Seven session involved management of pain and fatigue. Eight sessions involved skin care and hair care.

Second step: (improvement of selfefficacy)

То enhance self-efficacy and competence, two learning sessions per week for three weeks was held by demonstration and re- demonstration teaching methods and practical presentation method. The duration of each session about 30-45 minutes. Firstly, the researchers explained to the mothers about the related skill and its importance and the complications that arise due to lack of its control. The researchers presented the ultimate procedure of the skill in front of the mothers. Then, the mothers were

asked obtain self-efficacy in other components of the skill through practice and repetition and to be able it without to do researcher's attendance. Finally, the mothers got completely self-efficient in the skill, learning and the feeling of learning when capability resulted in their encouragement and increased selfesteem. Mothers requested to perform all learned skills in every group discussion sessions. The following practical presentation including: The first session addressed the practice of mothers that involved demonstration nutrition and personnel hygiene. The second session involved demonstration to prevention from infection and drug adminstration. The Third session involved demonstration to management of pain and fatigue. The Fourth session involved demonstration to skin care and hair care.

Third step: (process evaluation)

It included evaluation method. In order to assess feedback at the start of every session, two verbal questions were requested to mothers from the prior session. Moreover, evaluation of self-efficacy was performed by asking the mothers to indicate the related skills properly. Evaluation of selfesteem and confidence was assessed by level of cooperation in education. After four weeks of holding the latest session, the researchers were made calls telephone to every participant to present in hospital to assure on the recommended skills and to be confident about use of the presented materials.

Evaluation phase:

After the implementation of the family empowerment contents, the post test was carried out to assess mothers knowledge by using the same formats of pretest. This help to evaluate the effect of family empowerment implementation, this done was immediately after application of empowerment sessions. This phase took two month from the beginning of Febrauary to the end of March 2023.

III- Administrative Design:

An official approval was taken from the Dean of the Faculty of Nursing Benha University to Rheumatology and Immunology Outpatient Clinics at Benha University Hospital in Benha city. A clear explanation was given about the nature, importance and expected outcomes of the study to carry out the study with minimal resistance.

IV- Statistical Design: The collected data organized, tabulated and statistically analyzed using Statistical Package for Social Science (SPSS) version 21 for windows, running on IBM compatible computer. Descriptive statistics were applied (e.g. frequency, percentages, mean and standard deviation). Test of

significance, Chi-square test (γ 2) this test used to measure significant of qualitative variables and correlation coefficient (r) used for quantitative variables that were normallv distributed or when one of the variables is qualitative. These tests applied to test the study were hypothesis. Reliability of the study tools was done using Cronbach's Alpha. A highly significant level value was considered when p < 0.001, a significant level value was considered when p < 0.05 and. No statistical significance difference was considered when p > 0.5.

Results

According to mothers characteristic,Half (50.0%) of studied mothers were in the age group 30 < 40, with mean \pm SD= 31.2667 ± 6.516 . Also, less than three quarter (70.0%) of studied mothers were living in rural areas. Meanwhile, more than one third (40.0%) of studied mother had secondary education.

Table(1): Illustrats that, more than half (55.0%) of the studied children were in the age group 12 < 14 years, with Mean \pm SD = $12.033\pm.839$. In relation to educational level, more than half (55.0%) of the children were in preparatory school. According to gender, nearly two thirds (63.3%) of studied children were females.This table also shows that, less than half (46.6%) of studied children had onset of disease at age between 10< 14 years. Also, less than three quarter(71.6%)of studied children had family history of systemic lupus. Meanwhile, nearly two thirds (61.6%)of studied children diagnosed through clinical manifestations.

Table (2): Represents that, less than three quarter (70.0%, 60.0%, 66.7%) and 53.3%) of the studied mothers had incorrect unknown or answer regarding definition of systemic lupus, clinical manifestations , investigations , complications , treatment and role of steroids in treatment of it., in the pre family empowerment implementation phase. While, more than three quarters of them (88.3%, 85.0%) had correct answer regarding all items in the post and after three month of family empowerment implementation phase respectively. The difference was a highly statistical significant with Pvalue < 0.001.

Table (3): Clarifies that nearly three quarter (76.7% & 70.0% and 60.0%) of the studied mothers had incorrect or unknown answer regarding side effects of steroids, prevent side effects from steroids, method of withdrawing steroid , complications from stopped suddenly, steroid role of immunosuppress drug, side effects of immunosuppressant drug , side effects of antimalarial drug and role of antimalarial drug in treatment of lupus in the pre family systemic

empowerment implementation phase. While, 88.3% and 85.0% of them had correct answer regarding all items in the post and after three month of family empowerment implementation phase respectively. The difference was a highly statistical significant with Pvalue <0.001.

Table (4): illustrates that, less than three quarter(70.0% & 76.7% & 63.3%) of the studied mothers had poor quality of life level at pre family implementation. empowerment While, (73.3% & 78.3% & 71.7%) of studied mothers had good quality of life level at post and after three months of family empowerment implementation respectively. Moreover, there was а highly statistically significant difference at pre, post and after three months of family empowerment implementation regarding in all domains of quality of life ($P \le 0.001$).

Table (5): Presents that, there was a highly statistically significant difference mothers in reported practice regarding care of children with systemic lupus erythematosus at post and after three months of of family empowerment implementation as compared to pre of of family empowerment implementation (P=<0.001).

Table (6): Revealed that, there ispositive correlation between studiedmothers total knowledge,quality of

life, reported practice and self efficacy (p value < .001) after family empowerment implementation.

Fig (1): Illustrates that, less than one third (30.0%) of studied children had one pervious hospitalization.

Fig (2): Shows that, more than one third (34.0%) of children with systemic lupus had arthritis, 26.0% of them had fatigue and 18.0% of them had skin rash.

Fig (3): Illustrates that, more than one third (33.3%)of studied children were previously hospitalized due to complications of urinary system.

Fig (4): Demonstrates that, more than two third (60.0% & 78.3%) of studied mothers had good level of knowledge at post and after three months of family empowerment implementation as compared to pre family empowerment implementation.

Fig (5): displays that, less than one third 10.0% of studied mothers had good level of all domain quality of life at pre family empowerment implementation. While, majority (80.0% &78.3%) of studied mothers had good level of all domain quality of life at post and after three months of family empowerment implementation respectively.

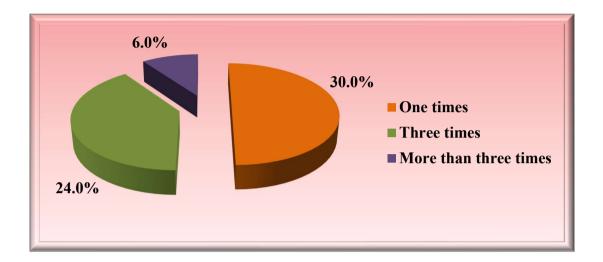
Figure (6): Illustrates that, less than one third 25.0% of studied mothers

had low self-efficacy level at pre family empowerment implementation, while, majority (90.0%) and 46.7% of studied mothers had high self-efficacy at post and after three months of family empowerment implementation. Fig (7): Illustrates that, majority (81.7% & 83.3%) of the studied mothers had good reported practice level at post and after three months of family empowerment implementation compared family as to pre empowerment implementation respectively.

 Table (1): Distribution of the studied children regarding their characteristics (n=60).

Children characteristics	Studied Children (n =60)					
	No.	%				
Child age						
8<10 years	9	15.0				
10< 12 years	14	23.4				
12< 14 years	33	55.0				
\geq 14 years	4	6.6				
Mean ±SD = 13.033±.839						
Child education						
Primary School	27	45.0				
Preparatory School	33	55.0				
Ranking						
First child	20	33.4				
Second child	21	35.0				
Third child	9	15.0				
Fourth child	10	16.6				
Onset of disease						
-3< 6 years	5	8.4				
6< 10 years	27	45.0				
10< 14 years	28	46.6				
Mean ±SD= 10.850±1.070						
Family history of systemic lupus						
Yes	43	71.6				
No	17	28.4				

Figure (1): Frequency distribution of studied children regarding to number of hospitalization (n=60).



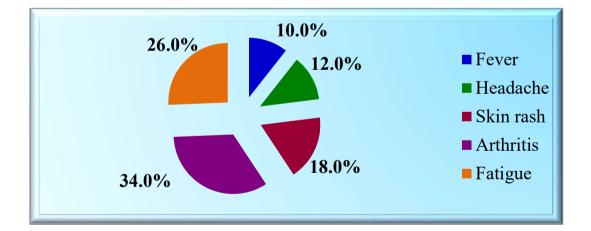


Figure (2): Frequency distribution of studied children regarding clinical manifestation (n=60).

Figure (3): Frequency distribution of studied children regarding causes of **pervious hospitalization (n=60).**

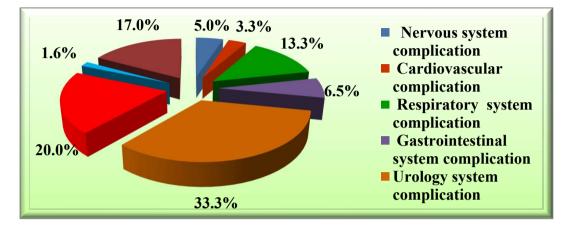


Table (2): Distribution of the studied mothers knowledge towards systemic lupus erythematosus thorough family empowerment implementation phases (n =60).

						Phases o	of famil	y empo	wermei	nt implen	nentati	on(n=0	50)									
Items of Knowledge related to systemic lupus erythematosus	Pre	Pre- family empowerment implementation							Post family empowerment implementation							empower entation	ment				0	
	Complete correct answer		Incorrect or unknown answer		Complete correct answer		Incomplete correct answer		Incorrect or unknown answer		Complete correct answer		Incomplete correct answer		Incorrect or unknown answer		X ² (1)	P value	X² (2)	P value		
	N.	%	N.	%	N.	%	N.	%	N.	%	N.	%	N.	%	N.	%	N.	%				
Definition of systemic lupus	2	3.3	22	36.7	36	60.0	51	85.0	9	15.0	0	0.0	54	90.0	6	10.0	0	0.0	19.687	<0.00	21.439	<0.00
Clinical manifestations of systemic lupus	2	3.3	16	26.7	42	70.0	53	88.3	7	11.7	0	0.0	52	86.7	8	13.3	0	0.0	10.220	<0.05	8.585	< 0.05
Investigations of systemic lupus	2	3.3	38	63.3	20	33.3	48	80.0	12	20.0	0	0.0	36	60.0	24	40.0	0	0.0	29.114	<0.00	8.585	< 0.05
Complications of systemic lupus	4	6.7	24	40.0	32	53.3	39	65.0	21	35.0	0	0.0	38	63.3	22	36.7	0	0.0	8.998	< 0.05	8.548	< 0.05
Treatment of systemic lupus	8	13.3	24	40.0	28	46.7	49	81.7	11	18.3	0	0.0	48	80.0	12	20.0	0	0.0	29.417	<0.00	24.122	<0.00
Role of steroids in treatment of systemic lupus erythematosus	4	6.7	16	26.7	40	66.7	44	73.3	16	26.7	0	0.0	48	80.0	12	20.0	0	0.0	9.455	<0.05	11.204	<0.05

 Table (3): Distribution of the studied mothers knowledge about medications of systemic lupus erythematosus thorough

 empowerment implementation phases (n= 60).

							Phase	es of emp	owern	nent impl	ement	ation										
Items of	Pre-	Pre- empowerment implementation						t empowei	rment	implemer	ntatior	l l	After	empowe	erment	t implen	aentati	ion				
knowledge related to medications of systemic lupus erythematosus	Complete correct answer		Incomplete correct answer		Incorrect or unknown answer		corr	Complete correct answer		Incomplete correct answer		orrect nown ver	correc	Complete correct answer		Incomplet e correct answer		orrect nown wer	X ² (1)	P value	X ² (2)	P value
	N.	%	N.	%	N.	%	N.	%	N.	%	N.	%	N.	%	N.	%	N.	%	'			
Side effects of steroids	5	8.3	25	41.7	30	50.0	47	78.3	13	21.7	0	0.0	45	75.0	15	25.0	0	0.0	12.543	<0.00	10.662	< 0.00
Prevent side effects from steroids	4	6.7	24	40.0	32	53.3	53	88.3	7	11.7	0	0.0	42	70.0	18	30.0	0	0.0	22.315	<0.00	18.968	<0.00
Method of withdrawing steroid dose from the child's body	2	3.3	22	36.7	36	60.0	50	83.3	10	16.7	0	0.0	48	80.0	12	20.0	0	0.0	12.204	< 0.05	10.251	< 0.05
Complications that occur from stopped steroid suddenly	2	3.3	16	26.7	42	70.0	53	88.0	7	12.0	0	0.0	53	88.0	7	12.0	0	0.0	8.186	< 0.05	8.186	<0.05
Role of immunosuppress drug in treatment of systemic lupus	2	3.3	12	20.0	46	76.7	49	81.7	11	18.3	0	0.0	48	80.9	12	20.0	0	0.0	4.155	>0.05	3.532	>0.05
Side effects of immunosuppressant drug lupus erythematosus	2	3.3	22	36.7	36	60.0	51	85.0	9	15.0	0	0.0	48	80.0	12	20.0	0	0.0	13.265	<0.05	12.602	<0.05
Side effects of antimalarial drug	4	6.7	24	40.0	32	53.3	48	80.0	12	20.0	0	0.0	46	76.7	14	23.3	0	0.0	24.210	<0.00	28.689	<0.00
Role of antimalarial drug in treatment of systemic	2	3.3	22	26.7	42	70.0	38	63.3	22	36.7	0	0.0	34	56.7	26	43.3	0	0.0	40.247	<0.00	33.003	<0.00

Fig (4): Distribution of the studied mothers total knowledge score regarding to systemic lupus erythematosus thorough family empowerment implementation phases (n= 60).

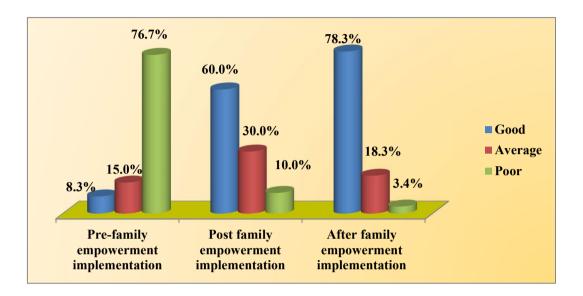


Table (4): Distribution of the total level of domains for studied mothers regarding their quality of life score thorough family empowerment implementation phases (n =60).

	Pha	ses of fa	amily	empov	verme	ent imple	ement	ation(n	=60)													
Domain	Pre family empowerment implementation						Post family empowerment implementation								ths family nplement			$X^{2}(1)$				
	Good		Average		Poor		Good		Ave			Poor		Good		Average		or	$X^{2}(1)$	P value	X ² (2)	P value
	N.	%	N.	%	N.	%	N.	%	N.	%	N.	%	N.	%	N.	%	N.	%				
Physical health	8	13.3	10	16.7	42	70.0	48	80.0	10	16.7	2	3.3	44	73.3	13	21.7	3	5.0	96.40	0.000	81.70	0.000
Psychological health	6	10.0	16	26.7	38	63.3	47	78.3	12	20.0	1	1.7	43	71.7	16	26.7	1	1.7	83.80	0.000	71.30	0.000
Social relationships	2	3.3	12	20.0	46	76.7	40	66.7	17	28.3	3	5.0	44	73.3	16	26.7	0	0.0	87.90	0.000	66.20	0.000
Environment	10	16.7	20	33.3	30	50.0	48	80.0	10	16.7	2	3.3	47	78.3	13	21.7	0	0.0	60.40	0.000	39.26	0.000

Figure (5): Distribution of the studied mothers regarding their total quality of life thorough family empowerment implementation phases (n = 60).

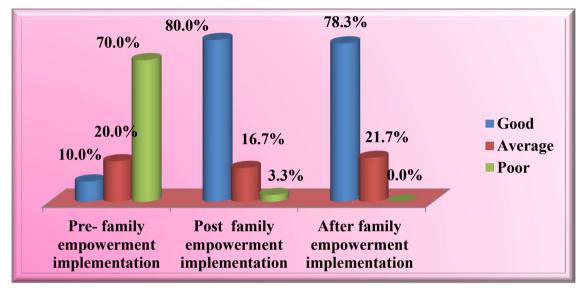


Figure (6): Distribution of the studied mothers self-efficacy scores regarding children with systemic lupus thorough family empowerment implementation phases (n = 60).

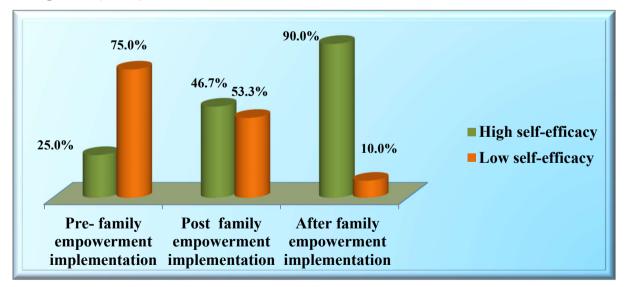


Table (5): Mean scores of the studied mothers reported practice regarding care of children with systemic lupus erythematosus thorough family empowerment implementation phases (n=60).

	Phases of family	empowerment imple	mentation(n=60)				
Items	Pre- family empowerment implementation	Post family empowerment implementation	After family empowerment implementation	Pair t (1)	P value	Pair t (2)	P value
	Mean ± SD	Mean ± SD	Mean ± SD				
Nutrition	$7.500{\pm}5.043$	15.450±6.431	14.716±6.375	14.437	0.00	13.889	0.00
Personnel hygiene	4.383±3.617	8.533±3.698	7.700±3.665	13.677	0.00	12.012	0.00
Drug adminstration	5.633±4.290	8.950±4.224	9.716±4.017	14.432	0.00	14.564	0.00
Prevention from infection	5.300±5.624	13.491±5.440	11.400±5.459	13.024	0.00	11.809	0.00
Management of pain and fatigue	5.283±4.166	8.583±3.562	9.100±3.563	14.774	0.00	14.337	0.00
Skin care	5.750±5.385	10.350±5.341	11.166±5.459	12.725	0.00	12.487	0.00
Hair care	4.650±4.095	9.216±4.438	9.966±4.352	12.899	0.00	12.848	0.00

Figure (7): Distribution of the studied mothers total reported practice scores regarding care for children with systemic lupus erythematosus thorough family empowerment implementation phases (n= 60).

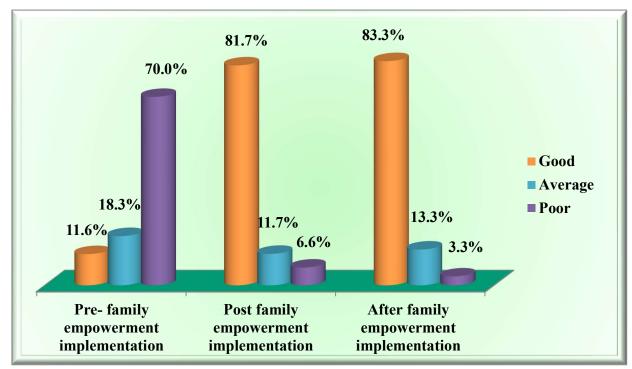


Table (6): Correlation between studied mothers total knowledge, quality of life, reported practices and self efficacy toward children with systematic lupus through family empowerment implementation (No= 60).

		Pearson correlation coefficient														
Items	Knowled	ge score	Repor practice		Quality scor		Self efficacy score									
	Pearson	Sig	Pearson	Sig	Pearson	Sig	Pearson	Sig								
Knowledge score	1	-	.879**	<.001	.940**	<.001	1	-								
Reported practice score	.879**	<.001	1	-	.938**	< .001	0.929	0.000**								
Quality of life score	.940**	<.001	.938**	<.001	1	-	0.480	0.000**								
Self efficacy score	0.929	0.000**	0.480	0.000^{**}	1	-	1	-								

** Correlation is significant at the 0.01 level (2- tailed). Discussion 36.68=

Systemic lupus erythematosus (SLE) is one of the most common autoimmune diseases in children caused by highly abnormal immune systems and accompanied by extreme morbidity and mortality rate and poor quality of life. It is a multisystem autoimmune disease with extensive organs involvement characterized by chronic and actuating course. Also, it constitutes a vital pediatric problem because of their influence on children's health and their strong correlation with behavioral, psychological, and social problems and associated with high significant of morbidity and mortality rate, decreased substantial direct and indirect economic costs and effect on quality of children life⁽²⁴⁾.

Regarding characteristics of studied mothers', the present study showed that, half of studied mothers were in the age group 30 < 40, with mean $\pm SD = 31.2667 \pm 6.516$. Also, less than three quarter of studied mother were living in rural areas. Meanwhile, more than one third of studied mother had secondary education. This result was paralleled with Phuti, et al. (2019) ⁽²⁵⁾, who studied "Living with systemic lupus erythematosus in South Africa, " and observed that, slightly more than half of the studied mothers their age was 31 years old and above, with mean age \pm SD (30.3 \pm 11.6). The educational level of about two thirds of mothers were secondary education. Also, this study accordance with Abdel Aziz, et al. (2022) ⁽²⁶⁾, who studied " Assessment of mothers' knowledge and practices towards systemic lupus erythematosus" and found that, 62% of the studied mothers were in the age group 30 < 40 years with a mean age

 $36.68 \pm$ 6.88 old. Concerning years educational level, 42% of the studied mothers had secondary education. Meanwhile, this finding incomparable with Tecza, & Pych. (2018) ⁽²⁷⁾: who studied" nursing care of a patient with systemic lupus erythematosus" and found that, more than half (55.9%) of the studied mothers were in the age group ≥ 40 years with \pm SD was 39.62 \pm 5.86 years and more than one third(38.3%) of them were intermediate education, while the majority 88.3% of them were housewives.

As regard, age of studied children, the current study revealed that, more than half of the studied children were aged 12< 14 years, with Mean \pm SD = 13.033 \pm .839. This result was paralleled with, Pradeep, et al. (2022) ⁽²⁸⁾, who studied, "Primary Healthcare Practitioners' Knowledge, Attitude, and Practice Toward Systemic Lupus Erythematosus" and found that reported in the majority of studies is between 11 to 12 vears. Also, This result matched with El-Sayed, & Mesbah . (2018), ⁽³⁾ who studied" effect of health education based intervention self-care among systemic lupus on erythematosus clients" and found that, the majority (85% and 83.3%) of the studied children was in the age group from 12-18 years and females respectively. This may 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

As regard, educational level of the studied children, the present study illustrated that, more than half of the children were in preparatory school. This study matched with Mohamady, et al. (2022)⁽²⁹⁾, who studied" effect of self- care management on health outcomes and symptoms for females with erythematosus" systemic lupus and mentioned that, 54% of the children were in preparatory school. While 36% of studied children were ranked as second children in their families. This finding was supported by Pilevar, et al. (2019)⁽¹⁹⁾, who studied "Effect of Implementing Family-centered Empowerment Model on the Quality of Life in School-age Children Diagnosed with Rheumatoid Arthritis" reported that, found that, 37.5% of the children are in preparatory school. Also, nearly two thirds of studied children (Intervention and control groups) were females, 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.

As regard clinical manifestation of systematic lupus, the current study illustrated that, more than one third of children with systemic lupus had arthritis, less than one third of them had fatigue and skin rash. This study accordance with Lewandowski, et al. (2017)(30), who studied missed " for timely opportunities diagnosis of pediatric lupus in South Africa: a qualitative study" and found that, the majority of SLE patients in this study 63% had severe symptoms such as arthritis, skin rash fatigue, GIT disturbance and pericarditis requiring intervention at the time of diagnosis. That's go in the same direction with Mohamady, et al. (2022)⁽²⁹⁾, the most common symptoms of studied females were fatigue 87.9%, pain

74.2%, skin rash 71.2% as well, 69.7% had hair loss & 60.6% complaining of arthritis As regards, previous hospitalization, less than one third of studied children had one pervious hospitalization. This result was supported Shoeib, et al. (2018) ⁽³¹⁾, who studied "Hospitalization of systemic lupus patients " and mentioned that more than two fifth of studied patient admitted to hospital one time, while more than three quarters of studied patient the cause of admission was nephritis. This result agreed with the result by Petrongolo, et al. (2020) (32), who studied" examining uncertainty in illness in parents and children with chronic kidney disease and systemic lupus erythematosus" and found that, the most frequently reported diagnoses were genitourinary 28.1%, followed by neurology-endocrinology 25.0%, hematology.

previous As regards. cause of hospitalization, the present study revealed, more than one third of studied children were previously hospitalized due to complications of urinary system. This result agreed with the result by Samar et al. (2020) (33), who studied" An audit study on the management of children with lupus nephritis admitted to Assiut University Children Hospital" and found that more than half of studied children to hospital due admitted to renal complications and nephritis. This may be due to the inflammation caused by lupus being able to affect many organs of body and can deposition in circulating immune be complexes in the glomerular basement membrane that can lead to lupus nephritis and renal failure.

On assessing mothers' total knowledge about systematic lupus erythematous, the present

study showed that, less than two third of studied mothers had good level of knowledge at post and after three months of family empowerment implementation as compared to pre family empowerment implementation. That's go in the same direction with Hovde, et al. (2019)⁽³⁴⁾, who studied" Multi-pronged approach to enhance education of children and adolescents with lupus, caregivers, and healthcare providers in New Jersey " and found that, 86% of mothers had unsatisfactory knowledge about systematic lupus before the program implementation. While, total knowledge satisfactory level of mothers increased at immediate post and one month after the program respectively with highly statistically significant difference P <. 0.001. Also, this result similar to Khawaja, et al. (2018) ⁽³⁵⁾, who studied" parental knowledge participation and in the management of children with systemic lupus erythematosus" and showed that, a highly statistically significant improvement was detected in the total mean scores of mothers' knowledge about systematic lupus immediate post and one month after attending the empowerment program with P.=0.001. Meanwhile, this study accordance with Asiri, et al. (2020)⁽³⁶⁾, who studied" awareness of systemic lupus erythematosus among general population in Abha, KSA" and found that, 90% of studied mothers had unsatisfactory level of knowledge toward systemic lupus at preprogram while 82% of studied mothers had satisfactory level of knowledge toward systemic lupus post program implementation. This may be due to mothers 'had lack of knowledge about nature of the disease and knowledge is important to help mothers' in the management of chronic disease to prevent complications.

In relation to total quality of life of studied mothers, this study clarified that, less than one third of studied mothers had good level of all domain quality of life at pre family implementation. empowerment While. majority of studied mothers had good level of all domain quality of life at post and after three months of family empowerment implementation respectively. This finding was supported by Ramos et al. (2015) ⁽³⁷⁾, who studied," Burden and quality of life of mothers of children and adolescents with chronic illnesses ". reported that, majority of mothers have low quality of life of mothers preprogram while 75% of mothers had high level of quality of life post and after three month of program implementation. This may be due to family caregivers of chronic children are under a lot of pressure as those at risk of disease are often referred to as a hidden disease. Family empowerment model provide mothers sufficient knowledge and practice help mothers to deal with children with systematic lupus erythematous. Furthermore, these practices reduce the psychological stress of family members and promote their QOL and self-efficacy.

Concerning, studied mothers reported practice, majority of the studied mothers had good reported practice level at post and after three months of family empowerment implementation as compared to pre family empowerment implementation. This result was congruent with the study done by **Abdel Aziz, et al. (2022)**⁽²⁶⁾, illustrated that, before the program all mothers had unsatisfactory level of reported practice. While as immediate and one month after 70%, and

50% had satisfactory level of practice respectively. Shoeib, et al. (2018)⁽³¹⁾, found that, there was highly statistically significance improvements in mothers' reported practices at immediately post and following up phases of guidelines implementation as regards all items of their reported practices about systemic lupus erythematosus in their children. Also, This study agreement with Tamrou, et al. (2019) who studied " Systemic lupus (38) erythematosus: state of the art on clinical practice guidelines" and found that, the majority (82.5%) of the studied mothers had incomplete practices level preprogram, while the majority (90%) of them had complete practices level post program with a highly statistically significant difference pre/post program, where (p<0.001). This result was in the same line with Faheim, et al. (2023)⁽³⁹⁾, who studied " Effect of Nursing Educational Guidelines on Knowledge and Practices of Mothers having Children with Systemic Lupus Erythematosus" and found that, there are 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 significant correlations between knowledge practices and mothers and age and occupational level at pre and follow-up guidelines implementation phases. This could be due to lack of continuous training and education performed for mothers' regarding care of their children with SLE.

Concerning, studied mother's self-efficacy, the current study illustrated that, less than one third of studied mothers had low self-efficacy level family empowerment at pre implementation, while, majority of studied mothers had high self-efficacy at post and after three months of family empowerment implementation. This study accordance with Barani, et al. (2021)⁽⁴⁰⁾, who studied " effect of educational intervention based on self-efficacy theory on the caring behavior of mothers having children with cancer " and found that, a significant difference in the mean score of mothers' self-efficacy after intervention (P < 0.001). Besides, the twoway self-efficacy score of the first and second follow-ups was p = 0.096. Furthermore, the mean score of caring behavior before and after the intervention indicated a significant difference (P < 0.001). Also, that's go in the same direction with <u>Hameed, et al.</u> (2021) (41) who studied " knowledge, attitude, practice, and self-efficacy of caregivers of children with epilepsy" and found that, significant improvements in the knowledge, attitude, and reported practice as well as the self-efficacy scores of caregivers of children with epilepsy following the implementation of the educational intervention. Meanwhile, this result similar to Hegazy, and Dawood. (2021)⁽⁴²⁾, who studied " effect of upgrading mothers' awareness regarding cardiovascular diseases on their self- efficacy to promote their children life style" and found that, the mothers had elevated self-efficacy mean scores immediately after the educational intervention 235.167±29.656 compared to before program. There were statistically significant differences regarding the total means scores of the mothers' self-efficacy before, immediately after and one month of educational after application the intervention (p<0.001).

Regarding, studied mothers total knowledge, quality of life, reported practice and selfefficacy, this study showed that, there is positive correlation between studied mothers total knowledge, quality of life, reported practice and self-efficacy (p value < .001) after family empowerment implementation. This study in accordance with Nada, et al. (2018) ⁽⁴³⁾, who studied" Effect of Health Education Intervention on Mothers' Performance of Their ChildrenSuffering from Systemic Lupus Erythematosus" and mentioned that, there statistical significant differences in knowledge 21.33 ± 2.23 , attitude 53.94 ± 9.45 , and self-efficacy 137.62 ± 11.32 in mothers before and after the intervention, with the difference being significant (P < 0.01). This could be due to mothers who attended good knowledge has good practice and knowledge is the baseline for the practices.From the researcher point of view ,present study show the important of family empowerment on knolwdge and reported practice of mothers that enhance to increase self efficacy and quality of life for mother caring children with sysrematic lupus erythmateous

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 reported practices levels pre, post-test, and after three months of family empowerment implementation. Also, mothers' knowledge significantly improved and mothers' reported practices significantly enhanced after the implementation of family empowerment implementation than pre family empowerment implementation. Meanwhile, that there was a highly statistically significant differences between mother's self-efficacy and quality of life improved in post and after three months offamily empowerment implementation than pre family empowerment implementation.

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, it may be fatal if neglected.

2. Dissemination of research updated pamphlets, posters and Arabic booklets 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. Family empowerment program should be conducted for caregiver periodically and regularly regarding systematic lupus erythematous to minimize complication among children

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