Effect of implementing Family Empowerment Model on the Quality of Life and Self-Efficacy of Mothers of Children with Systematic Lupus Erythematous

Amal A. Abdel-Salam 1, Seham Mohammed Abd-El Aziz 2, Maha El sayed El arabe 3, Sabah Mohamed Sharshour 4

1,2 Assistant Professor of Pediatric Nursing, Faculty of Nursing, Benha University
3 Lecturer of Pediatric Nursing, Faculty of Nursing, Tanta University
4 Assistant Professor of Pediatric Nursing, Faculty of Nursing, Tanta University

Abstract
Systemic lupus erythematous in children is a multisystem disease with extensive organ involvement. Mothers may struggle to manage their child’s health, their own emotions and had positive effect on mothers quality of life and self-efficacy. The aim of the study: Was to evaluate effect of implementing family empowerment model on quality of life and self-efficacy of mothers of children with systematic lupus. Research design: A quasi-experiental design. Setting: This study was conducted at Rheumatology and Immunology Department and Outpatient Clinics at Benha University Hospital


Results there was a highly statistically significant differences between total scores of knowledge and reported practices levels after family empowerment implementation. Also, that there was a highly statistically significant differences between mother’s self-efficacy and quality of life. Conclusion: implementation of family empowerment model were improving quality of life and self-efficacy of mothers of children with systematic lupus

Recommendation: Family empowerment program should be conducted for caregiver periodically and regularly to enhance care of their children with Systemic lupus erythematous.

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

Introduction
Systemic lupus Erythematous (SLE) is an autoimmune disease that affects the connective tissue in different organs. It is a long-term illness that causes organ dysfunction. (1) Systemic lupus Erythematous can cause a wide range of symptoms, including joint pain, rash, photosensitivity, and fatigue, as well as irreversible organ damage and death. It has been linked to significant morbidity and mortality, as well as significant negative effects on children perceptions of health and daily activities. (2) Other lupus symptoms are damage to a particular organ system, joint pain and stiffness, skin changes, changes in kidney function, the digestive system can be affected by medications used to treat lupus. Also, lupus can affect lung, heart, nervous system and eye. (3) Systemic lupus Erythematous (SLE) is a Significant global public health problem. The estimated 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 yearly (4). 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 (≤ 7 years); 73.3%, peri-pubertal; and 19.3% during early adolescence (5).

The nature of systematic lupus 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 care, and the role of the active member in child care in the family is very effective in the process of treatment and recovery of the child. (6) It is clear that children need concentration, self-control, and autonomy. In addition, the lack of physical activity may prevent the involvement of children with chronic disease in school and extracurricular activities creating a sense of humility and inadequacy (7).

The mothers are the primary caregivers for their children with a long-lasting disease and take responsibility for monitoring, management, and protection despite the level of skills and complexity involved in 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, to perform home care effectively each mother requires receiving extensive training skills, instructions about the child's care, and guidance about proper diet, sun protection, exercise, appropriate immunizations, and management of comorbid conditions, which leading to better self-efficacy and quality of life for mothers and improve child's health outcomes.

Quality of life (QOL) is an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their aims, expectations standards and interests, conditioned by the environment. (8,9) Self-efficacy was refers to the ability of performing a particular function that a person expects from his/her ability to do in different situations. Self-efficacy is the most important precondition to change behavior. Self-efficacy is one of the concepts of family-centered empowerment model. In fact, empowering the children and his family 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. (10) Awareness of mother about the disease is a vital part of the child care and is essential for caring and 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 child’s care 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. (11)

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. (12,13) The empowerment approach
should be tailored to the caring conditions of a child with a chronic disease or disability. Family-centered empowerment model is designed with an emphasis on the effectiveness of the family role in the dimensions of motivation, knowledge, attitude, and perceived threat, 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 promote health. (14)

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 skill development. In general, family-centered empowerment can be considered an important way to improve children self-care and to involve family members. 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 diseases can have adverse effects on family members, especially mothers, and can reduce self-esteem and increase anxiety and stress that may affect their quality of life. (15)

Meanwhile, nurses are one of the most appropriate members of the health team for training of mothers due to their vocational and professional responsibility and ability to undertake different roles in health service systems (3). Also, nurse can play an important role in the process of treatment of systemic lupus Erythromatosus especially during periods of exacerbation of the disease. Because the nurse helps 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 health education concerning lifestyle changes. The nurse supports the children and family by giving the necessary help, provides emotional support to the pediatric patient and family, undertaking educational actions connected with lifestyle and rehabilitation to improve their quality of life. (16,17)

**Significance of the Study**
Systemic lupus Erythematosus has a negative effect on mother’s quality of life and self-efficacy (18). The children with lupus represent a traumatic stressful for their mothers due to lack of mothers’ awareness to handling their children and expenses finance to manage their children with SLE (19). Systemic lupus Erythematosus (SLE) is a significant global public health problem. The estimated incidences of the systematic lupus in Egypt, is 1/100,000 population.

**Aim of the Study**
The aim of this study was to evaluate the effect of implementing family empowerment model on quality of life and self-efficacy of mothers of children with systemic lupus Erythromatosus.

**The research hypotheses:**
Mother’s quality of life and self-efficacy are expected to be improved after implementing family empowerment model. **Study Design**
A quasi-experimental research design was utilized for conducting the study.

**Setting**
The study was conducted at Rheumatology and Immunology Department and Outpatient Clinics at Benha University Hospital. Rheumatology and Immunology Department located in the Seventh floor, and 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 are 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 8-14 years old.
- 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.

Tool (I): Mothers knowledge questionnaire a structured interviewing questionnaire Sheet
This tool was developed by the researchers based on the previous related literatures (12) and used for collection of data related children with systematic lupus. It was divided into three main parts:

Part (1): Mothers' personal characteristics: including; age, educational level, occupation, number of family members, consanguinity and residence.

Part (2): Children' bio-soico-demographic characteristics :– It consisted of data related to children socio-demographic data including; data related to children, through individual interviewing of children and their accompanying mothers such as age, gender, education, residence and ranking. And Mothers knowledge regarding children's medical history including ; age of the child at diagnosis, onset of disease, family history of systemic lupus, duration of disease, systematic lupus symptoms, method of diagnosing lupus, number of previous hospitalization, and causes of previous hospitalization and duration of follow up. The researchers collected medical data of studied children.

Part (3): Mothers Knowledge Assessment Format
It was designed by the researchers based on Hockenberry and Wilson, (2021) (20), to assess Mothers' knowledge about systemic lupus Erythematosus questionnaire sheet. It was this part consisted of (14) multiple-choice 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, complication, investigation and management.

B) Mothers Knowledge regarding medications ; It included 6 questions: Type of treatment of systematic lupus, role of corticosteroid in treatment of lupus, side effect of corticosteroid,
method to prevent side effect from corticosteroid, 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 (≥ 60%) was ranged from (19 to 28) points.

**Tool (2): Mothers Quality of Life questionnaire**

It was a adapted from Skevington, et al., (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 domains: physical health (6 items) psychological health (6 items) social relationships (3 items) and environment (7 items).

**Scoring system Mothers Quality of Life**

- Mothers’ responses were 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 following, good level was ranged from (80-120) points,

- Poor level of knowledge < 60% = <71
- Moderate level of knowledge 60 – 80= 72-95
- High level of knowledge = 80% = 96 -120

**Tool (3): Mothers Self-Efficacy Scales**

Was adapted from a standardized likert type rating scale by Kankaras (2017) (22), to assess mothers self-efficacy. 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**

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-efficacy was ranged from (51 -85) points and low self-efficacy (less than 45) point.

- High self-efficacy ≥ 60%
- Low self-efficacy <60%

**Tool (4): Mothers Reported Practices Assessment 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 and after family
empowerment implementation. It consisted 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 and not done as reported by mothers 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 ≥ 60%
- Poor reported practice <40%

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 literatures 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 Mothers knowledge assessment sheet. Reliability of Mothers’ quality of life; the value was (0.79). Reliability of Mothers ‘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 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 mothers who accompanied their children to the study settings to collect baseline data. The researchers were visited Benha University Hospital 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 . 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 mother’s needs. It was constructed, revised and modified 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 at the study setting (teaching 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.

**Program Design**

**General objective**
The main goal of family empowerment implementation is to improve quality of life and self-efficacy of mothers of children with systematic lupus erythematous.

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

1. Define systemic lupus erythematos., list predisposing factors, types, clinical manifestation, complication, investigation and management, type of treatment, role of corticosteroid in treatment, side effect of corticosteroid and method to prevent it as well as possible 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 January 2023.

The implementation phase was achieved through sessions, each session started by a summary of the previous session and objective of the new one. Motivation and reinforcement during sessions were used to reinforce 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 enhance mothers self-efficacy and hence their quality of life confidence, advising about the disease, empowering against worried situations and getting with appropriate method of problem solving to increase mothers' quality of life and self-efficacy toward children with systemic lupus and decreases mothers strain level. Family empowerment nursing intervention contains four steps as follow:

**First step: (knowledge enhancement)**

To enhance Mothers' knowledge 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 total numbers of sessions were 10 sessions distributed as the following; (6) sessions 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, definition, causes, risk factors and types of Systemic Lupus Erythematosus. **The second session** included clinical 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 from the child’s body and complications happen if steroid stop suddenly. **The fourth session** included role of NSAD in treatment of systemic lupus, side effects of NSAD, measures followed to prevent side effect of 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 administration.

**Second step: (improvement of self-efficacy)**

To 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 to do it without 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 self-esteem. 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 about nutrition and personnel hygiene. **The second session** involved demonstration to prevention of infection and drug administration. **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 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 was done immediately after application of empowerment sessions. This phase took two month from the beginning of February to the end of March 2023.

**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.

**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 (χ2) this test used to measure significant of qualitative variables and correlation coefficient (r) used for quantitative variables that were normally distributed or when one of the variables is qualitative. These tests were applied to test the study 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.

**Result**

According to mothers characteristic, Half (50.0%) of studied mothers were in the age group 30<40, with mean ±SD= 31.2667±6 years. Also, less than three quarters (70.0%) of studied mothers were living in rural areas. Meanwhile, more than one third (40.0%) of studied mothers had secondary education.

**Table(1):** Illustrates that, more than half (55.0%) of the studied children were in the age group 12< 14 years, with Mean ±SD = 12.033± years. 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 quarters (70.0%, 60.0%, 66.7% and 53.3%) of the studied mothers had incorrect or unknown 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 highly statistically significant with P-value <0.001.

Table (3): Clarifies that nearly three quarters (76.7% & 70.0% and 60.0%) of the studied mothers had incorrect or unknown answer regarding side effects of steroids, prevention of side effects from steroids, method of withdrawing steroid, complications from stopped steroid suddenly, role of immunosuppress drug, side effects of immunosuppressant drug, side effects of antimalarial drug and role of antimalarial drug in treatment of systemic lupus in the pre family 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 P-value <0.001.

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

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

Table (6): Revealed that, there is a positive correlation between studied mothers total knowledge, quality of life, reported practice and self-efficacy (p value < .001) after family empowerment implementation.

Fig (1): 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 (2): displays that, less than one third 10.0% of studied mothers had good level of all domain quality of life at pre family empowerment
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.

Fig. (3): 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 (4): 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 as compared to pre family empowerment implementation respectively of knee that affect level of daily activity (66.7% and 60.0% respectively) at 2nd day of operation, which developed after 1st week of operation in the control and study groups to (56.7% and 23.3% respectively), then become much better in the control and study groups at the 2nd week of the operation (50% and 10% respectively).

Figure 3: Illustrate distribution of the studied patients according to their total of functional limitation of activity of daily living by Knee Outcome Survey-Activities of Daily living scale(ADL). The result show that more than half of studied patients in control and study groups were suffering from high functional limitation of activity of daily living (66.7% and 63.3% respectively) at 2nd day of operation, which developed
Table (1): Distribution of the studied children regarding their characteristics (n=60).

<table>
<thead>
<tr>
<th>Children characteristics</th>
<th>Studied Children (n =60)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
</tr>
<tr>
<td><strong>Child age</strong></td>
<td></td>
</tr>
<tr>
<td>8&lt;10 years</td>
<td>9</td>
</tr>
<tr>
<td>10&lt; 12 years</td>
<td>14</td>
</tr>
<tr>
<td>12&lt; 14 years</td>
<td>33</td>
</tr>
<tr>
<td>≥ 14 years</td>
<td>4</td>
</tr>
<tr>
<td><strong>Mean ±SD = 13.033±.839</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Child education</strong></td>
<td></td>
</tr>
<tr>
<td>Primary School</td>
<td>27</td>
</tr>
<tr>
<td>Preparatory School</td>
<td>33</td>
</tr>
<tr>
<td><strong>Ranking</strong></td>
<td></td>
</tr>
<tr>
<td>First child</td>
<td>20</td>
</tr>
<tr>
<td>Second child</td>
<td>21</td>
</tr>
<tr>
<td>Third child</td>
<td>9</td>
</tr>
<tr>
<td>Fourth child</td>
<td>10</td>
</tr>
<tr>
<td><strong>Onset of disease</strong></td>
<td></td>
</tr>
<tr>
<td>-3&lt; 6 years</td>
<td>5</td>
</tr>
<tr>
<td>- 6&lt; 10 years</td>
<td>27</td>
</tr>
<tr>
<td>- 10&lt; 14 years</td>
<td>28</td>
</tr>
<tr>
<td><strong>Mean ±SD= 10.850±1.070</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Family history of systemic lupus</strong></td>
<td></td>
</tr>
<tr>
<td>- Yes</td>
<td>43</td>
</tr>
<tr>
<td>- No</td>
<td>17</td>
</tr>
</tbody>
</table>
Table (2): Distribution of the studied mothers knowledge regarding Systemic Lupus Erythematosus before immediately after and three months after implementation of family empowerment program. (n =60).

<table>
<thead>
<tr>
<th>Items of Knowledge related to systemic lupus erythematosus</th>
<th>Phases of family empowerment implementation (n=60)</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pre-family empowerment implementation</td>
<td>Post family empowerment implementation</td>
<td>Three months After implementation OF family empowerment</td>
<td>( \chi^2 (1) )</td>
</tr>
<tr>
<td></td>
<td>Complete correct answer</td>
<td>Incomplete correct answer</td>
<td>Incorrect or unknown answer</td>
<td>Complete correct answer</td>
</tr>
<tr>
<td>N.</td>
<td>%</td>
<td>N.</td>
<td>%</td>
<td>N.</td>
</tr>
<tr>
<td>Definition</td>
<td>2</td>
<td>3.3</td>
<td>22</td>
<td>36.7</td>
</tr>
<tr>
<td>Clinical manifestations</td>
<td>2</td>
<td>3.3</td>
<td>16</td>
<td>26.7</td>
</tr>
<tr>
<td>Investigations</td>
<td>2</td>
<td>3.3</td>
<td>38</td>
<td>63.3</td>
</tr>
<tr>
<td>Complications</td>
<td>4</td>
<td>6.7</td>
<td>24</td>
<td>40.0</td>
</tr>
<tr>
<td>Treatment</td>
<td>8</td>
<td>13.3</td>
<td>24</td>
<td>40.0</td>
</tr>
<tr>
<td>Role of steroids in treatment of systemic lupus erythematosus</td>
<td>4</td>
<td>6.7</td>
<td>16</td>
<td>26.7</td>
</tr>
</tbody>
</table>
Table (3): Distribution of the studied mothers knowledge about medications of systemic lupus erythematosus thorough empowerment implementation phases (n= 60).

<table>
<thead>
<tr>
<th>Items of knowledge related to medications of systemic lupus erythematosus</th>
<th>Phases of empowerment implementation</th>
<th>( \chi^2 ) (1)</th>
<th>P value</th>
<th>( \chi^2 ) (2)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pre- empowerment implementation</td>
<td>Post empowerment implementation</td>
<td>After empowerment implementation</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Complete correct answer</td>
<td>Incomplete correct answer</td>
<td>Incorrect or unknown answer</td>
<td>Complete correct answer</td>
<td>Incomplete correct answer</td>
</tr>
<tr>
<td>N.</td>
<td>%</td>
<td>N.</td>
<td>%</td>
<td>N.</td>
<td>%</td>
</tr>
<tr>
<td>Side effects of steroids</td>
<td>5</td>
<td>8.3</td>
<td>25</td>
<td>41.7</td>
<td>30</td>
</tr>
<tr>
<td>Prevent side effects from steroids</td>
<td>4</td>
<td>6.7</td>
<td>24</td>
<td>40.0</td>
<td>32</td>
</tr>
<tr>
<td>Method of withdrawing steroid dose from the child's body</td>
<td>2</td>
<td>3.3</td>
<td>22</td>
<td>36.7</td>
<td>36</td>
</tr>
<tr>
<td>Complications that occur from stopped steroid suddenly</td>
<td>2</td>
<td>3.3</td>
<td>16</td>
<td>26.7</td>
<td>42</td>
</tr>
<tr>
<td>Role of immunosuppress drug in treatment of systemic lupus</td>
<td>2</td>
<td>3.3</td>
<td>12</td>
<td>20.0</td>
<td>46</td>
</tr>
<tr>
<td>Side effects of immunosuppressant drug lupus erythematosus</td>
<td>2</td>
<td>3.3</td>
<td>22</td>
<td>36.7</td>
<td>36</td>
</tr>
</tbody>
</table>
### Side effects of antimalarial drug

| 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 lupus erythematosus

| Role of antimalarial drug in treatment of systemic lupus erythematosus | 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 |

**P value:** <0.00

---

**Fig.(1) Distribution of the studied mothers total knowledge score regarding to systemic lupus erythematosus thorough family empowerment implementation phases (n= 60).**

---

Vol. 29. No. 2 (Suppl) ,May 2023
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).

<table>
<thead>
<tr>
<th>Domain</th>
<th>Pre family empowerment implementation</th>
<th>Post family empowerment implementation</th>
<th>After three months family empowerment implementation</th>
<th>$X^2$ (1)</th>
<th>P value</th>
<th>$X^2$ (2)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Good</td>
<td>Average</td>
<td>Poor</td>
<td>Good</td>
<td>Average</td>
<td>Poor</td>
<td>Good</td>
</tr>
<tr>
<td>Physical health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social relationships</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Environment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Fig. (2) Distribution of the studied mothers regarding their total quality of life thorough family empowerment implementation phases (n =60)
Fig. (3) Distribution of the studied mothers self-efficacy scores regarding children with systemic lupus thorough family empowerment implementation phases (n = 60)

<table>
<thead>
<tr>
<th>Phase</th>
<th>High self-efficacy</th>
<th>Low self-efficacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-family empowerment实施前</td>
<td>25.0%</td>
<td>75.0%</td>
</tr>
<tr>
<td>Post-family empowerment实施后</td>
<td>46.7%</td>
<td>53.3%</td>
</tr>
<tr>
<td>After-family empowerment实施后</td>
<td>90.0%</td>
<td>10.0%</td>
</tr>
</tbody>
</table>
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).

<table>
<thead>
<tr>
<th>Items</th>
<th>Pre-family empowerment implementation</th>
<th>Post family empowerment implementation</th>
<th>After family empowerment implementation</th>
<th>Pair t (1)</th>
<th>P Value</th>
<th>Pair t (2)</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nutrition</td>
<td>Mean ± SD 7.500±5.043</td>
<td>Mean ± SD 15.450±6.431</td>
<td>Mean ± SD 14.716±6.375</td>
<td>14.437</td>
<td>0.00</td>
<td>13.889</td>
<td>0.00</td>
</tr>
<tr>
<td>Personnel hygiene</td>
<td>Mean ± SD 4.383±3.617</td>
<td>Mean ± SD 8.533±3.698</td>
<td>Mean ± SD 7.700±3.665</td>
<td>13.677</td>
<td>0.00</td>
<td>12.012</td>
<td>0.00</td>
</tr>
<tr>
<td>Drug administration</td>
<td>Mean ± SD 5.633±4.290</td>
<td>Mean ± SD 8.950±4.224</td>
<td>Mean ± SD 9.716±4.017</td>
<td>14.432</td>
<td>0.00</td>
<td>14.564</td>
<td>0.00</td>
</tr>
<tr>
<td>Prevention from infection</td>
<td>Mean ± SD 5.300±5.624</td>
<td>Mean ± SD 13.491±5.440</td>
<td>Mean ± SD 11.400±5.459</td>
<td>13.024</td>
<td>0.00</td>
<td>11.809</td>
<td>0.00</td>
</tr>
<tr>
<td>Management of pain and</td>
<td>Mean ± SD 5.283±4.166</td>
<td>Mean ± SD 8.583±3.562</td>
<td>Mean ± SD 9.100±3.563</td>
<td>14.774</td>
<td>0.00</td>
<td>14.337</td>
<td>0.00</td>
</tr>
<tr>
<td>fatigue</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skin care</td>
<td>Mean ± SD 5.750±5.385</td>
<td>Mean ± SD 10.350±5.341</td>
<td>Mean ± SD 11.166±5.459</td>
<td>12.725</td>
<td>0.00</td>
<td>12.487</td>
<td>0.00</td>
</tr>
<tr>
<td>Hair care</td>
<td>Mean ± SD 4.650±4.095</td>
<td>Mean ± SD 9.216±4.438</td>
<td>Mean ± SD 9.966±4.352</td>
<td>12.899</td>
<td>0.00</td>
<td>12.848</td>
<td>0.00</td>
</tr>
</tbody>
</table>

(P=<0.001)
Fig (4) 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).

<table>
<thead>
<tr>
<th>Items</th>
<th>Knowledge score</th>
<th>Reported practice score</th>
<th>Quality of life score</th>
<th>Self efficacy score</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pearson</td>
<td>Sig</td>
<td>Pearson</td>
<td>Sig</td>
</tr>
<tr>
<td>Knowledge score</td>
<td>1</td>
<td>-</td>
<td>.879**</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>Reported practice score</td>
<td>.879**</td>
<td>&lt; .001**</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Quality of life score</td>
<td>.940</td>
<td>&lt; .001**</td>
<td>.938</td>
<td>&lt; .001**</td>
</tr>
<tr>
<td>Self efficacy score</td>
<td>0.929</td>
<td>0.000**</td>
<td>0.480</td>
<td>0.000*</td>
</tr>
</tbody>
</table>

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

Discussion

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 ±SD= 31.2667±6.516. Also, less than three quarters 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 ± SD (30.3±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± 6.88 years old. Concerning educational level, 42% of the studied mothers had secondary education. Meanwhile, this finding incomparable with Tęcza, & 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 ± SD was 39.62 ± 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 ±SD = 13.033±.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 years. Also, This result matched with El-Sayed, & Mesbah. (2018), (3) who studied" effect of health education based intervention on self-care among systemic lupus 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 systemic lupus erythematosus" 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 opportunities for timely 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.

As regards, cause of previous 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 admitted to hospital due 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 be deposition in circulating immune complexes in the glomerular basement membrane that can lead to lupus nephritis and renal failure.

On assessing mothers’ total knowledge about systematic lupus erythematos, 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, most of (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 < .001. Also, this result similar to Khawaja, et al. (2018) (35), who studied "parental knowledge and participation 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 Erythematous among general population in Abha, KSA" and found that, most of (90%) of studied mothers had unsatisfactory level of knowledge toward systemic lupus at preprogram while majority (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 quality of life at pre family empowerment implementation. While, majority of studied mothers had good 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 three quarters (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 erythematosus. 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) (38), who studied "Systemic lupus 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 were positive correlations between knowledge scores and educational level that were 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 and practices and mothers’ 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 mothers' self-efficacy, the current study illustrated that, less than one third of studied mothers had low self-efficacy level at pre family empowerment 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 two-way 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 Hameed, et al. (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 after application of the educational intervention (p<0.001) Regarding, studied mothers’ total knowledge, quality of life, reported practice and self-efficacy, 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 knowledge and reported practice of mothers that enhance to increase self-efficacy and quality of life for mother caring children with Sysmematic Lupus erythematous

Conclusion
Based on the results of the current study, it can be concluded that implementation of family empowerment model were improving quality of life and self- efficacy of mothers of children with systematic lupus

Recommendations
In the light of the findings of the current study the following recommendations were suggested:
1. Design an educational program for children and their mothers about SLE
2. Public awareness to educate people about SLE, its clinical manifestations, diagnosis, treatment, and complications, it may be fatal if neglected.
3. 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.
4. Further researches regarding SLE, is needed.
5. Family empowerment program should be conducted for caregiver periodically and regularly regarding systematic lupus erythematous to minimize complication among children.

References
13. Segers, E., Ochuijsen, H., Baarendse, P., van Eerden, I., and van den Hoogen, A. The impact of family

42. Hegazy S. M., Dawood, B. M. Effect of Upgrading Mothers' Awareness Regarding Cardiovascular Diseases on their self-efficacy to promote their children life style. Egyptian Journal of Health Care. 2021:12 (1)