

The effect of instructional guidelines on caregivers to improve quality of life for their children with systemic lupus erythematosus.

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Abstract

Background: Systemic lupus erythematosus 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.

Aims: This study aimed to evaluate the effect of instructional guidelines on caregivers to improve quality of life for their children with systemic lupus erythematosus.

Research design: A quasi-experimental research design used (one group pre/posttest).

Setting: This study was conducted at allergy and immunity out-patient clinic in pediatric hospital affiliated to Ain Shams university hospitals.

Subjects: A purposive sample composed of 120 care-givers (mainly mothers) accompanying their children's with systematic lupus erythematosus at the previously mentioned setting.

Tools of data collection: Four tools were used included; a structured interviewing questionnaire, lupus awareness's quizzed, lupus quality of life scale, and structured observational checklist.

Results: This study noted that, there was a highly statistically significant difference in relation to the total quality of life of the studied children pre and post implementation of instructional guidelines program with $P < 0.001$. Also, there was a highly statistically positive correlation between total mothers knowledge, reported practices, and quality of life with $p < 0.001$ pre and post program implementation.

Conclusion: The current study concluded that, the implementation of instructional guidelines on caregivers affect positively on quality of life for their children with systemic lupus erythematosus.

Recommendations: Continuous instructional guidelines program for mothers having children with systemic lupus erythematosus to increase their knowledge and practices regarding care of their children to improve their quality of life.

Keywords: Caregivers, Children, Quality of life, Systemic lupus erythematosus.

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Introduction

Systemic Lupus Erythematosus (SLE) is a multisystem autoimmune disease with extensive organs involvement characterized by chronic and fluctuating 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 [1].

The worldwide incidence rates of Childhood-onset SLE (CSLE) have been reported to be 0.3–0.9 per 100,000 children every year, with prevalence rates of 3.3–8.8 per 100,000 children and the higher prevalence rates have been reported in native American and Asian with a peak female to male ratio of 12:1 during the childbearing years between the ages of 15 and 45 years. Also, approximately 15%–20% of all SLE cases occurring from childhood to adolescence with acute and poorer

prognosis. In Egypt, found that, in the study conducted at rheumatology and allergy outpatient clinic at Cairo university on 1109 SLE children about 19.4% were children with age onset less than 16 years and 80.6% more than 16 years with 10.3% were males and 89.7% were female [2].

The etiology and pathogenesis for SLE not well understood and sometimes there is no apparent cause. Therefore factors that might influence the development of SLE including; genetic, environmental, hormonal and some drugs interactions. Meanwhile, the complex interaction with these factors leads to immune deregulation and breakdown of tolerance of self-antigens, resulting in auto-antibody production, inflammation, and destruction of end organ [3].

Consequently, there is no cure for SLE and the characteristic of its impact on child Quality of Life (QoL) in unique ways includes; physical health, psychological status, level of independence, social relationships, and personal beliefs. However, quality of Life is defined as being healthy, feeling

good and being independent, and able to do daily activities. Although, lupus is a life-long disease but the children with it have a right to live as normal through attend school, play sports, participate in extra-curricular activities to improve their function at the desirable level [4].

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 every 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 quality of life and child's health outcomes the significance of the study [5].

Systemic lupus erythematosus affects the children life style and causes a huge number of complications which affects all body systems and associated with significant morbidity and mortality. Therefore, advances in therapy have reduced mortality and emphasis on quality of life as an outcome measure in SLE [6].

As reported by Salah et al. in Egypt, the prevalence of juvenile systemic lupus erythematosus, which conduct in the pediatric rheumatology clinic at Cairo university were (69.6%) female and (30.4%) male in the study included 148 children with the female to male ratio was 2.3:1 between the age from 2 to 16 years. On barrel, as reported by statistical office in pediatric hospital affiliated to Ain Shams university hospitals were 130 cases between 3-18 years old with SLE at December, 2019 (follow up) and about 2-3 cases (newly cases). So, from the researcher point of view is very important to apply instructional guidelines regarding caregivers to improve quality of life for their children through provide positive reinforcement to them and help ensure that they emerge with a strong sense of self-worth, confidence, and the determination to keep going even when things are tough [7].

Aim of the study

This study aimed to evaluate the effect of instructional guidelines on caregivers to improve quality of life for their children with systemic lupus erythematosus through the following objectives:

- Assess knowledge and practice of caregivers regarding care of their children having SLE.
- Assess quality of life for children with SLE.
- Developing and implementing instructional guidelines for caregivers with their children having SLE.
- Evaluating the effect of instructional guidelines on caregivers to improve quality of life for their children with SLE.

Research hypothesis

The implementation of instructional guidelines on caregivers will affect positively on quality of life for their children with SLE.

Subjects and Methods

I-Technical design

The technical design for the study was included research design, setting, subjects and tools for data collection.

Research design

A quasi experimental study (one group pre/posttest) was used to achieve the aim of the current study.

Research setting

The study was carried out at allergy and immunity out-patient clinic in pediatric hospital affiliated to Ain Shams university hospitals.

Research subjects

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

Inclusion criteria: All available mothers having children with SLE with different level of education and all children with confirmed diagnosed of SLE from both sexes and free from any other physical or mental diseases.

Tools of data collection: Four tools were used in the current study.

Tool (I): A Structured Interviewing Questionnaire (pre/post-test); this tool was designed by the researcher after reviewing the related literature as Fries (1980) and Bruce (2003) to assess the health needs and problems of the children with SLE. It was written in a simple Arabic language and included six parts as the follows:

Part (1): It was included data about;

Personal characteristics of mothers included: Age, level of education, occupation, marital status, and data about family such as type of family, number of family members, child living, consanguinity between parent, and the presence of a family member suffering from SLE or any immune diseases and the degree of relationship. Personal characteristics of children with systemic lupus erythematosus included; age, gender, level of education, ranking, and residence.

Data about medical history of the studied children: Such as child current weight and height (using growth chart), taking routine vaccination and having SLE during taking it, disease duration, and the frequency of hospital admissions.

Part (2): Zarit Burden Interview (ZBI) Scale: It was adapted from Seng et al. and modified by the researcher as rephrased of

the statement and translated into simple Arabic language to assess the needs and stressors on the family resulting from child disease and was composed of 22 statements.

Scoring system

The scoring system for each item was scored according to mothers response as if it is; never response=(0), rarely response=(1), sometimes response=(2), quite frequently=(3), and nearly always=(4). The total score was 88 grades and categorized as following; little or no burden=0-21 grades, mild burden=21-40 grades, moderate burden=41-60 grades, and severe burden= 61-88 grades [8].

Part (3); Disability index scale: It was adopted from Van Groen et al. and composed of 20 statements to assess dressing and grooming, arising, eating, walking, hygiene, reach, grip, and various activities.

Scoring system

The scoring system for each item was scored according to child' response as if it is; without any difficulty=(0), with some difficulty=(1), with much difficulty=(2), unable to do=(3). The total score was 60 grades (equal 100%). The total score converted into percentage and then categorized as following; able child=<50% equal (0<30 grades), while disabled child = ≥ 50% equal (≥ 30 grades).

Part (4); Discomfort and pain scale (Wong–Baker Pain Faces Rating Scale) (WBFS): It was developed by Wong et al. to assess the severity of pain and discomfort which composed of six circles (faces) that start from "no hurts" with a score of (0) to maximum "hurts worst" with a score of (10). The child was instructed to place a vertical mark or circle on the number to indicate the severity of their pain [9].

Scoring system

The child response graded as follow; no pain = 0 grade, mild pain = 1-3 grades, moderate pain = 4-6 grades, and severe pain = 7-10 grades.

Part (5): Adherence of child's to therapeutic regimen: It was developed by cerner Multum Wolters et al. to assess the child adherence to medication, adherence to physician visits, adherence to diagnosis tests, and any arising medical problems and composed of (9) questions. If found adherence was scored (1), while (0) for not adherence to therapeutic regimen [10].

Part (6): Child satisfaction: It was adapted from Anthony and Eamon and composed of (10) questions. It was omitted by the researcher to (8) questions included; two questions to assess the child's satisfaction about his/her health and the mother's satisfaction about the health status of their children and presented in a vertical line which stated with "very poor" with a score of (0) at one end and "very well" with a score of (100) at the other. The child and mothers was instructed to place a circle on the number to indicate the degree of their satisfaction. Another (6) questions to assess the effect of the disease on the

child daily living activity and ability to go to school or university [11].

Scoring system

As regarding to the child's and mother's satisfaction, the total score was 100 degree (equal 100%). The total score converted into percentage and then categorized as following; dissatisfied=0 to <50% equal (0<50 degree), moderately satisfied=50-<65% equal (50-<65degree, and satisfied = ≥ 65% equal (≥ 65 degree). As regarding the effect of the disease on the child daily activity and ability to go to school or university, If yes effect was scored (1), while (0) for no effect.

Tool (II): Lupus Awareness's Quiz (pre/post- test): It was developed by Belotti et al. and was adapted and modified by the researcher after reviewing the related literature. It's a self-administered quiz to mothers for their children with SLE to assess their level of knowledge about SLE. It was translated into simple Arabic language to assure accuracy of this tool and the modification was done to be appropriate with the studied children age group. The quiz was included 20 multiple-choice questions related to SLE such as; definition, incidence, morbidity, mortality, pathophysiology, causes, signs and symptoms, complications, diagnostic measures, medical management, lifestyle changes, and management of general problems for children with SLE.

Scoring system

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

Tool (III): Lupus Quality of Life (QoL) Scale (pre/post-test): It was developed by Mc Elhone et al. for the QoL used in children with SLE and was adapted and modified by the researcher after reviewing the related literature. It was translated into simple Arabic language to assure accuracy of this tool and the modification was done to be appropriate with the studied children age group. It was a 34-items Systemic Lupus Erythematosus (SLE) specific health related quality of life (HRQoL) measures and was included (8) domains as follows; physical health (8 items) from 1-8, pain (3 items) from 9-11, planning for attending events in the future (3 items) from 12-14, intimate relationships (2 items) from 15-16, burden to others (3 items) from 17-19, emotional health (6 items) from 20-25, body image (5 items) from 26-30, and fatigue (4 items) from 31-34.

Scoring system

The child's response for each statement was made on a 5 point likert scale, where all the time=(0), most of the time=(1), a good bit of the time=(2), occasionally=(3), and never =(4). The

total score for all domains were calculated into poor QoL, average QoL, and good QoL as follows; poor QoL=0-<50%, average QoL=50-<65%, and good QoL= \geq 65%.

Tool (IV): Structured observational checklist (pre/post-test): It was adopted from Ralph et al. and Bowden et al. to assess mothers' reported practices for their children. It contained of (64) items for 10 procedures that included; measurement of axillary temperature (8 items), respiration (5 items), weight (6 items), height (5 items), teething brush (6 items), management of fever (8 items), vomiting (5 items), mouth and throat ulceration (5 items), extremities edema(11 items), and joint pain(5 items).

Scoring System

The scoring system consisted of two points; done was scored (1) and not done was scored (0). The total scores are 64 score (equal 100%) for all procedures. Accordingly, the scoring system of reported mothers' practices was classified into; incomplete practice \leq 60% equal (0<38 score), while complete practice \geq 60% equal (38 to 64 score).

Tool validity

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

Tool reliability

Reliability of the tools tested by using Cronbach's Alpha which detect excellent internal consistency of the tools was performed. Where Zarit burden interview scale=0.792, disability index scale=0.851, discomfort and pain scale=0.860, lupus awareness's quiz=0.795, lupus QoL scale=0.850, and structured observational checklist=0.801.

Ethical considerations

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

II- Operational design

Preparatory phase: It was include reviewing of past, current, national and international related literature and theoretical

knowledge of various aspects of the study using books, articles, internet, periodicals and magazines to developed tools for data collection.

Pilot study

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

Field work

The actual field work was carried out over a period of 6 months started from beginning of March to end of August 2021 for data collection. The study was done through the following four phases to achieve the aim of this study which included; assessment, planning, implementation, and evaluation phase.

Assessment phase

Assessment phase involved interviews with mothers' and their children with SLE to collect baseline data. At the beginning of interview; the researcher was introduced herself and welcomed the studied sample then simply and clear explained the aim of the study, duration, and activities to gain their cooperation. Also, the researcher took oral approval from the mothers and their children to participate in the study before any data collection. The researcher was available at morning shift from 8:00 AM to 2:00 PM by rotation two days weekly at the previously study setting and the number of mothers accompanying their children about fifteen weekly.

The study tools were filled in and completed by the researcher on two stages (pre and post implementation of instructional guidelines program). The researcher gave each mothers questionnaire sheet to filling it by the mothers if educated or by their children if suitable age with clarified any misunderstanding items but in case of illiterate mothers the researcher filled the questionnaire through ask questions in interviewing with mothers. The average time needed for the completion of each questionnaire was approximately 40-50 minutes; that started with (Tool I) it took nearly 10-15 minutes, (Tool II) took about 10 minutes, and (Tool III) took about 10 minutes. In the end (Tool IV) was took about 10-15 minutes. This period of pre-test took about 8 weeks (from the beginning of March to the end of April 2021).

Planning phase

All information gathered through data collection tools was analyzed to identify the mothers and their children learning needs. The instructional guidelines program was designed based on baseline data obtained from assessment phase and relevant review of literature to improve the quality of life for

children with systemic lupus erythematosus. The content was prepared according to mothers' and children level of understanding in simple Arabic language and the different methods of teaching were used include lecture, group discussion, brain storming, role play, hand out, power point presentation and then covered the practical skills through demonstration and re-demonstration.

Implementation phase

This phase take three month from the beginning of May to the end of July 2021. The implementation of instructional guidelines program was carried out through teaching sessions, each session started by the researcher provided feedback on the previous session, and the objectives of the new session. At the end of each session the researcher summarized the key topics and verified that to the mothers and their children. Motivation and reinforcement was used to enhance cooperation and active sharing in the program and take into consideration the used of clear and simple Arabic language that suitable to the mothers and their children.

The studied mother and their children were divided into two main groups each group from them composed of sixty and each group divided into four subgroup, each subgroup composed of fifteen mothers and their children. The total number of sessions were (12) sessions plan program about SLE which included eight sessions for theoretical part and four sessions for practices. The program sessions were taken 12 hours for each group and these sessions were repeated to each subgroup. Each session taken about one hour and the time for started teaching sessions was determined and scheduled with the mothers.

Evaluation phase

This phase took one month from the end of July to the end of August 2021. Post test was administered immediately post

program to evaluate the effect of instructional guidelines program on mother's accompanying their children with SLE to improve the quality of life, through filling the same pre-test tools immediately after completion of the instructional guidelines program.

III. Administrative design

After explanation of the study aim and objectives, an official permission was obtained from the dean of faculty of nursing, Helwan university, and the general manager of pediatric hospital affiliated to Ain Shams university hospitals asking for cooperation and permission to conduct the study.

IV. Statistical design

The collected data were organized, revised, scored, tabulated and statistically analyzed using Statistical Package for Social Sciences (SPSS) version "25" and Excel (2010) to evaluate the studied subjects' changes throughout the study phases (pre and post), and to evaluate the differences between the groups under the study as regards the various parameters. Data were presented in tables and charts. The following statistical analyses were used: number (No), percentage (%), mean score (\bar{x}), Standard Deviation (SD), chi-square (X^2), "r" test, "t" test, proportion probability of error (P-value), Cranach's alpha test and p-value to detect relations between the variables of the study.

Results

Table 1 is regarding the studied mother's characteristics, this table showed that, more than half (55.9%) of the studied mothers were in the age group ≥ 40 years with \pm 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 and almost all (93.3%) of them were married.

Mother's Characteristics	No	%
Age/years		
20 <30	1	0.8
30 < 40	52	43.3
≥ 40	67	55.9
SD=39.62 5.86 years		
Education		
Illiterate	30	25
Reading and writing	10	8.3
Primary school	18	15
Intermediate education	46	38.3
High education	16	13.4
Occupation		
Housewife	106	88.3

Working	14	11.7
Marital status		
Married	112	93.3
Divorced	8	6.7

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

Table 2 as observed from this table, the majority (85% and 83.3%) of the studied children was in the age group from 12-18 years and females respectively. Also, less than half (45%) of them in secondary school and 63.3% were live in urban area.

Children's Characteristics	No	%
Age/years		
<6	2	1.7
6<12	16	13.3
12-18	102	85
± SD=14.33 ± 2.93 years		
Gender		
Male	20	16.7
Female	100	83.3
Education		
Under school age	2	1.7
Primary school	16	13.3
Preparatory school	44	36.7
Secondary school	54	45
Don't go to school	4	3.3
Child rank		
Frist	36	30
Secondary	42	35
Third	28	23.3
Fourth and more	14	11.7
Residence		
Urban	76	63.3
Rural	44	36.7

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

Table 3 this table illustrated that, 71.7% and 73.3% of the studied children had more than normal weight and normal height respectively. Regarding the disease duration of the studied children, it was found that, almost all (93.3%) of them were ≥ 1 year with and SD was 1.2 ± 0.23 years for them.

Items	No	%
Child current weight		
Normal	28	23.3

Less than normal	6	5
More than normal	86	71.7
Child current height		
Normal	88	73.3
Less than normal	22	18.3
More than normal	10	8.3
Child taken all the vaccinations completely		
Yes	120	100
Child infected with SLE while receiving vaccinations		
No	120	100
Duration of disease		
<6 months	4	3.3
6 months <1 year	4	3.3
≥ 1 year	112	93.3

Table 3. Distribution of the studied children according to their medical history (n=120).

Figure 1 as observed from this figure, slightly less than half (46.6%) of the studied mothers were moderate burden preprogram, while more than two third (67.5%) of them were mild burden post program with a highly statistically significant among them, where ($p<0.001$).

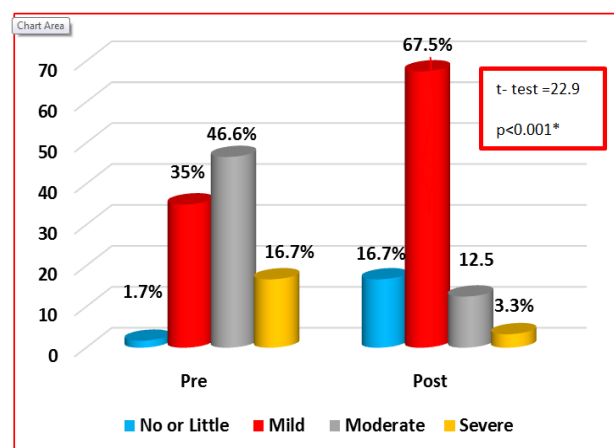


Figure 1. Percentage distribution of the studied mothers according to their total burden pre and post implementation of instructional guidelines program (n=120). *: $p<0.001$ highly significant.

Figure 2 this figure showed that, two third (63.3%) of the studied children were disabled child preprogram compared to slightly less than one third (29.1%) of them post program with a highly statistically significant among them, where ($p<0.001$).

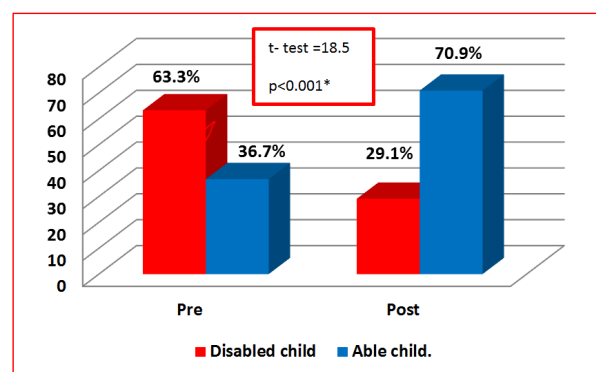


Figure 2. Percentage distribution of the studied children according to their total disability pre and post implementation of instructional guidelines program (n=120). *: $p<0.001$ highly significant.

Table 4 illustrated that, slightly less than two third (60%) of the studied children complained of severe pain preprogram, which decreased to slightly less than one fifth (17.5%) post program with a highly statistically significant improvement among them where, ($p<0.001$).

Items	Pre		Post	t- test	p-value	
	No	%	No			
Mild pain	10	8.3	38	23.3	9.6	<0.001*
Moderate pain	38	31.7	61	50.8		
Severe pain	72	60	21	17.5		
	3.55 ± 1.34		2.3 ± 1.0			

Table 4. Distribution of the studied children according to their total severity of pain pre and post implementation of instructional guidelines program (n=120).

Table 5 showed that, more than two third (66.7%, 70% and 66.7%) of the studied children adherence to medications, diagnostic tests, and follow up visits preprogram compared to

the majority (82.5%, 88.3% and 85%) of them post program respectively with a highly statistically significant difference among them, where ($p<0.001$).

Items	Pre		Post	Muknemar Test	
	No	%	No	%	p-value
Adherence to medications	80	66.7	99	82.5	0.002
Adherence to medications	84	70	106	88.3	<0.001*
Adherence to follow up visits	80	66.7	102	85	<0.001*

Table 5. Distribution of the studied children regarding adherence to therapeutic regimen pre/post implementation of instructional guidelines program (n=120). *: $p<0.001$ highly significant.

Table 6 regarding the satisfaction about health status related to disease pre/post program, this table illustrated that slightly less than three quarters (73.4%) of the studied children were

dissatisfied preprogram which decrease to one fifth (20.8%) post program with highly statistically significant difference among them, where ($p<0.001$).

Items	Pre		Post	t- test	p-value	
	No	%	No			
Dissatisfied	88	73.4	25	20.8	11.2	<0.001*
Moderately satisfied	28	23.3	41	34.2		
Satisfied	4	3.3	54	45		
± SD	3.45 ± 1.6		6.18 ± 2.0			

Table 6. Distribution of the studied children according to their total satisfaction about health status pre and post implementation of instructional guidelines program (n=120). *: $p<0.001$ highly significant.

Table 7 revealed that; more than two third (68.3%) of the studied mothers had unsatisfactory knowledge preprogram,

while the majority (88.4%) of them had satisfactory knowledge post program with highly statistically significant difference among them, where ($p<0.001$).

Total level of mother's knowledge	Pre		Post	t- test	p-value	
	No	%	No			
Satisfactory	38	31.7	106	88.4	15.4	<0.001*
Unsatisfactory	82	68.3	14	11.6		
± SD	15.45 ± 1.44		11.95 ± 1.982.0			

Table 7. Distribution of the studied mothers regarding to their total knowledge about systemic lupus erythematosus pre and post implementation of instructional guidelines program (n=120).

Figure 3 clarified that; more than two third (68.4%) of the studied children had poor quality of life preprogram, while less

than half (42.5%) of them had good quality of life post program with highly statistically significant difference among them, where ($p<0.001$).

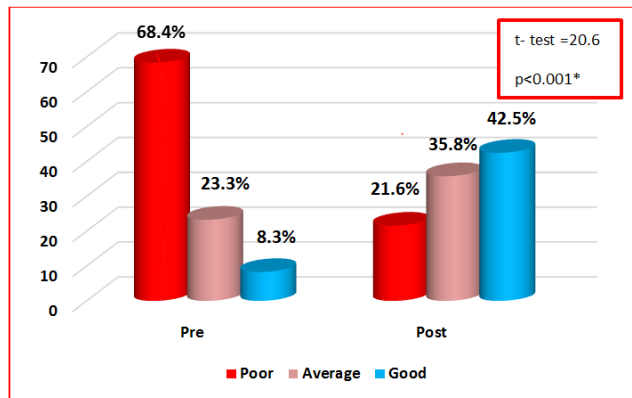


Figure 3. Percentage distribution of the studied children according to their total quality of life pre/post implementation of instructional guidelines program (n=120). *: p<0.001 highly significant.

Figure 4 Regarding to total reported practices pre/post program, this figure cleared 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).

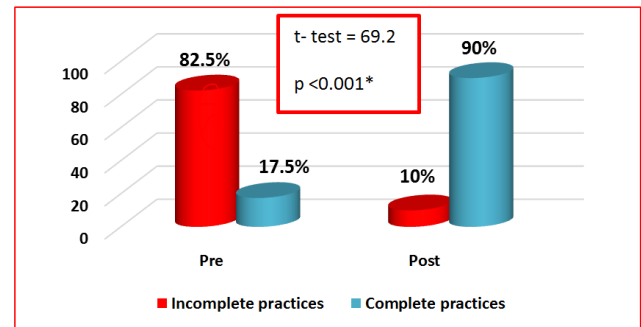


Figure 4. Percentage distribution of the studied mothers according to their total reported practices for their children pre/post implementation of instructional guidelines program (n=120).*: p<0.001 highly significant.

Table 8 cleared that; there were highly statistically significant differences with positive correlation between all variables of the studied children pre and post program, where (p<0.001).

Variables		Total mothers' knowledge		Total mothers' reported practices		Total burden		Total disability		Total quality of life	
		Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Total mothers knowledge	R										
	P										
Total mothers reported practice	R	0.502	0.604								
	P	0.000**	0.000**								
Total burden	R	-0.418	-0.592								
	P	0.005**	0.000**								
Total disability	R	-0.401	-0.58	-0.45	-0.601	0.522	0.633				
	P	0.007**	0.000**	0.005**	.000**	.000**	.000**				
Total quality of life	R	0.312	0.631	0.3	0.605	-0.501	-0.588	-0.497	-0.573		
	P	0.015*	0.000**	0.018*	.000**	.000**	.000**	.000**	.000**		
Total severity of pain	R	-0.428	-0.501	-0.453	-0.509	0.493	0.51	0.48	0.541	-0.518	-0.579
	P	0.000**	0.000**	0.000**	0.000**	0.000**	0.000**	0.000**	0.000**	0.000**	0.000**

Table 8. Correlation between total knowledge, total burden, total disability, total severity of pain, total quality of life and total report practices pre and post implementation of instructional guidelines program (n=120). r: Correlation coefficient test; p: p-value; **: p < 0.001: Highly significant.

Discussion

Systemic lupus erythematosus is a chronic disease that results in different and occasionally life-threatening condition and affecting quality of child life. Wherefore, the instructional guidelines program is a crucial for mothers who providing care for their children with SLE to maintain child health, prevent further complications and comorbidities and improve the child quality of life from all aspect [11].

Regarding the studied mother's characteristics, this study finding clarified that, more than half of the studied mothers were in age group from 40 and more years. In the same line, the

study of Fortuna-Reyna et al. [12], who studied psychosocial and economic impact of rheumatic diseases on caregivers of Mexican children, reported that, slightly less one third of mothers having children with juvenile systemic lupus erythematosus with age 40 years and the median from 36-46 years. From the researcher point of view, the mother's age was necessary in acquiring new information and experiences to increase their enthusiasm about caring of children with SLE.

Considering mother's education, the finding of the present study showed that, less than half of the studied mothers were intermediate education. On the contrary, Mohamed [13] in Egypt at Benha University, who studied the effect of

educational program on improving mother's knowledge, practice and child attitudes toward systemic lupus erythematosus, found that, two fifth of the studied mothers were graduated from secondary education. From the researcher point of view, the mother's education play an important role to understanding the nature of their children disease and how to dealing with it.

In relation to mother's occupation, this study finding cleared that, more than three quarters of the studied mothers were housewives. This result goes in the same line with Ethica et al. [14] in Indonesia, who studied socialization of lupus disease awareness for housewife group of Genting village, Ambarawa, and central java, reported that, all mothers of the counseling program were housewives. From the researcher point of view, the demands of treatment and frequent follow up for children with SLE may require housewives mothers to providing a suitable care for their children.

Concerning mother's marital status, this study finding showed that, almost all of the studied mothers were married. This study finding was in accordance with ELghareeb and Mohmoud [15] in Mansoura, Egypt, who studied influence of self-management instruction on outcomes of health for systemic lupus patient, found that, more than two third of the studied mothers were married. Regarding demographic characteristics of the studied children, the finding of the current study revealed that, the majority of the children with SLE age ranged from 12-18 years old with the mean age of 14.3 ± 2.9 years. This finding was in agreement with the study of Hossny et al. [16] in Egypt, who studied impact of pediatric systemic lupus erythematosus on the health-related quality of life, reported that, the children's ages ranged between 12-18 years old with the mean age of 12.2 ± 1.9 years. From the researcher point of view, this could be due to the peak incidence of SLE in adolescence due to puberty and hormonal changes.

Concerning gender of the studied children, the finding of the present study illustrated that, the majority of them were females. This finding was supported by Radwan et al. [17] in Egypt, who studied serum interleukin 17 expressions in a group of Egyptian patients with juvenile systemic lupus erythematosus, reported that, the majority of the studied children were females, while the minority was males. 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 [18].

In relation to education of the studied children, the current study showed that, less than half of them in secondary school. These finding was in disagreement with Mohamed et al. [19] in Benha, Egypt, who studied assessment of mothers' knowledge towards systemic lupus erythematosus, stated that, more than half of the studied children in preparatory school. From the researcher point of view, this could be due to the difference between two target samples [20].

Considering residence of the studied children, the present study illustrated that, less than two third of them were live in urban area. In the same line, the study of Gergianaki et al. [21] in

cross-sectional analysis of the Crete in Greece, who studied is systemic lupus erythematosus different in urban versus rural living environment? Data from the Cretan lupus epidemiology and surveillance registry showed that, more than two fifths of the studied children had lived in urban area. From the researcher point of view, the incidence increase in urban area due to life style and environmental pollutants which increase the risk of SLE occurrence.

Regarding medical history of the studied children, the finding of this study revealed that, more than two third of them had more than normal weight and normal height respectively. This finding was in accordance with Abdella et al. [22] in Oman, who studied growth pattern in children with systemic lupus erythematosus and found that, more than two fifth of the studied children were overweight while more than one third of them height less than normal. From the researcher point of view, increase child body weight due to high accumulated dose of corticosteroids as a protocol of SLE treatment.

Considering the disease duration of the studied children, the present study found that, almost all of the studied children were more than one year with mean and standard deviation was 1.2 ± 0.23 years for them. As well, this study finding was in accordance with Burnham et al. [23] in Philadelphia, who studied factors associated with variation in pediatric systemic lupus erythematosus care delivery, found that, the majority of the studied children with median disease duration of 2.3 years and diagnosed more than one year earlier.

In relation to the burden of the studied mothers, the current study clarified that, slightly less than half of the studied mothers were moderate burden preprogram, while more than two third of them were mild burden post program. In the same line, Uzuner et al. [24] in Istanbul, who studied caregiver burden and related factors in caregivers of patients with childhood-onset systemic lupus erythematosus, reported that, increase levels of burden among the mothers of pediatric patient with SLE. From the researcher point of view, the instructional guidelines program had a positive impact on mothers through providing them with adequate knowledge that decrease their burden.

Regarding disability of the studied children, this study clarified that, two third of the studied children were disabled preprogram compared to slightly less than one third of them post program with a highly statistically significance difference. This study finding was in accordance with Hersh et al. [25] in United States and Canada, who studied predictors of disability in a childhood-onset systemic lupus erythematosus cohort: results from the CARRA legacy registry, stated that, less than half of the studied children were disable, which decreased to one quarter during follow up visits. From the researcher point of view, when child follow instructional guidelines that provided, leading to increase their awareness regarding disease manifestations and increase their ability to dealing with manifestations to decrease it.

Regarding severity of pain, this study showed that, slightly less than two third of the studied children complained from severe pain preprogram, which decreased to slightly less than one fifth

post program with a highly statistically significant difference. This study finding supported by Mohammed et al. [26] in Mansoura, Egypt, who studied effect of self-management guidelines on health outcomes for patients with systemic lupus erythematosus, revealed that, more than three fifth of the studied children complains of moderate pain in preprogram implementation, while in post implementation no children have severe pain and 12.3% of them were have no pain with a highly statistically significant difference regarding severe pain. From the researcher point of view, the implementation of instructional guidelines had a positive effect on decreasing child pain post program than preprogram.

Regarding adherence of studied children to therapeutic regimen, the present study illustrated that, the majority of them adherence to medications, diagnostic tests, and follow up visits post program compared to preprogram with a highly statistically significant difference among them. In the same line, Cstagliola et al. [27] at the University of Pisa, who studied pediatric systemic lupus erythematosus: learning from longer follow up to adulthood, reported that, the majority of the studied children were adherence to medication, diagnostic tests and follow up regularly. From the researcher point of view, the instructional guideline play an important role in increasing mothers awareness regarding the necessary of child adherence to treatment, diagnostic test, and for follow up to maintain their health.

As regarding to child satisfaction about their health status, the current study illustrated that, slightly less than three quarters of the studied children were dissatisfied preprogram which decrease to one fifth post program. This study result is not compatible with Mostafa et al. [28] in Egypt, who studied self-management guidelines: effect on awareness of patients with systemic lupus erythematosus, found that, half of the studied children were good satisfaction about their health status pre-awareness program which increase nearly two thirds post program. From the researcher point of view, this difference might due to cultural diversity.

Regarding mother's total knowledge about systemic lupus erythematosus, these study finding revealed that, more than two third of the studied mothers had unsatisfactory knowledge preprogram, while the majority of them had satisfactory knowledge post program with a highly statistically significant difference. This finding was in accordance with Ethica et al. [29] who found that, three quarters from the studied mothers answer questions incorrectly before counseling program, while almost all of them answer correctly question after counseling program. From the researcher point of view, the instructional guidelines program was improve mother's knowledge about systemic lupus erythematosus post program than before.

In relation to total quality of life for the studied children, this study clarified that, more than two thirds of the studied children had poor quality of life pre-program, while less than half of them had good quality of life post program with highly statistically significant difference between all quality of life domains. In the same line, Li et al. [30] in China, who studied Sandplay therapy could be a method to decrease disease

activity and psychological stress in children with systemic lupus erythematosus, stated that, pediatric quality of life inventory showed that the scores of social function, school performance, and emotional health of the intervention group were higher than those of the control group. From the researcher point of view, the current result supports the research hypothesis which supposed that, the quality of life of SLE child had improved after implementation of instructional guidelines program.

Regarding total reported practices of the studied mothers, this study cleared that, the majority of the studied mothers had incomplete practices preprogram, while the majority of them had complete practices post program with a highly statistically significant difference between pre/post programs. This result was in congruent with Mohamed [31-33] who found that, nearly two thirds of the studied mothers had incomplete practices preprogram, while the majority of them had complete practices post program with a highly statistically significant difference pre/post program. From the researcher point of view, the mothers had high desire to educate more practices for increase their ability to caring and help their children to improve their heath and their quality of life.

Considering to correlation between total knowledge, total burden, total disability, total severity of pain, total quality of life and total report practices pre and post implementation of instructional guidelines program. The study finding showed that, there were highly statistically significant differences with positive correlation between all variables of the studied children pre and post program. In the same line, Elsayed et al. [34,35] in Benha, Egypt, who studied effect of health education based intervention on self-care among systemic lupus erythematosus clients, found that, there was positive correlation between total mothers knowledge and practices pre and post program implementation. Also, Hossny et al. [36] who found that, there was moderate correlation between children quality of life, disability and mother's burden. From the researcher point of view, this result supports the study hypothesis that the instructional guidelines program was affected positively on quality of life for children with SLE.

Conclusion

The instruction guidelines had a positive significant effect on mothers and improve quality of life for their children with systemic lupus erythematosus. Therefore, there was a highly statistical significant positive correlation between all the study variables included; total knowledge, total practices, total burden, total disability, total severity of pain, and total quality of life pre/post implementation of instructional guidelines program. Finally, the hypothesis of the study was accepted [37].

Recommendations

Continuous instructional guidelines program for mothers having children with systemic lupus erythematosus to increase their knowledge and practices regarding children caring to improve their quality of life. Provision the guidelines booklet

to ally newly admitted mothers having children with SLE in allergy and immunity out-patient clinics to provide them by needed information. Replication of the study on a large probability sample in others different settings is a highly recommended to achieve generalized results.

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