Effect of Self-Care Guideline on Quality of Life among Pregnant Women with Systemic Lupus Erythematosus

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ABSTRACT

Context: Systemic Lupus Erythematosus (SLE) is a complex chronic autoimmune condition representing a source of disability. It can create a burden of the low Quality of life in pregnant women and cause deleterious effects on maternal, fetal, and neonatal outcomes.
Aim: The study aimed at evaluating the effect of self-care guidelines on the Quality of life among pregnant women with SLE.
Methods: A quasi-experimental study design (time series, one group only, and pre-post intervention assessments) was used. Purposive sampling was used to recruit fifty pregnant women diagnosed with SLE. The study was conducted at three sites: Rheumatology Outpatient Clinic at Ain Shams University Hospital, Rheumatology Antenatal Outpatient Clinic, and Labor Unit at Ain Shams Maternity Hospital. Seven data collection tools were utilized in this study, and Arabic self-care guidelines were distributed as supporting educational material for pregnant women with SLE.
Results: Findings of the present study showed a highly significant improvement in SLE activity index, follow-up lab investigations, Quality of life, and health assessment by evaluating daily living activities after using self-care guidelines.
Conclusion: The current study results supported the research hypothesis that pregnant women with SLE exposed to self-care guidelines will have a better quality of life than their pre-intervention level, which reflected upon improving pregnancy outcomes. Based on the study results, the following recommendations are forwarded; application of the study intervention with the distribution of the clear Arabic self-care guidelines on a large scale in other sittings caring for pregnant women with SLE.

Keywords: Self-care, guideline, quality of life, pregnant women, systemic lupus erythematosus

1. Introduction

Systemic lupus erythematosus (SLE) is a chronic inflammatory multi-system disease, more common among women at childbearing age. SLE is of unknown etiology, but there are recognized risk factors, including environmental factors, e.g., exposure to ultraviolet rays, certain medications as penicillamine and isoniazid, some virus infections, exposure to smoking, physical or emotional stress, and genetic predisposition. SLE may induce complications during pregnancy as spontaneous abortion, intrauterine fetal death (IUFD), preeclampsia (PE), intrauterine growth retardation (IUGR), premature rupture of membrane (PROM), preterm birth, neonatal lupus, and secondary antiphospholipid syndrome *(Zhang, Liang, Xu, Zhang, & Chen, 2018).*

Pathophysiology of SLE embraces immune responses against endogenous nuclear antigens that are characteristic of SLE. Auto-antigens released by apoptotic cells presented by dendritic cells to thymus cells (T cells) leads to their activation. In turn, T cells help bone marrow cells (B cells) to produce antibodies to these self-constituents by secreting cytokines that result in the production of adaptive immune complexes, which amplify and sustain the inflammatory response. Moreover, SLE disease activity during pregnancy increases as a result of the increased levels of estrogen, progesterone, prolactin, T–helper cell, and cytokines. Hence treatment of SLE during pregnancy involves preventing flares and reducing their severity and duration when they occur. Treatment may include the following relatively safe drugs; corticosteroids as prednisone, non-steroidal anti-inflammatory drugs as Aspocid, Antimalarials as hydroxyl-chloroquine, and Immunosuppressants as azathioprine. Some other drugs, as cytotoxic drugs, cannot be used during the first trimester of gestation to avoid congenital fetal anomalies *(Goma, Abda, Selim, El-Hakeim, & Mohamed, 2018).*

SLE during pregnancy confers unique challenges of flares alternating with periods of remission of disease activity. Therefore, maternity nurses and a multidisciplinary collaborative team must provide close monitoring and care for those pregnant women with SLE, empower them, and encourage family indulgence with a women-centered self-care approach supported by educational guidelines *(Kim et al., 2018).* Consequently, improvement of their Quality of life (QoL) would result. QoL of pregnant women with SLE

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is a multidimensional construct that includes physical, psychological, and social domains. Interventions encouraging self-care (SC) strategy are defined as interventions that equip women with skills to actively participate and take responsibility in their care. The strategy functions optimally through acquiring knowledge and skills that enhance problem-solving and decision making abilities toward their treatments and pregnancy/SLE follow-up; also help to change their physical and psycho-social activities to adapt with their life during pregnancy and SLE *(Kusnanto, Purnama, Harmayetty, Efendi, & Gunawan, 2018)*.

The supportive educational guidelines mean equitable access to high-quality educational materials providing knowledge and required practical skills as self-care practices regarding antenatal care. These interventions are likely to improve the QOL of pregnant women with SLE in all its domains. Fortunately, due to medical advances, the women-centered health care directed to pregnant women with SLE has increased worldwide, and most pregnancies are successful *(McDonald et al., 2018)*.

Therefore, maternity nurses and other health team personnel involved in care, as well as skilled multidisciplinary collaborative health teams, must be able to take a more holistic approach with those women by being both "healers" and "helpers," so that those women may live and adapt with SLE lifestyle during pregnancy. Consequently, improve their quality of life *(Parastandechehr, Tahereh, Paragomi, Akhlaghi, & Akbarian, 2016 &; Goma et al., 2018)*.

2. Significance of the study

It is estimated that 5 million people worldwide have lupus disease, of which 70% have systemic lupus erythematosus. About 20% of people with SLE will have a parent or sibling who already has lupus or will develop lupus. Also, the disease will affect about 5% of the newborn to women with lupus, according to *(Control Disease Center "CDC," 2015)*. Furthermore, the prevalence rate of SLE at Ain Shams University Hospital in Egypt is 10866 cases yearly *(Information and Statistical Center of Ain Shams University Hospital, 2015)*.

Pregnant women with SLE are prone to relapse and remissions that result in cumulative damage. This fluctuation remains a challenge during antenatal management of those women with SLE. Therefore, close monitoring and collaborative self-care educational guidelines are crucial for a successful pregnancy outcome and improve the Quality of life with SLE.

3. Aim of the Study

This study aims to evaluate the effect of self-care guidelines on the Quality of life among pregnant women with systemic lupus erythematosus.

3.1. Research hypothesis

Pregnant women with SLE exposed to self-care guidelines will have a better quality of life than their pre-intervention level.

4. Subjects & Methods

4.1. Research design

A quasi-experimental design (time series), one group only, pre/post-intervention assessments used. Quasi-experimental research design is known as 'field experiment or 'in-situ experiment,' while quasi means "resembling." Thus it resembles not true experimental research, used to estimate the causal influence of an intervention on the target population.

The independent variable manipulated, study population are not randomly assigned or orders. These studies' design typically utilizes the target population that has already been established before the researcher decided to study their reaction to stimuli. Nevertheless, quasi-experiments still provide fruitful information for the advancement of research *(Braddock, 2019)*.

4.2. Research setting

The study was conducted at Rheumatology Antenatal Outpatient Clinic and Labor Unit at Ain Shams Maternity Hospital and Rheumatology Outpatient Clinic at Ain Shams University Hospital.

4.3. Subjects

A purposive sample was used to achieve the aim of this study. Sample size: the flow rate of SLE among pregnant women at Rheumatology Outpatient Clinic at Ain Shams University Hospital was (612 pregnant women) in the previous year (2015-2016). Accordingly, a sample size of (61) women included in the study represented 10% of the hospital flow-rate statistics. The final study sample was (50) pregnant women as (11) women dropped out.

Inclusion criteria

- The study included pregnant women diagnosed with SLE according to the classification criteria of Systemic Lupus International Collaborating Clinics /American College of Rheumatology (SLICC/ACR) by *(Petri et al., 2012)*.
- The study women were selected regardless of their education level.
- Pregnant women included in the study were of gestational age from 1 to 6 months.

Exclusion criteria

- The selection excluded hospitalized pregnant women at inpatient departments who suffered from the severe activity of SLE.
- Pregnant women with any other medical or gynecological diseases.
- Pregnant women above the gestational age of 6 months.

4.4. Tools for data collection

4.4.1. Structured Interviewing Questionnaire

The researcher developed it in the Arabic language after reviewing related advanced literature as *Chogle (2016); Daniel and Wallace (2017), World Health Organization (2016)*. It was divided into four parts with closed questions: Part 1 assessed general characteristics of

the women as age, educational level, address, occupation, marital status, and income, included (6 items).

Part 2 assessed the previous history of SLE as a family history for SLE, duration of disease, follow-up, treatment compliance, and clinical manifestations at SLE diagnosis, included (8 items). Part 3 assessed previous obstetric and gynecological history as a number of the previous gravida, para with or without SLE, mode of delivery, complications associated with pregnancy and labor, included (8 items) and Part 4 assessed women knowledge regarding SLE during pregnancy and its treatments as women knowledge about the definition, types of lupus, risk factors, manifestations, diagnosis, complications, and treatments of SLE, and source of their knowledge about SLE, included (8 items).

The last part was applied at once as pre and once as post-intervention assessments, while the first three parts were applied only pre-intervention. The Scoring system for knowledge regarding SLE was that an incorrect answer was scored as one, while the correct answer was scored as two. The mean score for each assessment was calculated. Overall test and retest reliability coefficient was alpha Cronbach value of 0.45.

4.4.2. Pregnancy Assessment Questionnaire

The researchers designed it after reviewing related advanced literature as *World Health Organization (2016); Aly, Mohamed, and Nabil (2016); Kroese et al. (2017),* to assess current pregnancy and labor outcomes. It was divided into two parts with open and closed questions: part 1 assessed current pregnancy outcomes as gestational age, SLE treatments during pregnancy, maternal and fetal complications of current pregnancy, and body mass index (BMI) before and during pregnancy included (11 items), this part used fifth times from initial visit till fifth follow-up visits during this study.

It is used in evaluation once pre-intervention and twice post-intervention assessments. While part (2) assessed current labor outcomes as the mode of delivery, maternal, fetal, neonatal complications, and neonatal birth weight, included (7 items), this part was used once only during labor at six follow-up visits this study. Overall test and retest reliability coefficients were alpha Cronbach values of 0.95.

4.4.3. Quality of Life (WHOQOL) Questionnaire

It was adopted from the *World Health Organization Quality of Life Bref "WHOQOL" (2004)* to assess the Quality of life of pregnant women with SLE with closed questions. This tool was in the English language, and it was translated into the Arabic language to suit Egyptian women by the researchers and modified by rephrasing some words. It subdivided into five parts: part (1) women physical QoL as physical manifestations of SLE, nutrition, exercise and sexual relation that included (21 items), part (2) women psychological manifestations of SLE, QoL as psychological that included (10 items), part (3) women social QoL as social relations, and social activities, that included (12 items), part(4) included (one item) about women evaluation

of their QOL levels, and part (5) included (one item) about women satisfaction regarding their health status during pregnancy.

This tool was used as once pre-intervention and twice post-intervention assessments. The Scoring system for QOL was that for each item of each domain of QOL, the women's expression of the negative effect of SLE scored as follows: Mild effect scored as one, Moderate effect scored as two, and the severe effect scored as three. Thus, the total score of the physical Qol domain score was 63, the total score of the psychological QoL domain was 30, and the total score of the social Qol domain was 36. Thus QOL total scores ranged from 45 to 135. The score from 1 to 45 was evaluated as mild total QOL, the score from 46 to 90 as moderate total QOL, and the score from 91-135 evaluated as severe total QOL.

Accordingly, the mean score for each assessment was calculated. The bigger was the mean score, the better was the QOL. While a score of other items of this tool included women evaluating the level quality of life as a percentage, was ranked as poor QOL if ≤ 50%, good QOL if 50-65%, and very good QOL if > 65%. Women's satisfaction regarding their health status during pregnancy was also ranked as dissatisfied with health status if it was ≤ 50%, satisfied with health status if 50-65%, and very satisfied with health status if it was > 65%. Overall test and retest reliability coefficients were alpha Cronbach values of 0.76.

4.4.4. Systemic Lupus Erythematosus Disease Activity Index (SLEDAI)

It was designed by *Petri et al., (2012)* to assess a cumulative and weighted index for health problems associated with SLE activity with closed questions (included 24 items). Each item represents one clinical manifestation of SLE. This tool was used fifth times from the initial visit till the fifth follow-up visit. It is used in evaluation once pre-intervention and twice post-intervention assessments.

SLE disease activity index weight scoring system calculated as follows: items of clinical manifestations in SLEDAI from number 1 to 8 as seizure, psychosis, each one manifestation was weight scored as 8, SLE clinical manifestations items from 9 to 14 as arthritis and myositis, each one manifestation was weight scored as 4, SLE clinical manifestations items from 15 to 21 as rash, alopecia, and mucosal ulcer, etc., each one manifestation was weight scored as two and SLE clinical manifestations items from 22 to 24 as fever, thrombocytopenia, and leukopenia each one manifestation was weight scored as 1. Thus, SLE disease activity index total scores ranged from 0 to 105.

Accordingly, the mean score for each assessment was calculated. Overall test and retest reliability coefficients were alpha Cronbach values of 0.67.

4.4.5. Health Assessment Questionnaire for Women with Systemic Lupus Erythematosus

It was designed by *the Ministry of Health, British Columbia (2012).* This tool was in English and was translated into Arabic to suit Egyptian women and modified with rephrasing some words to assess health status for pregnant women with SLE and determine their health needs. The tool included closed questions to assessed health state by assessing the difficulty inflicted by SLE disease in performing daily living activities (DLA).

This tool was used as once pre-intervention and twice post-intervention assessments. The overall purpose was to assess and follow up on the effect of self-care guidelines on health status and needs. The tool is divided into three parts of this questionnaire. These included: part (1) the degree of difficulty in performing daily living activities; it included eight types of DLA as dressing and grooming, arising, eating, walking, hygiene, reach, grip, and activities. With further 17 sub-types included sub-items for dressing and grooming as combing hair and wearing clothes, sub-items for rising as stand up from a chair and get in and out of bed. Sub-items of eating as women ability to perform cut uncooked meat and lift a full cup or glass to the mouth, and sub-items of walking as women ability to climb upstairs and walk outdoors on flat ground and so on for other sub-items.

Part 2 the needs for assisting devices in performing DLA as canes, walker, bath seat, and wheelchair; and part (3) the needs for human help in performing DLA as housing activities, walking, hygiene, dressing, and grooming and treatments. Health assessment scoring system for each sub-type of DLA calculated as follows: No difficulty with performing activities scored as one, Few activities performed with difficulty scored as two, Many activities performed with difficulty scored as three, and All activities performed with difficulty scored as four. So health assessment total scores ranged from 1 to 68. The mean score for each assessment was calculated. Overall test /retest reliability coefficients were alpha Cronbach values of 0.95.

4.4.6. Laboratory Investigations Record for Pregnant Women with SLE

It designed by the researchers after reviewing related advanced literature as *Doria, Gershwin, and Selmi (2016); Laboratory of Ain Shams University hospital, (2016); Hannahs (2017)* with closed questions to assess changes in the results of laboratory investigations done for the women for fifth times from initial visit till fifth follow-up visits. It was used in evaluation once pre-intervention and twice post-intervention assessments as complete blood count (CBC), erythrocyte sedimentation rate (ESR), urine analysis, and 24 hours urine protein and protein/creatinine ratio (PCR). The laboratory investigations record included 21 investigations, in which the standardized normal range of laboratory investigations of Ain Shams University Hospital used and mentioned in the following table of lab investigations. The Scoring system for laboratory

investigations record was that an abnormal lab investigations result of the study sample was scored as one. A normal result of their lab investigations results scored as two.

Labs investigations	Normal range
CBC	
WBCs	4-10 10^3/ul
Hb	12-15 g/dl
RBCs	3.80-4.80 10^3/ul
MCV	83-101 fl/cell
Platelet	150-410 10^3/ul
ESR	
ESR	1st hour 2-20 mm/hr
Urine analysis	
Casts	Absent
Albumin	Absent
RBCs	0-5/ HPF
Pus cell	0-4/ HPF
Immunological labs	
ANA	Negative (less than 0.9)
Anti ds-DNA	Negative less than 40 IU/ml Borderline 40-60 IU/ml Positive more than 60 IU/ml
Anticardiolipin IgG	Up to 23 GPU/ml
Anticardiolipin Igm	Up to 11 MPlu/ml
Lupus anticoagulant	31.6-43.4 sec
C3	80-160 mg/dl
C4	20-40 mg/dl
Anti –SSA (RO)	Negative (less than 20 units)
Anti –SSB (la)	Negative (less than 20 units)

4.4.7. Self-Care Practice Assessment Questionnaire

It was adopted from *Institute for functional medicine (2016)* to assess self-care reported by pregnant women with SLE. This tool was in English and was translated to Arabic by the researchers to suit Egyptian women. The tool was modified by rephrasing some words to assess self-care practices as reported by pregnant women with SLE before and after using self-care guidelines by rephrasing some words. It included closed questions (7 items). This tool was used as once pre-intervention and twice post-intervention assessments.

The Scoring system for self-care practices items was as follows: "Never follow" was scored as one, "sometimes follow" was scored as two, and "regular follow" scored as three. So self-care practices reported total scores ranged from 7 to 21. The mean score for each assessment was calculated. The mean score was evaluated as dissatisfactory if ≤ 50% (1-10), was evaluated as satisfactory if 50-65% (11-13) and was evaluated as very satisfactory if > 65% (14-21). Overall test and retest reliability coefficients were alpha Cronbach values of 0.76.

4.4.8. Supportive Material

It was in the form of simple "Arabic self-care guidelines," designed by the researcher after reviewing related advanced literature. The material is supported by

colored pictures of pregnant women with SLE for easy understanding. It included five parts: Part (1) included an overview of SLE (definition, causes, types, manifestations, effects on pregnancy, diagnosis, and treatment during pregnancy). Part (2) included antenatal care for pregnant women suffering from SLE. Part (3) included self-care instructions for physical aspects, common manifestations of SLE, and minor discomfort with pregnancy. Also, the psychological and social aspects of pregnant women suffering from SLE were identified. Part (4) included self-care instructions regarding preparation for labor. Part (5) included self-care instructions for the immediate postpartum period.

4.5. Procedures

Validity and Reliability of all tools: The developed tools and self-care guidelines reviewed for the appropriateness of items, and the concepts were measured by an expert jury panel of 5 experts: 3 Professors of maternity and gynecological nursing and 2 Professors of internal medicine and Rheumatology specialist" to assure content and face validity of the tools. Some questions were then rephrased accordingly. Reliability: The tools were tested and retested on the pilot sample of 6 women. Alpha Cronbach test was used to measure the internal consistency of all the tools used in the study.

Approval was obtained from the Scientific Research Ethical Committee in the Faculty of Nursing at Ain Shams University before starting the study. The researcher clarified the objectives and aim of the study to the women included in the study sample and obtained written informed consent from each of them. The researcher Maintained and assured the anonymity and confidentiality of the subject's data always considered. The women had the right to withdraw from the study without affecting their health care services received in the study settings. No harm was inflicted on the women or their fetuses during the study.

A pilot study was conducted from the beginning of March to the end of April 2017 on 10 % of the total study sample (6 women). Women included in the pilot study were included in the main study sample size because no modifications were made except for rephrasing some words. Data collection started from the beginning of May 2017 till the end of September 2018. The researcher attended one day weekly in each of the Rheumatology Outpatient Clinic at Ain Shams University Hospital and Rheumatology Antenatal Outpatient Clinic at Ain Shams Maternity Hospital.

The study program conducted on six successive visits as following;

Initial assessment visit: The researcher met each woman individually to explain the aim of the study and obtain written consent to participate in the study. The initial pre-intervention assessment was done using all tools of data collection as a pretest except tool no. (2) As only (part one) current pregnancy assessment questionnaire for women with SLE was used. Orientation offered for the women about the simple Arabic self-care guidelines content, how to

use it correctly, and its importance for their home self-care instructions regarding SLE during pregnancy. This session took approximately 45 minutes; each woman got a copy of the Arabic self-care guidelines supportive material. The researcher exchanged telephone numbers with the interviewed woman for any further explanation about the required items. The appointment of the next visit is fixed according to a suitable follow-up schedule for each woman.

Second and third visits were assigned for follow-up and educational sessions. The researcher used in the second and third visits to assess women and fetal conditions: tool no. (2) (Part one only) current pregnancy assessment questionnaire for women with SLE, tool no. (4) SLEDAI and tool no. (6) Lab investigation record. The educational session conducted at the second visit included a discussion of parts one and two of the self-care guidelines content. The educational session conducted at the third visit included a discussion of part three of the self-care guidelines.

Fourth visit: An evaluation conducted in the 7th months of gestation for possible preterm labor. For follow-up, the researcher made the first post-intervention assessment using all tools excluding (part two) of tool no. (2) As only (part one) current pregnancy assessment questionnaire for women with SLE was used. An educational session was conducted discussing part four of the self-care guidelines that included instructions for preparing the women for labor. The appointment of the next visit was fixed according to the follow-up schedule of each woman.

The fifth visit was conducted at the end of pregnancy for performing the second post-intervention assessment by using all tools, including only part four of tool no. (1), and only part one of tool no. (2). The educational session was conducted discussing part five of self-care guidelines, which included self-care instructions for preparing women for the immediate postpartum period — the expected time of labor for each woman considered.

Six visits have done for the women who delivered at the Labor Unit at Ain Shams Maternity Hospital (37 women). It was assigned to assess maternal, fetal, and neonatal outcomes by using tool no. (2) Part two only from the women's hospital files. The maternal and neonatal outcomes for the women delivered at other maternity hospitals (13 women) were obtained by telephone contact.

Evaluation phase: Three assessments were done for pregnant women with SLE. They were included in the study sample as one initial pre-intervention assessment followed by two post-intervention assessments after the women applied the self-care guidelines. The first post-intervention assessment was done at the 4th visit at the 7th month of gestation, while the second post-intervention assessment was made at the 5th visit at the end of pregnancy. The sixth visit was for assessing women and neonatal outcomes at labor. The researcher made regular telephone contact with the study women in-between the scheduled visits according to their needs to ensure continuity of using self-care guidelines correctly, respond to any inquiries or requests, and confirm the next appointment follow-up visit.

4.6. Limitation of the study

- This study for pregnant women with SLE has taken a long time to assure continuous follow-up according to their follow-up schedule throughout pregnancy till labor, which consumed time and effort during the study.
- Eleven pregnant women with SLE from the initial sample dropped out and were not replaced. Drop out was due to family problems and financial burdens, which led their husbands to refuse to come for their follow-up visits. Long distances from their residence. Women's photosensitivity to sun rays and critical health conditions interfered with antenatal and SLE follow-up of the scheduled study settings.

4.7. Data analysis

The collected data were coded, organized, revised, and analyzed through Pentium 4 computer using the program "Excel version 2010 and statistical package for social science (SPSS) version 16. Results are presented in tables, figures, and charts. Test of significance was used to find out the association between the variables using paired t-test and Chi-square used to compare mean scores of quantitative variables pre and post-intervention and correlation coefficient test was used to correlate the mean scores of quantitative variables that were not following normal distribution curve pre and post-intervention. Alpha Cronbach test was used to test the Reliability of tools used in the study. Statistically significant difference was considered at>0.05. Highly statistically significant difference was considered at >0.01.

5. Results

Table 1 shows that 46% of the study sample were aged 30-39 years, and 42% aged 20-29 years, while the mean age for the whole study sample was 28.220±5.437. 6%, 12%, 12%, 52%, and 18% of the study sample could not read or write, had secondary education and university education, respectively. As for their place of residence, 60% of the study sample lived in urban areas. It found that 92% of the study samples were housewives, and 94% were married. Also, the table showed that 94% of them believed that they did not have enough income.

As for SLE's previous history, table 2 indicates that 10% of the study sample had a family history of SLE. About 44% of them had SLE for four years or more. The table showed that 86% of the study sample had regular follow-up while 14% had an irregular follow-up. All of them took all types of SLE treatment, and 82% of the study sample reported regular compliance to the treatment. The most frequent clinical manifestation of SLE was Lupus Nephritis (48%), followed by Secondary Antiphospholipid Syndrome (16%) as reported by the study sample and confirmed by labs investigations did for them.

Moreover, table 3 reveals that pre-intervention, 80% of the study sample had incorrect knowledge, and 20% had correct knowledge about SLE with a mean knowledge score of 8.1±0.50. Meanwhile, 94% to 100% of the study sample had correct knowledge for all items at the post-intervention

assessment. The difference between the study sample means knowledge scores pre and post-intervention was of a high statistical significance.

In addition, table 4 reveals that there was a statistically significant improvement in study sample self-care practices as reported after using self-care guidelines at the second and the third post-intervention assessments with a mean score of 20.22±0.86 and 20.94±0.42, respectively when compared to their pre-intervention practices (mean score 14.68±0.97.

Moreover, table 5 shows that there was a highly statistically significant improvement in the study sample disease activities post-intervention after using self-care guidelines at the first assessment with a mean score of 26.35±6.01), and further improvement on the third assessment with a mean score of 21.96±9.00) compared to their pre-intervention level at a mean 32.02±1.51.

Table 6 shows statistically significant improvements in most of the sample follow-up lab investigations after using self-care guidelines at the second and third post-intervention assessments compared to their pre-intervention level.

Figure 1 illustrates an improvement in study sample activities of daily living regarding their need for device support or social support for fulfilling daily living activities post-intervention after using self-care guidelines at the second and the third assessments compared to the pre-intervention assessment.

Table 7 illustrates the distribution of the study sample according to current pregnancy and labor outcomes outcome. Concerning complications associated with current pregnancy, 8% of the study sample had associated maternal complications, half of them had preeclampsia, and the other half had GDM, and 8% had fetal complications in the current pregnancy, 25% of them had either congenital anomalies, IUGR, IUFD or intracranial hemorrhage. About 60% of them had labored at full term concerning their pregnancy outcome, while 28% had preterm labor. The remaining 12% suffered from abortion.

Regarding current labor outcomes, mode of current labor (n=44), 38.6%, and 61.4 % of them had NVD and CS, respectively. Regarding the type of maternal complications during current labor, 34% of mothers had complications, 86.6% of them were PROM, and 13.4% were bleeding during labor. Meanwhile, fetal distress was the only reported fetal and neonatal complication associated with current labor (n=8, 18.2%). Out of the delivered babies, 79.5% had healthy birth weight, but 20.5% had low birth weight.

Figure 2 shows the distribution of the study sample regarding their QOL at the pre- and post-intervention assessments, which indicated variable improvement.

Table 8 shows that there was a highly statistically significant improvement in the total mean score of the study sample QOL after using self-care guidelines at the second and third assessments (post-intervention) with a mean score of 49.62±3.06, and 78.26±8.25, respectively, as compared to the pre-intervention assessment when the mean score was 40.46±16.43.

Table (9) shows positive correlations with high statistical significance between study sample self-care practices as reported, each of QOL, disease activity, and daily living activities, at all the three pre- and post-intervention assessments.
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Table (1): Frequency and percent distribution of general characteristics of the study sample (n= 50).

General characteristics	No	%
Women age		
< 20	6	12
20-29	21	42
30-39	23	46
Mean ± SD	28.220±5.437	
Educational level		
Cannot read & write	3	6
Primary	6	12
Preparatory	6	12
Secondary	26	52
University	9	18
Place of residence		
Urban	30	60
Rural	20	40
Occupation		
Housewife	46	92
Worker	4	8
Marital status		
Married	47	94
Divorced	3	6
Income level		
Enough	3	6
Not enough	47	94

Table (2): The frequency and percentage distribution of the study sample according to their SLE previous history (n= 50).

Variables	No	%
Family history of SLE		
Positive	5	10
Negative	45	90
SLE duration		
Less than one year	4	8
1-	12	24
2-	7	14
3-	5	10
Four years and more	22	44
SLE follow up:		
Regular	43	86
Irregular	7	14
Cause of irregular follow up SLE(n=7)		
Fear from sun exposure	3	42.9
Time of follow up not suitable	1	14.2
The far distance of the place of residence	3	42.9
SLE treatment		
Yes	50	100
Types of SLE treatment		
All treatments enlisted	50	100
Compliance for SLE treatment		
Compliant	41	82
Not compliant	9	18
Causes of irregular SLE treatment compliance (n=9)		
Fear from the treatment side effect	4	44.4
Physician recommendations	1	11.2
Cannot buy the drugs	4	44.4
Kind of SLE clinical manifestations at SLE diagnosis		
Lung's affection	1	2
Serositis	2	4
Lupus nephritis	24	48
Cerebritis	2	4
Eye's affection	3	6
Pleural effusion	2	4
Vasculitis	2	4
Carditis	2	4
Secondary antiphospholipid syndrome	8	16
Deep venous thrombosis (DVT)	2	4
Musculoskeletal affection	2	4

Table (3): Comparison of the studied sample knowledge pre and post-self-care guidelines (n=50).

Items	Pre-self-care guidelines				Post-self-care guidelines			
	Correct		Incorrect		Correct		Incorrect	
	No.	%	No.	%	No.	%	No.	%
Definition of SLE	12	24	38	76	50	100	0	0
Types of lupus	2	4	48	96	47	94	3	6
Risk factors of SLE	2	4	48	96	48	96	2	4
Signs and symptoms of SLE	10	20	40	80	50	100	0	0
Diagnosis of SLE	10	20	40	80	50	100	0	0
Complications of SLE	6	12	44	88	47	94	3	6
Treatment of SLE	8	16	42	84	48	96	2	4
Total mean score	8.1± 0.50				12.0 ± 0.04			
Test of significance	T =54.6				P = 0.001			

Table (4): Comparison of the study sample's self-care practices pre and post self-care guidelines intervention (n=50).

Items	Pre-self-care guidelines			Post-self-care guidelines					
	First assessment			Second assessment			Third assessment		
	Never	Sometimes	Regular	Never	Sometimes	Regular	Never	Sometimes	Regular
	%	%	%	%	%	%	%	%	%
Follow up and treatments compliance	0.0	14.0	86.0	0.0	2.0	98.0	0.0	0.0	100
Nutrition's	0.0	88.0	12.0	0.0	0.0	100	0.0	0.0	100
Physical activities	28. 0	72.0	0.0	0.0	0.0	100	0.0	0.0	100
Hygiene as skin care	0.0	100	0.0	0.0	0.0	100	0.0	0.0	100
Self-care related to SLE clinical manifestations	0.0	100	0.0	0.0	30.0	70.0	0.0	0.0	100
Self-care related to minor discomforts during pregnancy	16.0	76.0	8.0	0.0	16.0	84.0	0.0	0.0	100
Risk management (avoid exposure for sun, exposure for overcrowded areas and exhausted activities)	0.0	100	0.0	0.0	30.0	70.0	0.0	0.0	100
Total mean score	14.68 ±0.97			20.22 ±0.86			20.94±0.42		
Test of significance	*T1= 53.349 #T2 =38.847			P1=0.000 P2= 0.000					

*T 1(pre versus post second) & # T2 (pre versus post third) P 1(pre versus post second) &# P2 (pre versus post third)

Table (5): Comparison of disease activity of the studied sample pre and post self-care guidelines intervention (n=50).

Items	Pre Self-care guidelines	Post-Self-care guidelines	
	First assessment	Second assessment	Third assessment
	Mean ± SD	Mean ± SD	Mean ± SD
Total mean score	32.02 ± 1.51	26.35 ± 6.01	21.96 ± 9.00
Test of significant		@T1= 8.92 #T2= 14.03	@P1= 0.001 # P2=0.001

@T 1(pre versus post second) & # T2 (pre versus post third)   @P 1(pre & post second) & #P 2 (pre & post third)

Table (6): Comparison between study sample follow-up labs investigations pre and post self-care guidelines intervention (n=50).

| Parameters	Pre-self-care guidelines		Post-self-care guidelines				$X^2$1	P1	$X^2$2	P2
	First assessment		Second assessment		Third assessment					
	No	%	No	%	No	%				
WBCs (white blood cell)							7.35	0.048	6.37	0.041
Normal	43	86.0	47	94.0	48	96.0				
Abnormal	7	14.0	3	6.0	2	4.0				
Hb (hemoglobin)							13.01	0.001	14.28	0.001
Normal	11	22.0	26	52.0	45	90.0				
Abnormal	39	78.0	24	48.0	5	10.0				
RBCs (red blood cells)							9.24	0.032	12.07	0.001
Normal	27	54.0	40	80.0	49	98.0				
Abnormal	23	46.0	10	20.0	1	2.0				
MCV (mean corpuscular volume)							8.95	0.041	10.85	0.001
Normal	29	58.0	42	84.0	44	88.0				
Abnormal	21	42.0	8	16.0	6	12.0				
Platelet							6.15	0.047	6.93	0.045
Normal	44	88.0	48	96.0	49	98.0				
Abnormal	6	12.0	2	4.0	1	2.0				
ESR (sedimentation rate)							7.35	0.048	12.07	0.001
Normal	3	6.0	16	32.0	32	64.0				
Abnormal	47	94.0	34	68.0	18	36.0				
Pus cell (HPF)							7.24	0.037	10.22	0.001
Normal	7	14.0	19	38.0	35	70.0				
Abnormal	43	86.0	31	62.0	15	30.0				

NB: $X^2$1, P1 (pre &first post) & $X^2$2, P2 (pre & second post).

Table (6): Comparison between women follow-up labs investigations pre and post self-care guidelines intervention (n=50) (continue).

Parameters	Pre-self-care guidelines First assessment		Post-self-care guidelines Second assessment		Third assessment		X²1	P1	X²2	P2
	No	%	No	%	No	%				
Protein creatinine ratio										
Normal	13	26.0	22	56.0	35	70.0	7.35	0.039	9.82	0.001
Abnormal	37	74.0	28	44.0	15	30.0				
24 hrs urinary protein										
Normal	13	26.0	22	44.0	35	70.0	7.35	0.039	9.82	0.001
Abnormal	37	74.0	28	56.0	15	30.0				
ANA (antinuclear antibodies)										
Normal	44	88.0	48	96.0	48	96.0	6.15	0.047	6.15	0.047
Abnormal	6	12.0	2	4.0	2	4.0				
Anti ds-DNA*										
Normal	42	84.0	47	94.0	49	98.0	7.03	0.042	6.71	0.048
Abnormal	8	16.0	3	6.0	1	2.0				
Anticardiolipin IgG*										
Normal	47	94.0	48	96.0	49	98.0	6.31	0.049	6.05	0.049
Abnormal	3	6.0	2	4.0	1	2.0				
Anticardiolipin IgM *										
Normal	48	96.0	48	96.0	49	98.0	3.31	0.34	3.67	0.35
Abnormal	2	4.0	2	4.0	1	2.0				
LAC (Lupus anticoagulant)										
Normal	46	92.0	49	98.0	49	98.0	6.34	0.047	6.34	0.047
Abnormal	4	8.0	1	2.0	1	2.0				
C3 (mg/dl)										
Normal	48	96.0	48	96.0	48	96.0	3.31	0.34	3.67	0.35
Abnormal	2	4.0	2	4.0	2	4.0				
C4 (mg/dl)										
Normal	43	86.0	43	86.0	48	96.0	3.31	0.34	6.34	0.047
Abnormal	7	14.0	7	14.0	2	4.0				
Anti –SSA (RO) (units)*										
Normal	48	96.0	48	96.0	49	98.0	3.31	0.34	3.67	0.35
Abnormal	2	4.0	2	4.0	1	2.0				
Anti –SSB (la) (units)*										
Normal	49	98.0	49	98.0	49	98.0	3.31	0.34	3.67	0.35
Abnormal	1	2.0	1	2.0	1	2.0				

*NB: $X^2 1$, P1 (pre &first post) & $X^2 2$, P2 (pre & second post).*

*Anti-ds-DNA: Antibody to double-stranded DNA antigen, IgM: Immunoglobulin M, IgG: Immunoglobulin G, C: Complement, Anti –SSA (RO): Autoantibodies directed against Ro/SSA, and Anti-SSB(la): Autoantibodies directed against Ro/SSB.
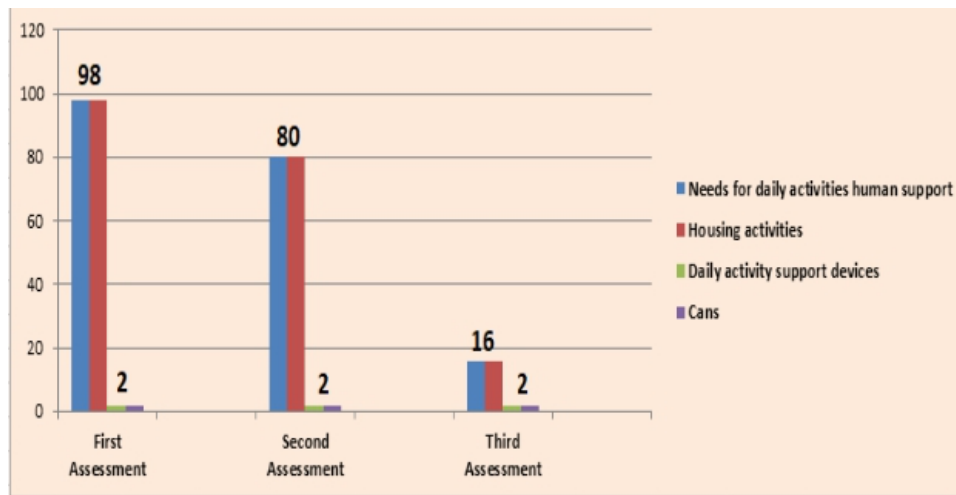
Figure (1): Percentage distribution of the study sample according to their daily living activities pre and post self-care guidelines intervention (N=50).

Table (7): The frequency and percentage distribution of the study sample according to their current pregnancy and labor outcome (n= 50).

Pregnancy and labor outcomes	No	%
Current pregnancy outcome:		
Maternal complications during current pregnancy:		
Yes	4	8
No	46	92
Kinds of maternal complications during current pregnancy(n=4)		
Preeclampsia	2	50
Gestational diabetes mellitus (GDM)	2	50
Fetal complications:		
Yes	4	8
No	46	92
Kinds of fetal complications(n=4):		
Congenital anomalies	1	25
Intrauterine growth retardation (IUGR)	1	25
Intrauterine fetal death (IUFD)	1	25
Intracranial hemorrhage	1	25
Pregnancy outcome:		
Abortion	6	12
Preterm labor	14	28
Full-term labor	30	60
Current labor outcome:		
Mode of current labor (n=44):		
Normal vaginal delivery (NVD)	17	38.6
Cesarean section (CS)	27	61.4
Maternal complications during current labor(n=44):		
Yes	15	34
No	29	66
Kinds of maternal complications during current labor:(n=15)		
PROM	13	86.6
Bleeding during labor	2	13.4
Neonatal complications during current labor (n=44):		
Yes	8	18.2
No	36	81.8
Kinds of neonatal complications during current labor(n=8):		
Fetal distress	8	100
Abnormal Apgar Score	0	0
Neonatal birth weight: (n=44)		
Low birth weight (less than 2500gm)	9	20.5
Normal birth weight (2500 - 4000gm)	35	79.5
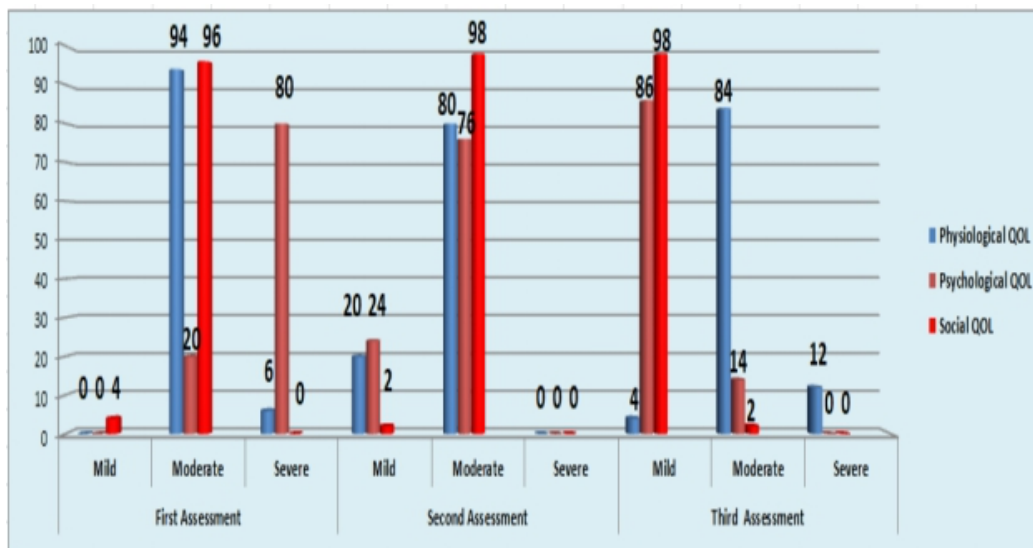
Figure (2): Percentage distribution of study sample QoL pre and post-self-care guidelines intervention (N= 50).

Table (8): Comparison of the study sample QOL pre and post-self-care guidelines intervention (n=50).

Items	Pre-self-care guidelines	Post-self-care guidelines	
	First assessment	Second assessment	Third assessment
Total mean score	40.46 ±16.43	49.62 ±3.06	78.26 ± 8.25
Test of significance and p value	t1= 16.19 t2= 26.73	$p1$=0.001 $p2$= 0.001	

NB: t 1, p1 (pre &first post) & t2, p2 (pre & second post)

Table (9): Correlations between self-care practices as reported, QOL, disease activity, and daily living activities of the study sample pre and post-self-care guidelines intervention (N= 50).

Items	Self-care practices as reported					
	Pre-self-care guidelines		Post-self-care guidelines			
	First assessment		Second assessment		Third assessment	
	r	P value	r	P value	r	P value
Quality of life	r= 0.28	P = 0.04	r= 0.43	P = 0.02	r= 0.49	P = 0.02
Disease activity	r= 0.270	P= 0.058	r= 0.315	P =0.04	r= 0.352	P =0.02
Daily living activities	r= 0.097	P= 0.501	r= 0.414	P= 0.02	r= 0.501	P= 0.03

6. Discussion

The present study aimed at evaluating the effect of self-care guidelines on the Quality of life among pregnant women with systemic lupus erythematosus. The study hypothesis was that pregnant women with SLE exposed to self-care guidelines would have a better quality of life than their pre-intervention level.

Concerning the general characteristics of the study sample, the results of the current study reveal that less than half of this study sample (forty-six percent) was in the age range between 30-39 years. This finding was somewhat comparable to that of *Wu and Di (2018)*, who found that most of their study sample was at the age range between 20-47 years old. That study also stated that the prevalence of high-risk pregnancy increased steadily with age. This comparability of the findings could be explained because SLE is more common among women in the reproductive age due to hormonal changes in adolescence and the perinatal period till premenopausal age.

In another study, *Mohamed and Kamel (2018)* reported that around half of the study samples (forty-seven percent) were at the age range between 30-40 years old, which was compatible with the current study's findings. This correspondence resulted from SLE affects young adults and starts in the second or third decade of life. It seemed that SLE occurred most frequently between the age ranges of 20-39 years. This high predisposition of childbearing age produced a significant concern for the care of this age group.

The current study results reveal that the study sample improved their knowledge significantly about SLE post-intervention assessments after using the self-care guidelines compared to the pre-intervention assessment. Lack of correct knowledge in this situation raises questions about the efficiency of study sample education.

As a counselor and a health educator, these findings show no nurse role for those study samples regarding SLE during pregnancy. The study demonstrates that implementing the education intervention supported with distributing the Arabic self-care guidelines had statistically significantly improved the study sample knowledge at post-

intervention assessments compared with their pre-intervention level.

The previous study finding was in line with *Barton-Ellis (2016)*. They found that most of the sample had incorrect knowledge regarding SLE and their source of knowledge was the experience or religious personnel. This lack of knowledge made these women reluctant as regards health-seeking behavior.

The current study results reveal that the study sample self-care practices had improved significantly in the second and third post-intervention assessments after using the self-care guidelines compared to the pre-intervention assessment. These findings agreed with *Mohamed and Kamel (2018),* who found a highly significant improvement in their studied sample reported self-care practices post-intervention. Also, the result was in agreement with *Sahebalzamani et al. (2017)*, who found that empowerment through health education and active involvement in the related interventions for members of the community affected by SLE are integral to health improvement.

Likewise, the results of the present study indicate that there was an improvement in the study sample health assessment (through decreasing the degree of difficulty in performing daily activities) as well as improved or decreased need for a device or human support post using self-care guidelines at the first and second post-intervention assessments. This result was sturdily in contrast with *Margiotta et al. (2018)*, who found that physical activity was insufficient to meet world health organization recommendations in sixty percent of their studied sample. SLE women spent a median of ninety-five percent every day in sedentary activities.

A comparison of the SLE disease activity index (SLEDAI) scores for the study sample during the assessments done pre and post-intervention showed that an improvement of high statistical significance occurred in the first post-intervention assessment. Moreover, the improvement noticed in the second post-intervention assessment was even more evident. This improvement has resulted from using self-care guidelines for SLE during pregnancy initiated by the study intervention and supported

by educational materials during the study program, besides continuous follow-up for the study sample according to their follow-up schedules. *Kusnanto et al. (2018)* strongly supported those findings of the current study, who found that the application of the self-care model not only achieved a high quality of life independently but also enhanced reductions in SLE flares which were triggered by the factor of physical stress. When flare was reduced, that improved general physical health, decreased joint and muscle pain (which were the most common symptoms reported), increased vitality, emotional stability, and adaptive coping.

The findings of the pre-intervention assessment disagreed with *Xie, Yang, Nie, Li, and Chen (2018)'s*, who found that the mean SLEDAI-2K scores were 10.1 and the frequent manifestations of SLEDAI-2K included hair loss, rash, arthritis, low complement, and proteinuria. As was found in the current study, the comorbidity of nephritis and hypertension were the most common.

The current study compared the results of the laboratory investigations as performed in the pre-intervention assessment to the follow-up results performed in the first and second post-intervention assessments. There was a statistically significant improvement in the follow-up lab investigations after using self-care guidelines. This improvement has resulted from using their treatments, that posted by application of self-care instructions as mentioned in educational materials self-care guidelines for SLE during pregnancy that was initiated by the study intervention and supported with receiving their follow up visits, besides continuous follow-up for the study sample according to their follow-up schedules during the study program and also enhanced with a telephone follow-up.

The overall distribution of the normality or abnormality of the lab results in the pre-intervention assessment was online with *Liu and Zhou (2017)*, who found that most studied samples (eighty-one percent) were anti-ds-DNA positive, about fifty-three percent anti-Ro/SSA antibody-positive, and thirty-one percent were anti-La/SSB antibody positive. On the other hand, all the studied samples were antinuclear antibody-positive. There was thirty-three percent of a low level of C3. Twenty-eight percent had a low level of C4, the presence of ACLA about ninety-five percent, recurrence occurred for them, and half of them had hypocomplementemia at some point.

The main aim of the current study was to evaluate the effect of applying the self-care guidelines on the Quality of life of the study sample. The results show a high statistically significant improvement in the study sample QoL at the post-intervention assessments compared to the pre-intervention level. The improvement was existing in each of the three domains of QoL (physiological, psychological, and social domains). Besides, the study showed an own sample evaluation of their QoL, and the degree of satisfaction with their QoL has also significantly improved after applying self-care guidelines. These improvements resulted from the intervention provided for the study sample at each visit to enhance self-care strategy. That intervention was supported by simple Arabic

educational self-care guidelines and regular telephone contact to correctly ensure the continuous use of self-care guidelines. The study findings were in line with *Kusnanto et al. (2018)*, who found that the self-care model was significantly effective in enhancing self-care agency (SCA) and improving the Quality of life; the most studied sample after four weeks from applying it.

On the other hand, this study results showed a significant positive correlation between using self-care guidelines and QOL at all assessments. However, this finding was in contrast with *Sari (2016)*, who found that self-care practices were uncorrelated with health-related Quality of life and health outcomes in SLE samples.

Furthermore, as for complications associated with the current pregnancy of the study sample, only eight percent of them had either preeclampsia or GDM. As far as fetal complications are concerned, again, only four of the study sample (eight percent) reported the presence of fetal complication, as one case of each of IUFD, IUGR, congenital anomalies, and intracranial hemorrhage. As for current labor complications, eighty-six and six percent of the study sample had premature rupture of membrane (PROM), while thirteen and four percent had bleeding during labor. Besides, as for neonatal birth weight, seventy-nine and a half percent of born babies had average birth weight while the others had low birth weight.

These results roughly agreed with *Chen, Zhang, Liang, Xu, and Zhang (2018)*, who found that two-thirds of the pregnancies ended in successful delivery without any fetal adverse pregnancy outcomes (APOs), and fetal loss was significantly low to less than five percent, although preterm births remained an important issue. The occurrence of moderate to severe disease flares remarkably reduced while severe maternal disease flares occurred in only less than one percent in the lupus study sample, which underwent planned pregnancy. Also, pregnancy-induced hypertension (PIH) occurred in eleven percent of the study sample, approximately twice over the general population in China.

As for fetal outcomes*, Chen et al. (2018)* found that about two-thirds had no APOs. On the other hand, preterm births were about twenty-two percent, IUGR about fifteen percent, and fetal distress, about eleven percent. The average birth weight was 790.0-4150.0 g. Forty-two preterm infants were delivered after the 34th week of gestation due to preterm premature rupture of membranes (PPROM), representing about thirty-five percent.

This similarity of the results of the present study and the published literature could be due to the increasing SLE disease activity during pregnancy; including periods of flares, thrombocytopenia, Anti-Cardio-Lipin Antibody (ACLA) positivity, and active lupus nephritis (LN) that demonstrates the strongest predictor of positive relationship with premature delivery, increased recurrence of hypertension, and PE. Also, the previous studies indicated that there was an association between ACLA and severe preeclampsia. As will be seen in the discussion, the results of the study justified this hypothesis.

As seen in the discussion, the results of the study justified this hypothesis.

7. Conclusion

Based on the results of the present study, the following could be concluded:

The current study results supported the research hypothesis that implementing self-care guidelines would improve the Quality of life of pregnant women with SLE. The observed improvement in QoL was linked to the highly significant improvement in disease activity, self-care practices as reported, daily living activities, and lab investigations after implementing the self-care guidelines.

8. Recommendations

Based on the study results, the following recommendations are forwarded: Application of the study intervention to distribute the clear Arabic self-care guidelines on a large scale in other sittings caring for pregnant women with SLE.

The study suggests studying the following:
- Evaluate the effect of preconception awareness-raising programs on women with SLE on their pregnancy outcomes.
- Investigate the effect of a multidisciplinary supportive system on the Quality of life among pregnant women with SLE.

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