Effect of Health Promotion Program on Quality of Life for Patients with Systemic Lupus Erythematosus

Eman Abd El-Azeem Mohamed Yousef, Magda Abd El-Azeez, Nematallah Gomaa, Dalia Ali Ameen
Medical Surgical Nursing Department, Faculty of Nursing, Ain Shams

Abstract

Systemic Lupus Erythematosus (SLE or lupus) is a multisystem disease associated with significant morbidity and mortality. Health promotion program is the activities or strategies that are directed towards raising the general level of health and well-being of an individual. **Aim:** the study aimed to evaluate the effect of health promotion program on the quality of life for patients with Systemic Lupus Erythematosus. **Study design:** a quasi-experimental design was utilized to conduct this study. **Setting:** this study was conducted at Rheumatology, Nephrology, Immunology and outpatients clinics at Ain Shams University Hospitals. **Subject:** A purposive sample of 70 patients, diagnosed with SLE, admitted to the previously mentioned settings was recruited for conducting this study. **Data collection tools:** 1) Health assessment questionnaire for patient with SLE. 2) Lupus QOL Questionnaire. 3) Lupus awareness's quiz. **Results:** the present study revealed that there was a highly statistically significant improvement regarding patient’s levels of awareness post implementation of SLE health promotion program. Moreover, there were highly statistically positive correlations between SLE patients’ levels of awareness and patients’ QOL and their socio-demographic characteristics as regards their education level. In addition, there were highly statistically significant positive correlations between patients’ total QOL and total lupus awareness for SLE patients under the study pre and post implementation of SLE health promotion program. **Conclusion:** The implementation of Systemic Lupus health promotion program has a statistically significant positive effect on the quality of life for patients with SLE which support the stated hypothesis. **Recommendations:** Designing a systematically continuous health promotion program for patients with SLE in hospitals in addition to media such as: newspapers, television, and radio to help improve the health status of these patients.

Key words: Health promotion program, QOL, SLE.

Introduction

Systemic Lupus Erythematosus (SLE or lupus) is a chronic inflammatory autoimmune disease of unknown etiology that commonly affects women of childbearing age. Similar to many other rheumatological diseases, it has a variable course and outcome and is subject to periods of exacerbation and remission. Frequently affecting the musculoskeletal system and skin, lupus can also cause inflammatory changes in the kidneys, lungs, heart and central nervous system (Balsamo & Santos, 2011).

Survival of patients with systemic lupus erythematosus (SLE) has increased greatly during the last three decades. Earlier diagnosis and better treatment of the disease and its complications are the most likely explanations for the extended life span of most patients. Although prolongation of life is of critical importance, health status and quality of life are also important outcomes, so health care personnel became more aware of improving the quality of life of patients with SLE (Burckhardt, 2013; Abu Shakra, et al., 2011).

In recent years, the impact of chronic illness such as systemic lupus erythematosus on QOL has become an increasing concern to society and health care professionals. Patients with chronic or critical illnesses began to raise concerns not only about their chances for survival but also about the quality of that survival (Ferrel, et al., 2012).

Quality of life evaluation has become an expected outcome in the treatment of chronic and terminal illnesses. These studies inform health care professionals not only about patients’ QOL in disease states but also the changes in QOL from treatments. Moreover, in recent years, QOL measures have become relevant in choosing therapy, managing symptoms, formulating interventions, and assessing outcomes (lash, 2011).

Health promotion program is the activities or strategies that are directed toward raising the general level of health and well-being of an individual. Activities include lifestyle modification: diet, exercise, weight control, sleep, stress management and other primary prevention strategies as smoking cessation and drug use (Moore, & Williamson, 2012).

Nurses play a key role in promoting health and wellness. Through health promotion and risk reduction, the individual develops behavior patterns that promote a healthy lifestyle and reduce the risk of disease. The challenge for nurses is to find ways to motivate clients and families to develop health-promoting behaviors. Client teaching is a major intervention for promoting health (Bennett, C., et al., 2013).

Significance of the study:

Systemic lupus erythematosus is a multi-system disease which affects the life style of the patients; also it causes a huge number of complications which affects all the body systems. Also, it is a complex disease to diagnose, treat and manage. So, patients should encourage taking control of their lupus, and managing it. It is important that patients are referred early for diagnosis and that they are also referred to members of the wider health professional team. Health education program enable patients to make informed choices about their life (David, 2011). The systemic Lupus Erythematosus Health education program had positive effects on the patients in decreasing reports of pain, reducing depression, increased functional abilities and a reduced number of hospitalization and physician visits and improving knowledge and coping skills.

Aim of the study:

This study aims to evaluate the effect of health promotion program on quality of life for patients with systemic lupus erythematosus through the following:

2. Planning and implementing health promotion program for patients with systemic lupus erythematosus.


**Research hypothesis:**

The current study hypothesized that: The implementation of health promotion program will affect the quality of life for patients with systemic lupus erythematosus positively.

**Subjects and Methods:**

**A- Research design:**

A quasi experimental design was utilized to meet the aim of the study.

**B- Research Setting:**

The present study was conducted at Rheumatology, Nephrology, Immunology and outpatients clinics at Ain Shams University Hospitals.

**C- Subjects:**

Sample type: A purposive sample of 70 patients diagnosed with systemic lupus erythematosus. Admitted to the previously mentioned settings, sample size was calculated according to power analysis equation calculating the flow rate of patients diagnosed as SLE admitted to Ain Shams University hospital within the year 2013/2014. They were as follows:

- Type I error (α) = 0.05
- Type II error (β) = 0.1
- With power of test 0.90 (1-B) 90%

**Inclusion criteria:**

- Adult patients from both sexes with different educational levels.
- Patients at the remission stage not at the flare-up stage.
- All patients who did not attend/follow any similar health promotion program and agree to participate in the study.

**D- Tools for data collection:**

The study data was collected through the following three tools:

1. **Health assessment questionnaire for patient with SLE:** It was interview questionnaire to the patients with SLE, to assess the health needs of the patients. It was developed by Fries (1980), recently updated by Bruce (2003), and was adapted and modified by the researcher based on reviewing the current study. It includes five parts as follows:
   - **Part 1: Socio-demographic characteristics and medical history of the patients under study:** It was adapted from Przegl Lek (2008) and was modified by the researcher. It was used to assess: (age, …etc).
   - **Part 2: Disability index:** It was adopted from Stanford HAQ Disability Scale (2008). It is composed of 20 statements designed to assess (dressing,…etc).

   - **Scoring system for the Disability Index:**
The score is calculated by multiplying the highest score (3) by the number of questions (20) to yield the final composite score (60 grades) and then graded as following: ≥ 50% (=30 grades) considered as disabled patient, and <50% considered as able patient.

- Part 3: it divided into a) Discomfort and pain scale (Brief Pain Inventory) “BPI”: it was developed by McCorkle & Young, (2013). It was used to assess the severity of pain and discomfort. It is composed of a horizontal line where each end represents the opposite ends of a continuum. It is stated with “no pain” (with a score of 0) at one end and “very severe pain” (with a score of 10 at the other. Patients are instructed to place a vertical mark (number) on the line to indicate the severity of their pain.

b) Symptoms and sexual satisfaction scale: It was adopted by "Paul, et al., 1997". This part also includes the symptoms as stated by the patient and sexual satisfaction scale.

- Scoring system for Discomfort and Pain Scale (Brief Pain Inventory) “BPI”:
  The patient response graded as follow; 0= no pain, 1-5= moderate pain, and 6 - 10 = sever pain.

- Scoring system for symptoms: The patient response graded as follow; yes symptoms = 1 & no symptoms = 0.

- Scoring system for Sexual Satisfaction Scale “SSS”:
  o Satisfied = 4 - < 12
  o Moderately satisfied =12 - < 15
  o Dissatisfied = 15 -24.

- Part 4: Adherence of patient to therapeutic regimen: It was adopted from Cerner Multum & Wolters (2011). It includes 9 questions designed to assess the (patients’ adherence to medication,…etc).

  - Scoring system for adherence of patient: The patient response graded as follow; yes adhere= 1 & no= 0.

- Part 5: Patient satisfaction. It was adopted from The RAND Corporation (1994). It composed of 10 questions designed to assess (satisfaction of the patient about his/ her health…etc).

  - Scoring for satisfaction about health status:
    o Satisfied (Very well)= 65% & more
    o Moderately satisfied =50- < 65%
    o Dissatisfied (Very poor) = 0- < 50%

2- Lupus QOL Questionnaire sheet: it was a 34-item Systemic Lupus Erythematosus (SLE) specific health-related quality of life (HRQOL) measure. It was adopted from "McElhone K.,et al., 2007". The Lupus QOL consists of eight domains: physical health (8 items from 1-8), pain (3 items from 9-11), planning (3 items from 12-14), intimate relationships (2 items from15-16), 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 for Lupus QOL Questionnaire:
    o Poor QOL = 0 - < 50%
Effect of Health Promotion Program on Quality of Life for Patients with Systemic Lupus Erythematosus

- Average QOL = 50 - < 65%
- Good QOL = 65%
& more

3- Lupus awareness's quiz:

It was a self-administered quiz to the patients with SLE; it was used to assess the level of knowledge for patients with SLE; it was adopted by Bellotti (2003). The quiz includes 20 multiple-choice questions related to Systemic Lupus Erythematosus, which was divided into 4 main categories with 5 questions for each one.

- Scoring system:

The total score of lupus awareness quiz was 20 marks. Each correct answer was given one mark and the incorrect answer was given zero. It was categorized as follows: ≥ 60% (=12 marks) satisfactory level of knowledge, and < 60% unsatisfactory level of knowledge.

- Health promotion program for the patients with systemic lupus erythematosus: it was designed and developed by the researcher in Arabic-language booklet in the light of related literature (Davidson's F, 2014, Lupus Foundation of America, 2012, Makover & Zieve, 2011, Ginzler, Dooley & Merrill, 2011; & Goroll & May, 2009); and then reviewed by a jury of (7) medical and nursing expert consultants of Rheumatology, Nephrology, Immunology and medical departments at Ain Shams University Hospitals. The program is divided into 4 parts as follows:

Part one: general knowledge about SLE, part two: pathophysiology - causes - signs and symptoms, part three: complications and diagnostic measures, part four: medical management, life style changes, management of general problems of SLE.

II. Operational design:

The operational design includes preparatory phase, validity and reliability, pilot study and fieldwork.

- Preparatory phase:

This phase was carried out through the following steps:

1- Developing the data collection tools after reviewing the recent related literatures in periodicals, internet research and other resources.

2- Outlining all areas to be included in the health promotion program and educational booklet through extensive review of the literature and other available resources.

3- Designing the health promotion program, preparation of its content and developing the educational booklet.

4- Obtaining experts' opinion to ensure booklet's validity.

- Validity and reliability:

Validity: assessing face and content validity of the suggested tools, through a group of experts.

Validity was tested through a jury of 7 experts who composed of: (3 professors, 3 assistant professors, one lecturer) from Medical Surgical Nursing at faculty of Nursing, Ain Shams University for the content validity. The jury reviewed the tools for clarity, relevance, comprehensiveness, and simplicity; then based on the opinion of the jury minor modifications were done, and then the final forms were developed.
Reliability: Alpha Chronbach test was used to measure the internal consistency of the 3 tools used in the current study.

- Pilot study:

A pilot study was conducted on (10% of the study subjects = 7 patients with SLE) in order to test the applicability of the study tools, the clarity of the study tools, as well as estimating the average time needed to complete the tools. Accordingly, necessary modifications were made for the final development of the study tools. Some questions and items were omitted, added or rephrased and then the final forms were developed. Patients selected for the pilot study were excluded from the study subjects.

- Field work:

The study was started and finished through the following phases:

A) Assessment and planning phase:
- The preparation and translation of the tools for data collection took about 3 months, starting from June 2014 to August 2014. Data collection was started and completed within 6 months; from October 2014 to March 2015.

- The purpose of the study was simply explained to the patients who agree to participate in the study prior to any data collection; the study tools were filled in and completed by the researcher on 2 stages (pre & post implementation of the health promotion program).

- The researcher was available at the Inpatient Departments of Rheumatology, Nephrology, Immunology and medical departments, Ain Shams University Hospital 3 days/week at morning and afternoon shifts to collect data from the selected patients.

- The patients who fulfilled the inclusion criteria were selected. The researcher obtained the patients’ oral consent for participating in this study after explaining the aim of the study.

- Collection of data was begun with the health assessment questionnaire, and it was completed by the researcher within (10-15 minutes for each patient). After that, the lupus awareness quiz was also completed by the researcher within about (10 min. for each patient); in the end the Lupus QOL Questionnaire took about (10-20 min. for each patient) so, each patient need about 30 to 45 min.

- Filling in the previous mentioned tools was done by the researcher before implementation of the health promotion program according to the patients’ understanding and health condition.

- All information gathered through data collection tools was interpreted to identify the individualized learning needs.

- The researcher set up a teaching session plan based on identified needs covering all objectives. These objectives were categorized into general and specific objectives.

- The program resources and facilities were allocated (printed material and location of session that best serve the learners).

- The researcher determined the teaching strategy (timetable of sessions, teaching methods, media used and learners’ activities).

- After data collection, the appointment for starting teaching sessions
was detected and scheduled with the patients for the following weeks within the same previously mentioned days.

**B) Implementation phase:**

- The teaching sessions were conducted in a classroom in the inpatient department. The classroom was air conditioned, quiet, well ventilated, well furnished, and had adequate lighting and adequate spacing for implementing health promotion program activities.
  - Implementation of health promotion program lasted over a period of 3 months for all patients under the study.
  - At the beginning of the first session, an orientation of the health promotion program and its purpose took place. The importance and benefit of the health promotion program were explained to all the patients under the study to motivate them to follow instructions which were included in it.
  - Each session started by greeting the patients, assessing the patients’ motivation for learning, getting feedback about what was given through the previous session, and present the objectives of the new topic, taking into consideration using simple language to suit the educational level of the patients.
  - The researcher emphasized the importance of adherence to each step of the health promotion program, and the rationale for and the benefits of engaging in each new behavior were explained. The researcher encouraged the patients to express his/her readiness for changing their behavior.
  - Motivation, problem solving and reinforcement techniques were used to enhance active participation for all patients in the program plan. The booklet was handed for every patient.
  - Each session of the health promotion program had taken about 45-60 minutes/day for 3 days per week. These sessions were conducted for small groups; each group did not exceed five patients.
  - The collection of data after the application of the health promotion program lasted over a period of six months; starting from October 2014 to March 2015.
  - Follow-up sessions were conducted via the phone as some of the patients faced difficulty in coming to the hospital due to the long distance for giving the patients’ reassurance to complete the health promotion program.

**C) Evaluation phase:**

The evaluation phase was done to determine the effect of the health promotion program on the quality of life for patients with systemic lupus erythematosus through filling in the same tools again after implementation of the health promotion program then comparing the collected data pre and post implementation of the health promotion program.

**III. Administrative Design:**

An official letter was issued from the faculty of Nursing, Ain Shams University to the director of Rheumatology, Nephrology, Immunology, Hematology and and outpatients clinics at Ain Shams University Hospitals at which the study was conducted, explaining the purpose of the study and requesting the permission for data collection from the study group.

**IV. Statistical Design:**
The collected data were organized, categorized, tabulated and statistically analyzed using the Statistical Package for Social Science (SPSS) to evaluate the studied subject’s changes throughout the study phases (Pre & Post) and to evaluate the differences between the groups under study as regards the various parameters. Data were presented in tables and charts. The statistical analysis includes; percentage (%), mean, standard deviation (SD), Paired T test, r-test, and P-value. Also, Alpha Chronbach test was used to test reliability of tools.

The observed differences and association were considered as follows:

- Non-significant (NS) difference obtained at \( p > 0.05 \).
- Significant (S) difference obtained at \( p \leq 0.05 \).
- Highly significant (HS) difference obtained at \( p < 0.001 \).

**Results:**

**Table (1):** shows that the mean age for SLE patients included in the study were 29.48±7.51 and the majority of them (98.6%) were females. As regards residence, more than half of them (57.1%) resided in rural areas.

In relation to the marital status, it was found that more than two thirds of the patients under the study (70%) were married. Additionally, more than half of them (51.4%) had secondary educational level. As regards the patients’ occupation, about two thirds of them (64.3 %) were unemployed.

Regarding the effect of the disease on patients’ role in the family, the majority of the patients under the study (88.6%) were affected. In relation to the type of effect, it is mostly physical effect (81.4%) for them.

As regards the treatment cost, more than half of the patients under the study (55.7%) were treated at the government expense. In addition, about three quarters of them (74.3%) had no enough monthly income. Moreover, more than two thirds of them (67.1%) hadn’t enough monthly income for the treatment cost as the patients reported.

**Table (2):** shows that, the highest means and standard deviations post implementation of health promotion program were regarding all items of the lupus awareness with a highly statistically significance improvement regarding these items of the lupus awareness (\( P<0.001 \)).

**Table (3):** It was observed that, there are a highly statistically significant differences between the mean and standard deviation of disability index among the patients under the study as regards dressing and grooming, arising, eating, walking, personal hygiene, reach object, grip and various activities pre and post implementation of systemic lupus health promotion program (\( P<0.001 \)).

**Table (4):** reveals that more than half of patients (61.4%) were complain of severe pain pre implementation of systemic lupus health promotion program which decreased post implementation of systemic lupus health promotion program to one third (30.0%) with a highly statistically significance improvement between them (\( P< 0.001 \)).

**Table (5):** presents that, more than half of the patients under the study (58%) were dissatisfied with sexual life related to the disease pre-implementation of health promotion program which decreased post implementation of health promotion program to more than one
third of the patients under the study (32%) with a highly statistically significance improvement between them pre and post implementation of systemic lupus health promotion program (P< 0.001).

Table (6): It was observed that, more than one third of the patients under the study (37.1%) were dissatisfied with their health status related to the disease pre-implementation of health promotion program which decreased post implementation of health promotion program to less than one third of the patients under the study (24.3%) with a highly statistically significance improvement between them pre and post implementation of systemic lupus health promotion program (P< 0.001).

Table (7): presents that, more than three quarters the patients under the study (82.8%) had poor QOL related to the disease pre-implementation of systemic lupus health promotion program which decreased post implementation of health promotion program to more than one third (31.4%) with a highly statistically significance improvement between them (p<0.001)
**Table (1):** Frequency and percentage distribution of the socio-demographic characteristics of SLE patients under the study

<table>
<thead>
<tr>
<th>Socio-demographic characteristics</th>
<th>N=70</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (In years):</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15- ≤ 26</td>
<td>14</td>
<td>20.0</td>
</tr>
<tr>
<td>26- ≤36</td>
<td>38</td>
<td>54.3</td>
</tr>
<tr>
<td>36- ≤ 46</td>
<td>15</td>
<td>21.4</td>
</tr>
<tr>
<td>46- ≤55</td>
<td>3</td>
<td>4.3</td>
</tr>
<tr>
<td><strong>Range</strong></td>
<td>15-55</td>
<td></td>
</tr>
<tr>
<td><strong>Mean±SD</strong></td>
<td>29.48±7.51</td>
<td></td>
</tr>
<tr>
<td><strong>Gender:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
<td>1.4</td>
</tr>
<tr>
<td>Female</td>
<td>69</td>
<td>98.6</td>
</tr>
<tr>
<td><strong>Residence:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>30</td>
<td>42.9</td>
</tr>
<tr>
<td>Rural</td>
<td>40</td>
<td>57.1</td>
</tr>
<tr>
<td><strong>Marital status:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>16</td>
<td>22.9</td>
</tr>
<tr>
<td>Married</td>
<td>49</td>
<td>70.0</td>
</tr>
<tr>
<td>Divorced/ Widow(er)</td>
<td>5</td>
<td>7.14</td>
</tr>
<tr>
<td><strong>Educational level:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illiterate</td>
<td>6</td>
<td>8.6</td>
</tr>
<tr>
<td>Read and write</td>
<td>16</td>
<td>22.9</td>
</tr>
<tr>
<td>Secondary education</td>
<td>36</td>
<td>51.4</td>
</tr>
<tr>
<td>University education</td>
<td>12</td>
<td>17.1</td>
</tr>
<tr>
<td><strong>Occupation:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>25</td>
<td>35.7</td>
</tr>
<tr>
<td>Unemployed</td>
<td>45</td>
<td>64.3</td>
</tr>
<tr>
<td><strong>Job condition after disease:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full time</td>
<td>9</td>
<td>12.9</td>
</tr>
<tr>
<td>Part time</td>
<td>13</td>
<td>18.6</td>
</tr>
<tr>
<td>No work</td>
<td>3</td>
<td>4.3</td>
</tr>
<tr>
<td><strong>Does the disease affect your role in family?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>8</td>
<td>11.4</td>
</tr>
<tr>
<td>Yes</td>
<td>62</td>
<td>88.6</td>
</tr>
<tr>
<td><strong>If yes, what is the type of effect?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Economic</td>
<td>54</td>
<td>77.1</td>
</tr>
<tr>
<td>Psychological</td>
<td>50</td>
<td>71.4</td>
</tr>
<tr>
<td>Social</td>
<td>55</td>
<td>78.6</td>
</tr>
<tr>
<td>Physical</td>
<td>57</td>
<td>81.4</td>
</tr>
</tbody>
</table>

**Treatment cost:**
Table (2): Patients’ satisfactory level of awareness regarding SLE pre and post-implementation of SLE health promotion program

<table>
<thead>
<tr>
<th>Lupus awareness items</th>
<th>Pre-program Mean ± SD</th>
<th>Post-program Mean ± SD</th>
<th>t-test</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definition and incidence of SLE</td>
<td>56.29±22.14</td>
<td>76.86±19.15</td>
<td>8.80</td>
<td>0.000 **</td>
</tr>
<tr>
<td>Signs &amp; symptoms of SLE</td>
<td>52.86±21.81</td>
<td>65.71±19.00</td>
<td>7.65</td>
<td>0.000 **</td>
</tr>
<tr>
<td>Complications of SLE</td>
<td>36.86±16.20</td>
<td>60.57±15.21</td>
<td>11.82</td>
<td>0.000 **</td>
</tr>
<tr>
<td>Management of SLE</td>
<td>52.29±16.07</td>
<td>71.71±15.78</td>
<td>8.44</td>
<td>0.000 **</td>
</tr>
</tbody>
</table>

**P<0.001 highly significant

Table (3): Means and standard deviations distribution of the disability index among SLE patients under the study pre and post implementation of SLE health promotion program

<table>
<thead>
<tr>
<th>Disability items</th>
<th>Pre-program Mean ± SD</th>
<th>Post-program Mean ± SD</th>
<th>t-test</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dressing &amp; grooming</td>
<td>0.49±0.63</td>
<td>0.09±0.28</td>
<td>6.41</td>
<td>0.000 **</td>
</tr>
<tr>
<td>Arising</td>
<td>0.44±0.53</td>
<td>0.13±0.34</td>
<td>5.62</td>
<td>0.000 **</td>
</tr>
<tr>
<td>Eating</td>
<td>0.85±0.41</td>
<td>0.27±0.38</td>
<td>12.15</td>
<td>0.000 **</td>
</tr>
<tr>
<td>Walking</td>
<td>1.41±0.74</td>
<td>0.70±0.65</td>
<td>11.02</td>
<td>0.000 **</td>
</tr>
<tr>
<td>Personal hygiene</td>
<td>1.18±0.35</td>
<td>0.55±0.47</td>
<td>12.78</td>
<td>0.000 **</td>
</tr>
<tr>
<td>Reach object</td>
<td>1.87±0.59</td>
<td>0.97±0.62</td>
<td>19.49</td>
<td>0.000 **</td>
</tr>
<tr>
<td>Grip</td>
<td>0.79±0.42</td>
<td>0.23±0.40</td>
<td>11.20</td>
<td>0.000 **</td>
</tr>
<tr>
<td>Various activities</td>
<td>1.86±0.48</td>
<td>0.96±0.43</td>
<td>26.35</td>
<td>0.000 **</td>
</tr>
<tr>
<td>Total disability</td>
<td>22.37±6.15</td>
<td>11.60±4.75</td>
<td>25.32</td>
<td>0.000 **</td>
</tr>
</tbody>
</table>

**P<0.001 highly significant

Table (4): Overall pain severity among SLE patients under the study pre and post implementation of SLE health promotion program

<table>
<thead>
<tr>
<th>Severity of pain</th>
<th>Pre-program</th>
<th>Post-program</th>
<th>t-test</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>%</td>
<td>No</td>
<td>%</td>
</tr>
<tr>
<td>NO Pain</td>
<td>11</td>
<td>15.7</td>
<td>13</td>
<td>18.6</td>
</tr>
<tr>
<td>Moderate</td>
<td>16</td>
<td>22.9</td>
<td>36</td>
<td>51.4</td>
</tr>
<tr>
<td>Severe</td>
<td>43</td>
<td>61.4</td>
<td>21</td>
<td>30.0</td>
</tr>
</tbody>
</table>

**P<0.001 highly significant
Table (5): Overall sexual satisfaction among SLE patients under the study pre and post implementation of SLE health promotion program

<table>
<thead>
<tr>
<th>Sexual satisfaction</th>
<th>Pre-program</th>
<th>Post-program</th>
<th>t-test</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>%</td>
<td>No</td>
<td>%</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>29</td>
<td>58</td>
<td>16</td>
<td>32</td>
</tr>
<tr>
<td>Moderately satisfied</td>
<td>15</td>
<td>30</td>
<td>23</td>
<td>46</td>
</tr>
<tr>
<td>Satisfied</td>
<td>6</td>
<td>12</td>
<td>11</td>
<td>22</td>
</tr>
</tbody>
</table>

**P<0.001 highly significant

Table (6): Overall satisfaction about health status among SLE patients under the study pre and post implementation of SLE health promotion program

<table>
<thead>
<tr>
<th>Satisfaction about health status</th>
<th>Pre-program</th>
<th>Post-program</th>
<th>t-test</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>%</td>
<td>No</td>
<td>%</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>26</td>
<td>37.1</td>
<td>17</td>
<td>24.3</td>
</tr>
<tr>
<td>Moderately satisfied</td>
<td>23</td>
<td>32.8</td>
<td>30</td>
<td>42.8</td>
</tr>
<tr>
<td>Satisfied</td>
<td>21</td>
<td>30.0</td>
<td>23</td>
<td>32.8</td>
</tr>
</tbody>
</table>

**P<0.001 highly significant

Table (7): Overall lupus QOL among SLE patients under the study pre and post implementation of SLE health promotion program

<table>
<thead>
<tr>
<th>Total lupus QOL scores</th>
<th>Pre-program</th>
<th>Post-program</th>
<th>t-test</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>%</td>
<td>No</td>
<td>%</td>
</tr>
<tr>
<td>Poor</td>
<td>58</td>
<td>82.8</td>
<td>22</td>
<td>31.4</td>
</tr>
<tr>
<td>Average</td>
<td>12</td>
<td>17.1</td>
<td>48</td>
<td>68.6</td>
</tr>
<tr>
<td>Good</td>
<td>0</td>
<td>0.00</td>
<td>0</td>
<td>0.00</td>
</tr>
</tbody>
</table>

** P0.001 highly significant

Discussion

Regarding the socio-demographic characteristics of SLE patient under the study the findings of this study revealed that, patients’ age was fifteen to forty five years. This in agreement with Lupus Foundation of American (2012), and Sestak, et al., (2011) who referred that; the most common age for SLE is between 15-45 years which is called the bearing age which means that in this period hormones influencing vulnerability to this disease.

Also the current study showed that the majority of patient under the study were females. This in the same line with
Tsokos (2011) who stated that SLE affecting women nine times more than men.

As regards residence, the present study findings revealed that more than half of the patient under the study resided in rural areas. This is in accordance with Scultz & Winstead, (2011) who reported that, the majority of SLE subjects were residing urban areas.

In relation to marital status, it was found that more than two thirds of patients under the study were married, this finding were in agreement with Mendoza & Carrasco (2011) who reported the same results in their study on patients with SLE. This could be due to the incidence of the disease is usually occurring at the bearing age and marital age in Egypt is early.

Regarding educational level, more than half of patient under the study had secondary educational level. This finding was in line with Mozes et al., (2014), who discovered a positive correlation between the level of education of chronically ill patients and their QOL. This could be due to the incidence of the disease is usually occurring at 15 to 45 years and increase educational level.

As regards patients' occupation, the study reveal that about two thirds of patient under the study were unemployed and the majority of them have physical effect due to SLE. These findings were correspondent with Hakim, Furnrohr, & Amann (2011) who reported that; more than half of their study group was unemployed. This might be due to the majority of the patients were females, so they are housewives. Also, due to that disease could cause physical disability.

The present study showed that, more than half of patient under the study were treated at the government expense in the El-Demerdash hospital. These findings were consonant with De Groot (2009) who stated that; patients with SLE were treated mostly at the national hospital for free or on the account of their health insurance. Also, Meacock et al., (2013) who stated that; the burden of SLE was found to be substantial, not only for patients but also for the health services.

Regarding income the present study showed that, about three quarters of patient under the study had no enough monthly income also; more than two thirds of them hadn’t enough monthly income for the treatment cost. This result was supported by lash (2011) who reported that, the majority of his SLE subjects had no enough monthly income. The researcher suggested this might due to that mostly SLE attacking females who have no economical source.

Regarding satisfactory level of awareness about definition and incidence of SLE, signs & symptoms of SLE, complications of SLE and management of SLE among patients under the study the current study shows that, a highly statistically significance improvement regarding these items post implementation of systemic lupus health promotion program. This finding is in the same line with Yariz et al., (2012) who reported that; three quarters of patients with SLE are usually acquiring information about the nature of disease, pathology, treatment, prognosis and life style changes.

Regarding to total disability among SLE patients under the study pre and post implementation of SLE health promotion program the present study shows that, there are a highly statistically
significant differences between the mean and standard deviation of disability index among the patients under the study as regards dressing and grooming, arising, eating, walking, personal hygiene, reach object, grip and various activities pre and post implementation of systemic lupus health promotion program. This finding in the same line with *Parez (2011)* who found that; more than half of the patients in his study were unable to perform usual daily activities.

Regarding pain severity related to the disease pre and post-implementation of SLE systemic lupus health promotion program among the patients under the study the current study reveals that, more than half of patients complained of severe pain pre implementation of SLE health promotion program which decreased to moderate pain post implementation of SLE health promotion program with a highly statistically significance improvement between them. This results consonant with *Gordon & Smythe (2011)* who reported that; more than three quarters of patients with SLE complain of moderate to severe pain occurring from the muscle and bone aches regarding the degenerative effects of Lupus on the body systems. This might explain the feeling of generalized pain resulted from the multiple inflammations of blood vessels of various body organs.

Regarding sexual satisfaction related to the disease among SLE patients under the study the current study showed that, more than half of SLE patients under the study were dissatisfied with sexual life related to the disease pre-implementation of SLE health promotion program which decreased post implementation of SLE health promotion program to more than one third of the patients under the study with a highly statistically significance improvement between them pre and post implementation of SLE health promotion program. This come in line with *Abd-Elhady (2013)*, who mentioned that loss of sexual function may have many implications to the patient and the spouse, it frequently leads to other stress and social strains of the marriage among SLE patients.

Regarding satisfaction about health status related to the disease pre and post-implementation of SLE health promotion program, the present study presented that more than one third of SLE patients under the study were dissatisfied with their health status related to the disease pre-implementation of SLE health promotion program which decreased post implementation of SLE health promotion program to less than one third of the SLE patients under the study with a highly statistically significance improvement between them pre and post implementation of SLE health promotion program. This finding are not compatible with *Kulczycka et al., (2012)* who founded that; more than two thirds of SLE patients stated their satisfaction about health status as low.

Regarding total QOL related to the disease pre and post-implementation of systemic lupus health promotion program, and it’s reveals that more than three quarters the patients under the study had poor QOL related to the disease which decreased post implementation of health promotion program to more than one third with a highly statistically significance improvement between them. These results were inconsistent with *Abu-Shakra (2011)*, as he found that SLE patients were found to have significantly lower scores on items of health, work, life satisfaction, active recreation, and independence compared with healthy ones.
Conclusion:

There was a highly statistically significance improvement regarding patient’s levels of awareness post implementation of SLE health promotion program. Also, more than three quarters of SLE patients under the study had poor QOL related to the disease which decreased post implementation of SLE health promotion program to more than one third with a highly statistically significance improvement between them. It was observed from the current study that, there were highly statistically significant positive correlations between patients' total QOL and total lupus awareness for SLE patients under the study pre and post implementation of SLE health promotion program. Moreover, there were a highly statistically significant positive correlations between SLE patients' levels of awareness and QOL and their socio-demographic characteristics as regards their education level. The implementation of SLE health promotion program has a statistically significant positive effect on the quality of life for patients with SLE.

Recommendations:

- Replication of the current study on a larger probability sample is recommended to achieve generalization of the results and wider utilization of the designed program.

- Design a systematically continuous health promotion program for patients with SLE in hospitals in addition to media such as: newspapers, television, and radio to help in improving the health status of these patients.

- A simplified, comprehensive and illustrated Arabic guided images booklet about SLE should be distributed for each newly admitted patient diagnosed with SLE.

- Encouraging the holistic approach for caring of SLE patients through interdisplinary team including (physician, nurses, social workers and psychologists).

References:


Lupus Foundation of America (2012): What are the risks for developing lupus? URL Available at: http://www.lupus.org/webmodules/
Effect of Health Promotion Program on Quality of Life for Patients with Systemic Lupus Erythematosus


