Self- Management Guidelines: Effect on Awareness of Patients with Systemic Lupus Erythmatosus

Introduction: Systemic lupus erythematosus (SLE) is a prototypic autoimmune disease with a diverse array of clinical manifestations, which is characterized by the production of antibodies to components of the cell nucleus. It is a complex multisystem disease difficult to monitor. Not only does SLE potentially affect just about every bodily part, but it also affects each organ's different structural components with varying frequencies.

Aim of the study: The present study aimed to:

1. Assess the needs of the patients with Systemic Lupus Erythmatosus.
2. Plan and implement self-management guidelines for patients with Systemic Lupus Erythmatosus.
3. Evaluate the effect of self-management guidelines on awareness of patients with SLE.

Research hypothesis:
- self-management guidelines will affect the awareness of patients with S L E.

Research Design:
A quasi-experimental design was utilized to accomplish the aim of this study.

Research Setting:
The present study was conducted at the Rheumatology unit at Cairo University Hospital.

Subjects:
A purposive sample was utilized in the current study. The sample composed of (75) adult female patients from 18 to 45years old, with different educational levels who were admitted to the rheumatology department with different signs and symptoms .

Tools of data collection: Two Tools were used in the current study as follows:
1.   Health Need Assessment Questionnaire.
2.   SLE awareness's quiz.
1. Health Need Assessment Questionnaire-HAQ: it's a Self-administered questionnaire filled by the patients with SLE, to assess and identify their health needs. The questionnaire constructed of 5 parts as following:
-**Part 1:** Demographic characteristics' of the patient. It was used to assess; age, sex, phone number, marital status, occupation, treatment costs, smoking, and medical history.
-**Part 2:** Disability index: to assess dressing & grooming, arising, eating, walking, hygiene, reach, grip, and activities, also it used to assess any used assistive devices or help form another person for doing those activities.
-**Part 3:** Discomfort and pain scale. It was used to assess severity of pain and discomfort. This part includes also the symptoms as stated by the patient.
-**Part 4:** Drug Side effects: To assess the prescribed medications, and any arising problems during the past 6 months.
-**Part 5:** Patient satisfaction: it was used to assess satisfaction of the patient about his/ her health and also the effect of the disease on his/ her job and activities of daily living during the past 6 months.
2- **SLE awareness's quiz:** it's a Self-administered quiz to the patients with SLE. It is used to assess the knowledge level of patients with SLE as follows: definition and incidence of SLE, signs and symptoms of SLE, complications of SLE, and treatment & self-management of SLE.

Results: The results of the study showed that: the mean age for patients included in the study was 33.54 ± 12.02. reveals the highest means and standard deviations post implementation of the self-management guidelines were regarding all items of the lupus awareness. Also this table shows a

statistically significance difference regarding complications of SLE, and shows a highly statistically significance difference related to treatment and self-management of SLE. The percentage distribution of the patients regarding level of awareness pre/post-implementation of the self-management guidelines, it reveals that more than two thirds (66.67%) of the patients included in the study post-implementation of self-management guidelines were had satisfactory awareness level. Also this table shows high statistically significance regarding satisfactory level of awareness. Overall mean & standards deviations of self-management items regarding pre and post implementation of self-management guidelines, it revealed that, there was a statistically significance difference between pre & post mean scores of the total level of awareness at (p>0.05).

Conclusion
Based on the findings of the present study, it can be concluded that:
More than two thirds of the studied patients had satisfactory awareness level, post implementation of the self-management guidelines. Moreover, there was statistical significant relation between patient's levels of awareness pre and post implementing of self-management guidelines.

Recommendations
Based on the results of the present study, the following recommendations are suggested:
▪ Design a systematically continuous self-management programs 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.
▪ An Arabic guided images booklet about SLE should be distributed for each newly admitted patient diagnosed with SLE.
▪ An Egyptian Lupus Organization should be developed to be in contact with the problems of these patients.
▪ Further researches about self-management of patients with SLE are highly recommended to reach the peak level of health satisfaction among those patients.