

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

## **Protocol**

Submitted for Partial Fulfilment of the Requirement of  
Doctorate Degree in Nursing Science (Medical- Surgical  
Nursing)

**By**

**Eman Abd El-Azeem Mohamed Yousef**  
Assistant Lecturer in Medical Surgical Nursing Department  
Faculty of Nursing – Ain Shams University

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## **Under Supervisions of:**

**Professor Dr. Magda Abd El-Aziz Mohamed**

Professor of Medical Surgical Nursing  
Faculty of Nursing – Ain Shams University

**Assistant Professor Dr. Nematallah Gomaa**

Assistant Professor of Medical Surgical Nursing  
Faculty of Nursing – Ain Shams University

**Dr. Dalia Ali Ameen**

Lecturer of Medical Surgical Nursing  
Faculty of Nursing – Ain Shams University

**Faculty of Nursing  
Ain Shams University**

**2016**

بِسْمِ اللَّهِ الرَّحْمَنِ الرَّحِيمِ

”قَالُوا سُبْحَانَكَ لَا عِلْمَ لَنَا  
إِلَّا مَا عَلَّمْتَنَا إِنَّكَ أَنْتَ  
الْعَلِيمُ الْحَكِيمُ”

صدق الله العظيم

سورة البقرة الآية ٣٢



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*Eman Abd El-Azeem*



*I would like to dedicate this thesis  
to my beloved family, especially  
my father, mother, sister, brothers,  
husband & daughter to whom I will  
never find adequate words to express  
my gratitude for dealing so patiently  
and tactfully during this work.*

*Eman Abd-El Azeem*



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## *List of abbreviations*

Abbreviation	Meaning of abbreviation
ACR	American College of Rheumatology
ADL	Activity of Daily Living
ANA	Antinuclear antibody
Anti-Sm	Anti-Smith
AP	Acupuncture
APS	Antiphospholipid Syndrome
BLyS	a B-lymphocyte stimulator
CBC	Complete blood count
CRP	C-reactive protein
CVA	Cerebrovascular accident
DILE	Drug-induced Lupus Erythematosus
DLE	Discoid Lupus Erythematosus
DMARDs	Disease-modifying antirheumatic drugs
DNA	Deoxyribonucleic acid
dsDNA	Double-stranded DNA
ELEF org.	European Lupus Erythematosus Federation Organization
ENH	Evanston North-western Health Care Organization
EULAR	European League Against Rheumatism
FM	Fibromyalgia
FDA	Food and Drug Administration
HAQ	Health Assessment Questionnaire
HL	Hodgkin's Lymphoma

## *LIST OF ABBREVIATIONS (CONT.)*

Abbreviation	Meaning of abbreviation
HLA	Human leukocyte antigen
HP	Health promotion
HRT	Hormone replacement therapy
IV	Intravenous infusion
IVIGS	Intravenous Immunoglobulins
LE	Lupus Erythematosus
NIAMS	National Institute of Arthritis and Musculoskeletal and Skin Diseases
NIH	National Institute of Health
NHL	non-Hodgkin's Lymphoma
NSAIDs	Non-steroidal anti-inflammatory drugs
QOL	Quality Of Life
ROM	Range-of-motion
SLE	Systemic Lupus Erythematosus
SPF	Sun Protection Factor
UVA	Ultraviolet A
UVB	Ultraviolet B
WHO	World Health Organization

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## *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.

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**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*).

Systemic Lupus Erythematosus is a multisystem disease associated with significant morbidity and mortality. Advances in therapy have reduced mortality, and emphasis is therefore increasingly placed on the quality of life (QOL) as an outcome measure in SLE. QOL scales measure the effect of illness and therapy related morbidity and therefore allow a more precise assessment of outcome than mortality data (*Thumboo, et al. 2014*).

Despite the fact that Systemic Lupus Erythematosus is a global problem with plus a million sufferers reported worldwide, the general population is mainly unaware of its existence. It has been called “the disease with 1000 faces” (*Bonney, 2011*). Systemic Lupus Erythematosus has been considered uncommon in Africa. There have been no large series in African adults. In reference to Egypt, a study was conducted, but the results does not allow to make

definite inferences regarding the pattern of SLE in Egyptian children because of the small number of patients, but it suggests that the occurrence of childhood onset SLE in Africa or at least North Africa has been underestimated and it needs increased awareness among pediatricians in this area (*El-Garf & Salah, 2012*).

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 et al., 2013; Abu-Shakra, et al., 2011*).

Because Systemic Lupus Erythematosus is a chronic disease, patients require extensive health education in terms of their responsibility in managing their condition. This requires compliance with office visits and medications, and lifestyle modifications to reduce or prevent associated problems such as hyperlipidemia, obesity and hypertension. An ongoing partnership between the primary care physician and the rheumatologist is essential in the long-term management of patients with Systemic Lupus Erythematosus (*Fritzler MJ. et al., 2015*).