

Assessment of Quality of Life in Patients with Systemic Lupus Erythematosus (Ain Shams Lupus Cohort)

Thesis

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LIST OF ABBREVIATIONS

Abbrev.	Full Term
ACE	Angiotensin converting enzyme inhibitors
ACL	Anticardiolipin
ACR	American college of rheumatology
AGDS	Acute gastrointestinal distress syndrome
AHA	Autoimmune hemolytic anemia
AIMS	Arthritis impact measurement scale
ANA	Anti-nuclear antibody
Anti BLys	Anti-B-lymphocyte stimulator
Anti CCP	Anti-citrulline containing peptide
Anti-DNA	Anti double stranded DNA antibodies
APC	Antigen presenting cell
APS	Antiphospholipid syndrome
ARBs	Angiotensin receptor blockers
AVN	Avascular necrosis
AZA	Azathioprine
BAFF	B cell activating factor
BILAG	British Isles lupus assessment group
CLE	Cutaneous lupus erythematosus
CMV	Cytomegalovirus
CNS	Central nervous system
CPV	Creatine phosphokinase
CRP	C-reactive protein
CSA	Cyclosporin A

LIST OF ABBREVIATIONS (CONT.)

Abbrev.	Full Term
CT	Computed tomography
CTLA UIQ	Cytotoxic-T-lymphocyte-associated antigen
CVD	Cardiovascular disease
CYC	Cyclophosphamide
DHEA	Dehydroepiandrosterone
DILE	Drug induced lupus erythematosus
DMARDS	Disease-modifying antirheumatic drugs
DRVVT	Dilute russel viper venous time
EBV	Epstein – barr virus
ECLAM	European community lupus activity measure
EQ-5D	European QOL scale
ESR	Erythrocyte sedimentation rate
FDA	Food drug administration
G6PD	Glucose-6-phosphate dehydrogenase deficiency
GFR	Glomerular filtration rate
GI	Gastrointestinal
HAQ	Health assessment questionnaire
HCQ	Hydroxychloroquine
HRQOL	Health related quality of life
IFN	Interferon
ISN/RPS	International society of nephrology/renal pathology society

LIST OF ABBREVIATIONS (CONT.)

Abbrev.	Full Term
IVIG	Intravenous immunoglobulin
LDH	Lactate dehydrogenase
LJP	La Jolla Pharmaceuticals
LN	Lupus nephritis
L-QoL	The systemic lupus erythematosus quality of life questionnaire
MAC	Membrane attack complex
MCS	Mental health component summary score
MMF	Mycophenolate mofetil
MOCA	Montreal cognitive assessment
MRA	Magnetic resonance angiography
MRI	Magnetic resonance imaging
MTX	Methotrexate
NIH	National institutes of health
NPSLE	Neuropsychiatric SLE
NRH	Nodular regenerative hyperplasia
NSAIDs	Non steroidal anti inflammatory drugs
PCS	Physical health component summary score
PE	Pulmonary embolism
QOL	Quality of life
RBCs	Red blood cells
SELENA	Safety of estrogen in lupus erythematosus national assessment

LIST OF ABBREVIATIONS (CONT.)

Abbrev.	Full Term
SF20	Short form 20
SF36	Short form 36
SL	Satisfaction with life
SLAM	Systemic lupus activity measure
SLE	Systemic lupus erythematosus
SLEDAI	Systemic lupus erythematosus disease activity index
SLE-QoL	Systemic lupus erythematosus-specific QoL
SLICC	Systemic lupus international collaboratory clinics
SLICC/ACR	Systemic lupus international collaborating clinics/American college of rheumatology
SMILEY	Simple measure of impact of lupus erythematosus in youngsters
SPF	Skin protection factor
TLR-9	Toll like receptor
TNF	Tumor necrosis factor
TV	Teva Pharmaceuticals
UVR	Ultraviolet radiation
WBCs	White blood cells
WD	Work disability
Who QoL-BREF	World health organization-Qol scale



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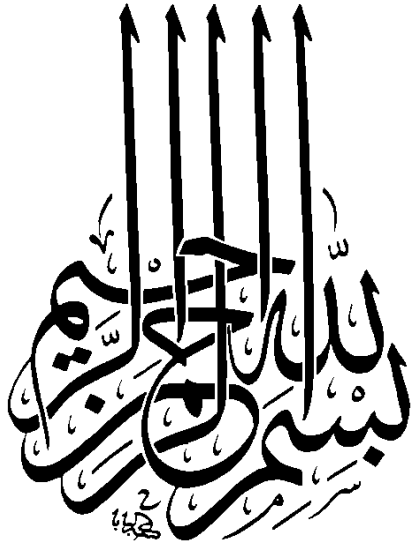
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﴿قَالُوا سُبْحَانَكَ لَا عِلْمَ كُنَّا

إِلَّا مَا عَلَّمْتَنَا إِنَّكَ أَنْتَ الْعَلِيمُ الْحَكِيمُ﴾

صدق الله العظيم

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Introduction

Systemic lupus erythematosus (SLE) is a prototype of autoimmune diseases affecting predominantly women. It is characterized by dysregulation of self-reactive B cells leading to autoantibody production, immune complex deposition and complement activation with tissue damage (**Rojas-Villarraga et al., 2010**).

Systemic lupus erythematosus most often harms the heart, joints, skin, lungs, blood vessels, liver, kidneys, and nervous system. The course of the disease is unpredictable with period of illness (called flares) alternating with remission (**Rahman and Isenberg, 2010**).

With improvement in mortality in SLE, the functional status of these patients, assessed using health – related quality of life (HRQoL) instruments, is increasingly being recognized as an important outcome measure in clinical research. Domains of HR QoL of particular importance to systemic lupus erythematosus patients include fatigue, ability to work, good, health, independence, social and family life, learned helplessness, (reflecting the unpredictability of lupus), pain and the home environment. The SF-36 currently appears to be the best available generic instrument (**Strand et al., 2006**).

A study done by **Kulczycka et al. (2010)** found that systemic lupus erythematosus patient's quality of life (QoL) as

assessed by short form 36 and satisfaction with life (SL) was rather low. Those with photosensitivity as well as neurological symptoms presented lower QoL in particular domains, while those with renal manifestations of systemic lupus erythematosus assessed their QoL as higher. Similar observations were made for SL only in relation to neurological symptoms. Moreover their findings showed that although SL is part of HQoL, both these parameters should be distinguished in order to fully assess the state of the patient.

It has been shown that SLE patients have poorer functional status than the general population, and that specific manifestations of systemic lupus erythematosus (disease activity, previous renal involvement and fibromyalgia) may influence HRQoL (**Grootscholten et al., 2003A**).

HRQoL in systemic lupus erythematosus patients has been improved by (1) psycho-educational interventions including telephone counseling, a self-help course, group psychotherapy; (2) therapies (**Thumboo and Strand, 2007**).