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قسم

نقسم بالله العظيم أن المادة التي تم توثيقها وتسجيلها علي هذه الأقراص المدمجة قد أعدت دون أية تغيرات

يجب أن

تحفظ هذه الأقراص المدمجة بعيدا عن الغبار

Health-Related Quality of Life Assessment in Pediatric Systemic Lupus Erythematosus

Thesis

Submitted for Partial Fulfillment of Master's Degree in Pediatrics

By

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Mohamed Tarek

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List of Abbreviations

Abb.	Full term
ANA	Antinuclear antibody
AZA	Azathioprine
CBC	Complete blood count
CHAQ	The Childhood Health Assessment Questionnaire
CMP	Complete metabolic panel
CRP	C-reactive protein
CYC	Cyclophosphamide
dsDNA	Double-stranded DNA
ESR	Erythrocyte sedimentation rate
EULAR	European League Against Rheumatism
GCs	Glucocorticoids
HAQ	Health Assessment Questionnaire
HCQ	Hydroxychloroquine
HRQOL	Health- related quality of life
IQR	Interquartile range
MCTD	Mixed connective tissue disease
MMF	Mycophenolate mofetil
PedsQL	Pediatric Quality of Life Inventory
PJP	Pneumocystis jirovecii pneumonia
PRO	Patient-reported outcome
pSLE	Pediatric SLE
QOL	Quality of life
RNP	Ribonuclear protein
SF-36	Short Form-36
SLE	Systemic lupus erythematosus

List of Abbreviations Cont...

Abb.	Full term
SLEDAI	Systemic Lupus Erythematosus Disease Activity Index
SLEQOL	SLE-specific Quality of Life questionnaire
SLICC	Systemic Lupus International Collaborating Clinics Classification Criteria
SMILEY	Simple Measure of the Impact of Lupus Erythematosus in Youngsters©

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INTRODUCTION

Pediatric systemic lupus erythematosus (pSLE) is an autoimmune disease which predominantly affects females (Nazri et al., 2018). The incidence of pSLE varies between 0.3 and 0.9/100,000 per year. Children tend to have a more severe disease than adults at the onset (Aygün et al., 2019).

HRQOL is defined as the perception that individuals have of their position in life, in the context of the culture and system of values in which they live and in relation to their objectives, expectations, standards, and concerns. HRQOL can change according to the environment and the experiences, as well as in response to certain diseases (Didsbury et al., 2016).

Different questionnaires have been developed to assess HRQOL. Validated Arabic version of SLEQOL is a developed generic instrument, based on the adult version, which provides the opportunity to address a child's HRQOL, regardless of the disease (Ravens-Sieberer et al., 2010a; Ravens-Sieberer et al., 2010b).

AIM OF THE WORK

Our objective is to assess the health-related quality of life HRQOL of patients with systemic lupus erythematosus in the pediatric age group using validated Arabic version of SLEQOL as a step to implement this service in the protocol of care for SLE in the Pediatric Allergy and Immunology Unit of Ain Shams University.

PEDIATRIC SYSTEMIC LUPUS ERYTHEMATOSUS

Definition:

Systemic lupus erythematosus (SLE) is a chronic, multi-system, autoimmune disease of unknown etiology with a heterogeneous range of clinical and serological manifestations. It affects multiple organ, and its hallmark is the production of auto-antibodies (Guzman and Hui-Yuen, 2020). Childhood-onset systemic lupus erythematosus (cSLE) is occurring in patients less than 18years (Silva et al., 2012).

Incidence of SLE:

The incidence of cSLE is about 0.3-0.9 per 100 000 children per year, and the prevalence is about 3.3-24 per 100 000 children (Macedo et al., 2016). cSLE is more common in African Americans, Asians, Hispanics, and Native Americans compared to whites (Hiraki et al., 2009).

The median age at presentation is around 11-12 years, with cSLE rarely reported under the age of 5 years. cSLE has a strong female preponderance; the female to male ratio is at 4:3 and 4:1 for disease onset in the first and second decades of life, respectively (Levy and Kamphuis, 2012).