بسم الله الرحمن الرحيم

MONA MAGHRABY

شبكة المعلومات الجامعية

التوثيق الالكتروني والميكروفيلم

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جامعة عين شمس

التوثيق الإلكتروني والميكروفيلم

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MONA MAGHRABY

Assessment of the Quality of Life in Patients with Multiple Sclerosis

Thesis

Submitted for partial fulfillment of master's degree in Neurology and Psychiatry

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List of Abbreviations

Abb.	Full term
Ab	Antibodies
ADL	Activities of daily living
AE	Adverse effects
ALC	Absolute lymphocyte count
ARR	Annualized relapse rate
BMI	Body mass index
BVL	Brain volume loss
CBT	Cognitive behavioral therapy
CIS	Clinically isolated syndrome
CNS	Central nervous system
COP	Coping
CRH	Corticotrophin-releasing hormone
CSI	Caregiver Strain Index
DMDs	Disease modified drugs
DMF	Dimethyl fumarate
EAE	Experimental autoimmune encephalomyelitis
EDSS	Expanded Disability Status Scale
e-Health	Electronic health
GA	Glatiramer acetate
GAD	Generalized Anxiety Disorder
HAQUAMS	Hamburg Quality of Life Questionnaire in MS
HCPs	Health care professionals
HLA	Human leukocyte antigen
HRQoL	Health-related quality of life
IFNs	Interferons
JCV	John Cunningham polyomavirus
LUTS	Lower urinary tract symptoms
MDR	Multidisciplinary rehabilitation
MHC	Major histocompatibility complex

List of Abbreviations Cont...

Abb.	Full term
MS	Multiple sclerosis
NEDA	No evidence of disease activity
OCD	Obsessive-Compulsive Disorder
ON	Optic neuritis
OPC	Oligodendrocyte precursor cells
OT	Occupational therapy
PFMT	Pelvic floor muscle training
PML	Progressive multifocal leukoencephalopathy
PPMS	Primary-progressive multiple sclerosis
PWB	Psychological well-being
QoL	Quality of life
REJ	Rejection
REM	Rapid eye movement
RFA	Relationships with family
RFR	Relationships with friends
RHCS	Relationships with healthcare system
RIS	Radiological isolated syndrome
RLS	Restless legs syndrome
RR	Relapsing remitting
RRMS	Relapsing-remitting multiple sclerosis
SPMS	Secondary-progressive multiple sclerosis
SSL	Sentimental and sexual life
SSN	Social support network
SSRIs	Selective serotonin reuptake inhibitors
SYMP	Symptoms
UI	Urinary incontinence
WBC	White blood cell

INTRODUCTION

Multiple sclerosis (MS) is a chronic demyelinating autoimmune disorder affecting the central nervous system (CNS) and targets the myelin sheaths around nerves leading to inflammation, myelin loss, and axonal destruction ***(Koutsouraki et al., 2010).***

MS affects the physical, psychological and social function of patients. These disturbances have a negative impact in the daily life activities and the quality of life of patients ***(Costa et al., 2017).***

The impact of MS is often profound. In coping with their disease, individuals with MS may face many challenges, including changes in physical ability, cognition, employment status, and effects on their mental health and well-being ***(Kantor et al., 2018).***

A diagnosis of MS is life-altering. Because the course of MS is heterogeneous, patients may face uncertainty in terms of long-term physical and cognitive challenges, potential loss of employment, and the risk of social isolation ***(Kantor et al., 2018).***

Based on the immune basis of MS, different kinds of drugs are used to suppress the disease. The number of disease modifying drugs (DMDs) available for the treatment of MS has increased considerably in recent years. Each of these drugs has

its own efficacy and indication of usage. However, new treatments also come with new safety concerns and monitoring requirements with which physicians must familiarize themselves ***(Jongen et al., 2017).***

AIM OF THE WORK

This study helps to assess the quality of life of MS patients to identify the impact of MS on different aspects of personal and social life of a group of Egyptian MS patients, and how future studies may help directing them to different coping and adapting strategies. And also to assess patient's treatment needs to add recommendations, aiming to improve the quality of life.

Chapter 1

MULTIPLE SCLEROSIS

History and demography:

MS is a chronic neurodegenerative disease that affects the CNS; it is initially inflammatory and demyelinating, with a variable neurodegenerative component ***(Ton et al., 2017).***

MS was first defined and termed in 1868 by a French neurologist, Jean Martin Charcot (1825–93). He delivered a series of major lectures, establishing MS as a novel disease of the nervous system ***(Zalc, 2018).***

It is noted that MS epidemiology has changed in important ways over the past several decades. Thus, the incidence of MS is increasing, especially in women. A switch in the latitude gradient for MS incidence has been reported. Because MS genetics seems unlikely to have shifted in so short an interval, these observations presumably relate to a change in the environmental determinants of MS ***(Orton et al., 2006).***

Some environmental changes are known to be taking place (e.g., increasing atmospheric concentrations of CO_2, CH_4, and other pollutants; increasing global temperatures; a depletion of stratospheric ozone; a greater dietary consumption of trans-fats, etc.). One recent change is that people are