Assessment of Fatigue, Pain, Disability and Quality of life for Patients with Multiple Sclerosis

# Assessment of Fatigue, Pain, Disability and Quality of life for Patients with Multiple Sclerosis

Lamiaa Zaki Ahmed <sup>1</sup>, Nadia Mohamed Taha <sup>2</sup>, and Howida Kameel Zatton <sup>3</sup> and Rehab Ragab Bayomi <sup>3</sup>

- (1), Clinical Instructor of Medical Surgical Nursing Faculty of Nursing, Zagazig University, Egypt
- (2) Professor of Medical Surgical Nursing, Faculty of Nursing, Zagazig University, Egypt
- (3) Assist Professor of Medical- Surgical Nursing , Faculty of Nursing , Zagazig University, Egypt
- (3) Assist Professor of Medical- Surgical Nursing , Faculty of Nursing , Zagazig University, Egypt
- \*Corresponding author: Lamiaa Zaki Ahmed

E-mail:Lamiaazaki631@yhaoo.com

## **Abstract**

**Background:** Multiple sclerosis [MS] is a central nervous system inflammatory demyelinating disease that is the second most common cause of physical disability in young patients. which leads to impaired cognitive, motor and or sensory functions. The aim of this study was to assess of Fatigue, Pain, Disability and Quality of life for Patients with Multiple Sclerosis. **Design:** A descriptive research design was carried out. **Setting**: the study was conducted at Neurology outpatient clinic, at Zagazig University Hospitals .Sample: A purposive sample of 60 patients suffering from multiple sclerosis. Tools: five tools were used to collect the study data: I) a structured interview questionnaire. II) Fatigue Severity Scale (FSS) III) Numeric Rating Scale. IV) Patient-Determined Disease Steps (PDDS) V) Multiple Sclerosis Impact Scale (MSIS-29) Results: The current study shows that the mean age was  $32.32 \pm 8.1$  years and 70.0 % of them were females, also, majority of studied patient had Unsatisfactory Knowledge and Unsatisfactory practice, in addition 80.0 % were classified a severe fatigue based on FSS, more than three quarter of studied patient had pain, the mean of Physical impact and Psychological impact composite scores of the Quality of life and disability were 61.47±12.95, 31.38 ±5.74 and 3.46±1.71 respectively. **Conclusion:** There was a strong statistically significant positive correlation between fatigue and quality of life (physical impact) and disability, there is a significant correlation (P <.001) between the physical and Psychological scores of QOL Recommendation: developing an educational and therapeutic program, based on disease related and targeted exercise instruction that is aimed at improving fatigue and

Assessment of Fatigue, Pain, Disability and Quality of life for Patients with Multiple Sclerosis

physical disability and evaluate and compare the changes that occur after the functional rehabilitation program in patients with MS, Education at initiation of therapy and throughout the course of disease, management of patients' expectations about treatment and optimal support could improve adherence and optimize outcomes.

Multiple sclerosis, Fatigue, pain, Disability, Quality of life

Tob Regul Sci. ™ 2023;9(1): 39-62 DOI: doi.org/10.18001/TRS.8.1.287

## Introduction:

multiple Sclerosis (MS) is an inflammatory immunemediated disease characterised by demyelination of axons within the CNS that is frequent in young adults and commonly causes a lifelong disability Binshalan et al., (2022). In Egypt, the Ministry of Health and Population's statistics show that MS cases comprise 1.4% of all neurological diseases. The latest edition of the Atlas of MS shows there are 2.8 million people living with MS around the world. The data released in 2020 indicated that almost 59,670 people are living with MS in Egypt. This equates to one in every 1,500 people. The major problem with MS is that it usually strikes at a very early age, affecting those between the ages of 20 and 40 in 70% of cases (Deif., 2022)

Approximately 85% of patients with MS present with a relapsing–remitting course of the disease (RRMS), and the majority of these, as shown in natural history studies, advance to a progressive disease course — termed secondary progressive MS (SPMS) — after 15–20 years of disease manifestation The remaining ~10–15% of patients have a slow and continuous neurological deterioration without definable relapses, a type known as primary progressive MS (PPMS) (cree et al., 2021)

The cause of multiple sclerosis is unknown. It is consider an autoimmune disease which the body's immune system attacks the central nervous system. Early exposure to some types of viruses or other infections has been linked to MS, but the evidence is mixed. While not a genetic disease, MS can be caused by genetic causes (i.e., a destruction caused by the human immune system) MS is not contagious (Abdallah et al 2022)

The progressive nature of Multiple Sclerosis (MS), variability of its symptoms lead to emotional or social changes and create a complex combination in which challenge healthcare professionals **Shawli et al (2019)**. People with MS typically develop symptoms in their late 20s; Symptoms of MS are unpredictable and vary greatly from person to person, and from time to time in the same person. Multiple Sclerosis can cause symptoms such as extreme fatigue, lack of coordination, weakness, tingling, impaired sensation, vision problems, bladder problems, and cognitive impairment and mood changes. They may initially have partial recovery, but over time develop progressive disability (Olek, 2021).

Assessment of Fatigue, Pain, Disability and Quality of life for Patients with Multiple Sclerosis

fatigue is defined as 'a subjective lack of physical and/or mental energy, perceived by the individual or caregiver to interfere with usual and desired activities Fatigue in MS afects up to 90% of patients, and at least one half of them report it as one of their worst symptoms. The pathophysiological causes of the fatigue vary. Mostly, the primary cause of fatigue in MS is the infammation in the central nervous system whereas the secondary cause may include fatigue from muscle weakness. Depression, anxiety, and increased attemps in daily activities owing to physical disability also play a role in fatigue (Giedraitiene et al., 2022)

People with multiple sclerosis (pwMS) report their pain as one of the most annoying symptoms of their disease. While being a chronic unpleasant sensory experience, pain is an underestimated component of multiple sclerosis (MS) Yilmazer et al (2020) these symptoms have profound effects on the daily lives of individuals with MS. People with MS endorse pain-related interference in sleep, work, and recreational activities. Fatigue, which individuals often describe as their most disabling symptom, contributes to work-related difficulties (e.g. unemployment) and decreased social participation Valentine et al., (2021)

QoL is defined as the subjective perception of the degree to which the disease affects physical and mental domains of health which include other components such as physical function, emotional well-being, role limitations, health distress, sexual function, satisfaction with sexual function, cognitive function, energy, pain and social function (Reina-Gutiérrez et al., 2020). One of the most important determinants to optimize care for PwMS involves quantifying their functional status (i.e., the ability to walk, to perform daily activities, to meet basic self-care needs). Functional status should be evaluated from different perspectives and at different points along the affected person's disease progression. Indeed, this functional status, especially walking deterioration (Sagawa et al 2021). The current treatment for multiple sclerosis includes two main categories: disease-modifying and symptomatic therapies. Disease-modifying drugs like immunomodulatory and/or immunosuppressive treatments are aimed at decreasing the number, severity, and duration of relapses. It also can help maintain remission and slow disease progression (Maniscalco et al 2022). symptomatic therapies are prescribed to relieve the disabling symptoms of the disease. This group of drugs includes anticholinergics for bladder dysfunction, anticonvulsants for neuropathic pain, and botulinum toxins for spasticity Nevertheless, prescribing symptomatic treatment may be limited because of their potential toxicity (Mustafa et al., 2020).

The goal of the nurse in sustaining MS care is focused on maintaining well-being, coordinating referrals, identifying community resources, and advocating for comprehensive care. Nurses continually reformulate the patient's primary and long-term goals of care. They exercise their role as advocates, helping fulfill patient needs while maintaining good stewardship of resources. Nurses sustain the therapeutic relationship over time, providing caring throughout the MS disease trajectory (Maloni, et al., 2015).

Assessment of Fatigue, Pain, Disability and Quality of life for Patients with Multiple Sclerosis

# Aim of the study

The aim of the current was to assess fatigue, pain, disability and quality of life for patients with multiple sclerosis.

## Research Questions:

What is the level of patients knowledge and practice regarding Multiple sclerosis?

What is the level of fatigue, pain and disability for patients with Multiple sclerosis?

What is the effect of Multiple sclerosis on quality of life of patients with Multiple sclerosis?

# Subjects and Methods

A descriptive exploratory design was used to conduct this study, The study was conducted in the neurology outpatient clinics at Zagazig University Hospitals. A Purposive sampling technique was used in the recruitment of this study subjects from the above mentioned setting and who fulfilled the study inclusion criteria. Agree to participate in the study. All types of multiple sclerosis Age ranged between 20-60 years. Ambulatory, and able to talk.

Sample size It was calculated by statistical computer program (Epi-Info software version 6.04) at power 80% and at confidence limit 95% and assuming the prevalence of MS among 200 patients to be 13.74% (Ahmed. 2020) and the least percentage of improvement after the intervention program will be 10% then the sample should include 60 patients.

## Tools of data collection:

Tool I-A structured interview questionnaire was developed by the researcher which is consisted of four parts:

Part 1: Demographic characteristics of patient e.g. (age, sex, marital status, occupation, level of education ...etc)

Part 2: Medical history of the studied patients Medical history of patient e.g. chronic illness, family history, chief complain, disease duration and types of MS

Part 3: Patient's knowledge regarding multiple sclerosis was adapted from (Giordano et al, 2009) and modified by researcher it will include definition of multiple sclerosis, causes, clinical manifestations, treatment and complications ...etc).

Part 4: Patient's practice regarding multiple sclerosis will include how to cope with fatigue, spasticity, sleep problems ....etc)

# Scoring System for Patient's Knowledge Assessment:

Each question is scored "zero" for the incorrect and "one" for the correct answer, and these

Assessment of Fatigue, Pain, Disability and Quality of life for Patients with Multiple Sclerosis

points are counted for each patient. The general patients' knowledge is classified into satisfied knowledge if the score is  $\geq$  60% from the maximum score and unsatisfied knowledge if it is < 60% based on statistical analysis.

# Scoring System for Patients' Practice Observational Checklist

Each step is scored "zero" for not done and "one" for done correctly; and these points are counted for each patient. The general patients' practice is classified into satisfied practice if the score is  $\geq 60\%$  from the maximum score and unsatisfied practice if it is < 60% based on statistical analysis

Tool II: Fatigue Severity Scale (FSS) :it was developed by Krupp et al. (1988), which measures the severity of fatigue and its effect on a person's activities and lifestyle in patients with a variety of disorders. It was originally devised for patients with Multiple Sclerosis, A self-report scale of nine items about fatigue, its severity and how it affects certain activities. Scoring system interpretation: Mean of all the scores with minimum score being 1 and the maximum score being 7. Mean (SD) FSS scores for healthy individuals; 2.3 (0.7). A cutoff score of 4 or more is considered indicative of problematic fatigue. With a score of ≥4 indicating abnormal fatigue and a score of ≥5 indicating severe fatigue

**Tool III: Pain Assessment Questionnaire**: will be designed by the researcher after revising of related literature and include the following:

Part one: Pain characteristic assessment it was developed by López et al.,(2010) e.g. Duration, Onset, Location ...etc)

part two: A Numeric Rating Scale, :it was developed by Downie, et al (1978) it was designed to assess the severity of pain, it consist of a vertical or horizontal line, scoring system interpretation a. no pain is represented as 0 on the scale b. Mild pain is defined as 1 to 3 c. Moderate pain is defined as 3 to 7 d. Severe pain is defined as 7 to 10)

Tool IV: Patient-Determined Disease Steps (PDDS) it was developed by Hohol et al. (1999): based on motor and ambulatory dysfunction representing the main recognizable features of MS disability, The PDDS has nine ordinal levels ranging between 0 (normal) and 8 (Bedridden) Interpretation of scores system:Mild disability is defined 0-2 Moderated disability is defined 3-5 Severe disability is defined 6-8

Tool V: Multiple Sclerosis Impact Scale (MSIS-29) it was developed by Ware et al. (1993) it was designed to assess the impact of MS on patients HRQL in terms of physically and psychological wellbeing, it included two scales: physical impact (20 items) and psychological impact (9 items) which has four point response categories for each items "Not at all equal 1, "a little equal 2 "moderately equal 3 "and "extremely equal 4 . Scoring system interpretation, scores on the physical impact scale can range from (20 to 80) and on the psychological impact

Assessment of Fatigue, Pain, Disability and Quality of life for Patients with Multiple Sclerosis

scale from (9 to 36), with lower scores indicating little impact and higher scores indicating greater impact.

# Content validity and Reliability

Content validity was used for the modified tools and the designed booklet to determine whether the tools covered the aim or not. It developed by a jury of 5 experts ,four professors from faculty of Nursing, Zagazig University and Professssors of Neurology department from the Faculty of Medicine, Zagazig University, Reliability was done by using Cronbach test It was used to examine whether the FSS, NRS, PDDS and MSIS-29 had internal consistency or not. The test was done and the agreement percentage was 89%.

# Administrative and Ethical considerations:

The study was ethically approved from the dean of the faculty of Nursing, the manager of Zagazig University Hospitals, the head of Neuology department, ethics committee at the faculty of nursing and from Ethical committee of faculty of medicine.

# Statistical Design:

Data entry and statistical analysis were done using SPSS 23.0 statistical software package. Data were presented using descriptive statistics in the form of frequencies and percentages for qualitative variables, and means and standard deviations and medians for quantitative variables. Cronbach alpha coefficient was calculated to assess the reliability of the developed scales through their internal consistency. Quantitative continuous data were compared using the non-parametric Mann-Whitney or Kruskal-Wallis tests and paired t test. Qualitative categorical variables were compared using chi-square test.

## Result:

Table (1) reveals that, the age of studied patients ranged from 20-52 with Mean  $\pm$  SD (32.32  $\pm$  8.1) and three quarter were female (70%) in addition, the majority of studied patient (56.7%) have intermediated education. concerning occupation, (68.3%) are Employee and 61.7% have insufficient income

Table (2) shows that three quarter (70.0%) of studied patients were diagnosed by MRI. As well, 81.3 % of studied patient have attack. Regarding diseases duration that table reveals that Mean duration of the disease was  $4.23 \pm 1.8$ . The most common presenting manifestation was motor weakness and the most common phenotype was relapsing remitting 43.3%, 35.0% respectively.

Table (3): indicates total knowledge among studied patients As illustrated in the table all most of studied patients were having unsatisfactory knowledge preprogram (98.3%). total mean score

Assessment of Fatigue, Pain, Disability and Quality of life for Patients with Multiple Sclerosis

of knowledge was 2.53±.43 and 100% of studid patient have unsatisfactory practice with mean score 1.08± 1.2.

**Figure (1):** portrays the level of fatigue severity level among studied patients : it was found 80% have severe fatigue and only 5.0% have mild fatigue.

**Table (4)** clarifies that, more than three quarter 76.7% have pain. 26.7% of them have pain in thigh followed by the knee 23.3%. Up to 50% have intermittent pain, the most frequent being referred as ache (56.7%), followed by painful spasms (18.3%), numbness (13.3%), tightness (5%) and burning (6.7%). a very characteristic symptom of MS patients,

Figure (2) demonstrates pain severity it was found about 30.0% of studied patients have severe pain and only 20.0% with mild pain

**Table (5)** shows the grads of physical disability among studied patients, it was found 38.3% of patients have gait disability and only 5.0% normal physical according to the level of disability among studied patient figure (3) showed that 65.0% have moderated disability and 11.7% severe.

**Table (6)** reveals mean score of parameters of study knowledge, practice ,Fatigue, pain ,disability and quality of life among studied patients with MS

Table (7) portrays that statistically significant correlation between total fatigue score and physical disability total score, physical impact (QOL) score, age, duration of MS and working

Discussion: MS is a chronic inflammatory demyelination disease of the central nervous system. It was first described in 1868 by Jean-Martin Charcot, and since then several forms of the disease have been identified. MS is the commonest non-traumatic disabling disease to affect young adults, especially women. In 2020, an estimated 2.8 million people were affected by MS worldwide (Bouchal, et al 2022) Multiple sclerosis many complications through the patient's life. This may cause many physical complications such as muscle stiffness or spasms, paralysis, typically in the legs, problems with bladder, bowel or sexual function, fatigue, mental changes, such as forgetfulness or mood swings, depression, epilepsy, inappropriate coping skills and weak family relationships (Kołtuniuk et al., 2020).

Regarding the demographic characteristics of studied patients, the findings of the current study revealed that the mean age of studied sample was 32.32 ± 8.1 and nearly three fifth of them had Secondary education, this may be interpreted that the disease usually strikes young adults and the onset of disease usually occur under 25 years old, These findings were supported by Elshaaer et al., (2021) they found that the mean age of the studied patients was 34.235 ± 7.65 and Salime et al., (2022) they reported that the mean age of studied patients was 30.83 ± 7.039 put on the other hand Braley et al., (2022) in this study that found mean age was 51.2 and also Arriaza et al., (2022) they found that mean age was 53 years this difference due to

Assessment of Fatigue, Pain, Disability and Quality of life for Patients with Multiple Sclerosis

early diagnosis and definition of MS and open new center in every city to clinical diagnosis for MS.

Related to sex: results of the present study showed that majority of the patients were females (three quarter) The present result is consistent with Ozer & Altun., (2022) they reported that majority of studied patient 71.8% were female moreover, Homayuni., (2021) Who's found that most of the study samples were females in his study. From the researcher point of view this can be discussed as the immune system may be stimulated by sex steroid hormones during puberty. Additionally, the growing incidence of MS in females suggests that hormonal differences make women more susceptible to environmental risk factors

Pertaining to working status: the current study revealed that more than two thirds of patients were unemployed (68.3 %) and majority of studied patients have insufficient income (61.7%) this may be interpreted that multiple sclerosis patients usually suffering from motor skills abnormalities, easy fatigability and cognitive impairment which affect their working abilities and their income which may be related to the cost of treatment and physiotherapy or didn't have constant work and income due to the disease condition, the present result is consistent with Abdallah et al., (2022) they revealed that more than two thirds of patients were unemployed, this result were in contrast with koziarska., (2018) found that the number of unemployed patients were less than half of total sample. From the investigator point of view these findings may be due to impact of disease on their physical ability to carry or lifting objects, on the other hand lack of mobility with time lead to worsen of their condition.

Relating the duration of disease (MS) more than three quarter had MS for less than 5 years with mean years  $\pm$  SD 4.23  $\pm$  1.8 this in line with **Fahmi et al.**, (2021) stated that the mean duration of MS was (6.23  $\pm$  4.65) further more **Shawli et al.**, (2019) reported that the mean duration of MS was around five years on the other hand **Javdan et al.**, (2021) found that the average duration of MS is 8.20  $\pm$  5.15

Pertaining knowldg level regarding MS it was found the majority of studied patients have unsatisfactory knowledge level regarding MS and mean knowledge score among the study cohort was 8.07±3.1, The low knowledge level can be explained by the fact that the signs of MS are usually invisible and thus many people may not understand the disease. Some cultural beliefs can cause MS patients to hide their illness from others as they feel isolated; thus, fewer people know about the disease. This result is agreement with Claflin et al., 2022) And also with Dehghani., (2020) they revealed that majority of studied paients have poor knowledge level regarding their disease may indicate shortage in the available information about the disease in the internet or TV.

Pertaining to the relation between demographic characteristics and total patients' knowledge, the current study revealed that there were no significant variation regarding age and sex of

Assessment of Fatigue, Pain, Disability and Quality of life for Patients with Multiple Sclerosis

participants. The study was agreed with Amer et al., (2016) and Farran et al., (2021), the study is incongruent with Elshaaer et al., 2021) revealed that there were highly statistically significant relation between patients' age and total knowledge level of studied patients

Regarding total level of practice. Results of this study revealed unsatisfactory practice regarding MS, the total mean (SD) score of practices was 1.08 ±1.2 due to MS patients have increased susceptibility to poor self-management due to chronic nature of MS disease, therefore require more attention from all medical team, where nurses play important role through establish a healthy partnership between the patient and care provider, enhance MS patient to participate in planning and decision making of the medical care or treatment. this is agreement with Momenabadi et al., (2020) found mean score of self care practice was 2.86 (0.64) According to obtained results about the average self-care practice this consider poor patient adhering regarding practice

Relation between total practice score and physical impact QOL score, the current result revealed that there was significant negative correlation between practice and low physical this is agreement with Habibi et al., (2022) stated that The quality of life of the MS patients is heavily influenced by self-care practices

Pertaining to patients' fatigue the current study showed that, fatigue is more prevalent amongst patient with MS with total fatigue mean score  $54.37\pm10.21$  the study is consistent **Salter et al., 2019**) they revealed that the mean (SD) Fatigue score was  $56.8\pm11.0$  the study is incongruent with **Hassan (2021)** they found that 60% of studied patients have total mean score was  $28.0\pm8.4$  this could be due to variances in clinical features and other factors that contribute to fatigue, as well as the scales employed in different research. Fatigue has been connected to the severity of disease and the overall severity of neurological impairment

the current study revealed that there was a high positive correlation between physical disability score and fatigue score ( $r = .379^{**}$ , P < .01) the study is consistent with (Salter et al., 2019) they showed a strong correlation between fatigue severity and physical impact QOL( $r = .384^{**}$ , P < .01)

Pertaining to relation between fatigue and age, the current study revealed that there were highly statistically significant relation between fatigue and age, the researchers believes that fatigue in MS increase and worsens with the age as result of its progressive disease course and early self-management strategies on early MS stage in young adult can helps in maintaining good Quality of life and prevent later complications or disability in MS patients. The study result in consistent with Shawli et al., (2019) that found there was statistically significant relation between fatigue and age.

Assessment of Fatigue, Pain, Disability and Quality of life for Patients with Multiple Sclerosis

Pertaining to patients' pain this study shows that a large percentage of patients (76%) diagnosed with MS report pain at the time of the interview. This figure is similar to that reported in other studies also describing a high prevalence of this symptom in patients with MS. In our study we noted that most patients presented pain symptoms in more than one location. the most frequent were the

lower limbs (34.8%), particularly the thighs, followed by the knee (19.6%) this may be interpreted that MS with focal demyelinating lesions at different levels of the central nervous system (CNS) leads to different pain location. We also noted that the majority of patients in our study (30%) described their pain as severe (according to a NRS). The study result in consistent with (Wallace et al 2021) they reviewed that 63% of MS patients reported pain, We could not establish a significant relationship between pain and fatigue this result is consistant with Öztürk et al., (2018)

Pertaining to patients physical disability , according to grads of disability , The most frequent PDDS score was (38.3 %) gait disability and score (5.0%), physically normal and 13.3% moderated disability , with total mean score of physical disability is 3.46±1.71 , the result of current study is agreed with Bayas et al,(2022) they showed that Mean (SD) of physical disability score was 3.8 (2.2) in the total population

Pertaining to relation between disability and patient age , the current study revealed that there were

statistically significant relation between patients' level of disability and patient age, duration of disease this result is consistent **Stanikić et al.**, **(2022)** demonstrated that MS duration and age were independently associated with having at least moderate gait disability. Further more with **Cortese et al.**, **(2022)** revealed that The age-related decline in physical health is accelerated by 15–30 years in MS patients this may be interpreted that older patients with MS can accumulate substantial disability throughout life.

Pertaining to patients' total quality of life regarding physical domain, the current study revealed that majority of studied patients (80%) had poor physical quality of life, may be related to patients' suffering from weakness in the muscles of extremities inability to perform work, diminished ability to perform ADLS, the study is agreed with Visser et al., (2020) and Elshaaer et al., (2021) they revealed that more than half of studied patients had negative quality of life due to greater impact of physical symptoms such as fatigue, physical weakness, problems with balance and coordination, and heat/cold sensitivity on the performance of activities of daily living this result were in contrast with Ochoa-Morales et al., (2019) they found that the highest level of physical HRQOL in patients with MS in the Americas was found in Mexico (mean=61.93), which was in the good range The policies of some countries on how

Assessment of Fatigue, Pain, Disability and Quality of life for Patients with Multiple Sclerosis

to deal with patients with multiple sclerosis, which seek to improve the quality of life of patients, whether physically or psychologically.

Pertaining to patients' total quality of life regarding psychological domain, the current study showed that, the majority of studied patients (86.7%) had poor quality of life, from the invesigator point of view this may be related to poor socialization, recurrent mood change, lifelong impaired mobility, dependence on others to meet their daily needs and certain medication side effects that may cause depression. The study is agreed with Elshaaer et al., (2021) they revealed that majority of studied patients had a poor quality of life regarding psychological dimension of multiple sclerosis, depression and loss of cognitive function usually affect the employment status and social functioning of the patient, some patients believe that these symptoms are more important than their physical impairments, depression may be corresponding to the pathologic changes in the CNS, mainly in the left frontal and temporal lobes.

Regarding the relation between patients' demographic characteristics and total patients' quality of life, physical impact, the current study illustrated that there were a highly statistically significant relation between patients' age and quality of life, younger patients had good quality of life than older patients, this may be interpreted that younger patients had less disabilities, psychological depression, lack of socialization and greater dependence on their self, this result congruent with **Kan et al., (2020)** they revealed that there were statistically significant relation between patients' age and their quality of life due to disease influence on physical, psychological and cognitive health

Pertaining to the relation between patients' total quality of life physical impact and employment status, the current study revealed that there were statistically significant relation between patients' total quality of life and their wok nature may be related to that working patients had more social relation, spending more time on work receiving support from friends and had less emotional and psychological problems, the study is agreed with Elshaaer et al., (2021) whose study showed that there were statistically significant relation between patients' employment status and quality of life regarding multiple sclerosis

Pertaining to the relation between patients' total quality of life physcial impact and duration of MS

the current study revealed that there were statistically significant negative relation between patients' total quality of life and duration of disesase this result is inline with Kan et al., (2022)

it was found positive correltion beween physical disability and physical impact of MS the study was supported by Dymecka et al., (2022) they showed that the physical disability score was significantly and positively related to the physical impact of the MS (strong strength) The

Assessment of Fatigue, Pain, Disability and Quality of life for Patients with Multiple Sclerosis

present study showed a strong significant positive correlation between physical and psychological QOLscore r= .295\*\* This finding is in agreement with Tabrizi&Radfar,(2015).

#### conclusion:

based on the results of the present study, these findings indicate a lack of understanding of the basics of MS with poor knowledge and practice scores. fatigue is one of the most serious symptoms observed in MS patients. Inaddition fatigue is significantly and differentially correlated to reduced QOL and independently of physical disability, Levels of pain identified and reported in MS patients range from mild to severe.

## Recommendations:

- Conducting health educational programs to raise the multiple sclerosis patients" awareness about the disease and improving practice.
- Developing a simplified and comprehensive booklet including guidelines about MS management.
- Structured, multidisciplinary rehabilitation programmes and physical therapy (exercise or physical activities) can improve functional outcomes (mobility, muscle strength, aerobic capacity), and quality of life.
- conducting the study on a large sample size and different hospitals setting in order to generalize the results.

## References

- 1. Abdallah, Z., Mohammed, A., Rabee, S., Abd elwahab, A (2022) Assessment Of Health Related Quality Of Life Among Patients With Multiple Sclerosis At Minia University Hospital Minia Scientific Nursing Journal (Print ISSN 2537-012X) (Online ISSN 2785-9797) Vol. (11) No. (1) June 2022
- 2. Amer, M., Wejdan A AlZahrani, W., AlZahrani, A., Altalhi, F., Alrubaie, S., Rawan A Alsini, R., AlZahrani, S., and Samaher H Altowairqi, S. (2016) assessment of multiple sclerosis awareness: knowledge and attitude among saudi population in taif city, ksa. Int. J. Adv. Res. 4(12), 1758-1766
- 3. Arriaza, M., Vazquez, A., Hernández, T., Delgado, D., and Meca-Lallana, V (2022)
  Disability and Fatigue in Multiple Sclerosis: Can Rehabilitation Improve Them through a
  Structured Retraining Program? Volume 2022 | Article ID 7908340 |
- 4. Bouchal, S., Lahmadi, N., Zejli, S., Chtaou, N., Hafidi, Y., Faouzi Belahsen, F(2022) Rituximab for the Treatment of Multiple Sclerosis: A Retrospective Observational Cohort in Morocco Case Reports in Clinical Medicine > Vol.11 No.10, October 2022

- 5. **Binshalan, T., Nair, K., McNeill ,A(2022)** The Effectiveness of Physiotherapy Interventions for Mobility in Severe Multiple Sclerosis: A Systematic Review and Meta-Analysis Hindawi Multiple Sclerosis International Volume 2022, Article ID 2357785, 15 pages https://doi.org/10.1155/2022/2357785
- 6. Braley, T., Whibley, D., Alschuler, K., Ehde, D., Chervin, R., Clauw, D., Williams, D., and Anna L Kratz, A.(2020) Cannabinoid use among Americans with MS: Current trends and gaps in knowledge Multiple Sclerosis Journal Experimental, Translational and Clinical v.6(3)
- 7. Claflin, S, Bessing B., der Mei, I. Campbell, J., Taylor., B (2022) Gains in multiple sclerosis knowledge following completion of the Understanding Multiple Sclerosis online course are maintained six months after course completion. Multiple Sclerosis and Related Disorders Volume 67, November 2022, 104085
- 8. Cortese, M., Bjornevik, K., Chitnis, T., Ascherio, A., Munger, K.(2022) Aging with multiple sclerosis- a longitudinal study of physical function, mental health, and memory in two cohorts of US women ult Scler. 2022 January; 28(1): 121–131
- 9. Cree, B., Arnold, D., Chataway, J., Chitnis, T., Fox, R., Ramajo, A., Murphy, N., and Hans Lassmann, H(2021) Secondary Progressive Multiple Sclerosis Neurology. 2021 Aug 24; 97(8): 378–388.
- 10. **Deif I.,(2022)** MS in Egypt: Doctors shed light on the challenges and new treatments Available at: <a href="https://english.ahram.org.eg/News/466230.aspx">https://english.ahram.org.eg/News/466230.aspx</a>
- 11. Downie W, Leatham P, Rhind V, Wright V, Branco, Anderson J (1978): Studies with pain rating scales. Annual Rheumatoid Disease; 37: 378-81.
- 12. Dymecka, J., Gerymski, R., Tataruch, R., and Bidzan, M. (2022) Sense of Coherence and Health-Related Quality of Life in Patients with Multiple Sclerosis: The Role of Physical and Neurological Disability J. Clin. Med. 2022, 11, 1716. <a href="https://doi.org/10.3390/jcm11061716">https://doi.org/10.3390/jcm11061716</a>
- 13. Elshaaer, A., Hussien Ali, Z., Elsayed, E(2022) Quality of Life Needs for Patients with Multiple Sclerosis International Journal of Novel Research in Healthcare and Nursing Vol. 8, Issue 3, pp: (1-15), Month: September December 2021, Available at: <a href="https://www.noveltyjournals.com">www.noveltyjournals.com</a>
- 14. Fahmi., R, El Ebeary, M., Abdalrasheed, E., Elkhatib, T,(2021) Association Of Obesity With Relapsing Remitting Multiple Sclerosis Disability In Zagazig University, zagazig university medical journal Volume 28, Issue 5, September 2022, Page 912-1175

- 15. Faissner, S., Plemel, J., Gold, R., & Yong, W (2019) Progressive multiple sclerosis: from pathophysiology to therapeutic strategies Nature Reviews Drug Discovery volume 18, pages905–922
- Farran, E., Waggas, D., Alkhunani, T., Almuwallad, S., and Rola A. Aljohani, R. (2021) Assessment of Multiple Sclerosis Awareness and Knowledge among the Community of Jeddah, Saudi Arabia J Neurosci Rural Pract. 2021 Oct; 12(4): 733–738. doi: 10.1055/s-0041-1734009
- 17. Giedraitiene, N., Gasciauskaite, G., and Kaubrys, G.(2022) Impact of autologous HSCT on the quality of life and fatigue in patients with relapsing multiple sclerosis Sci Rep. 2022; 12: 15404.
- 18. Giordano, A., Messmer Uccelli, M., Pucci, E., Martinelli, V., Borreani, C., Lugaresi, A., Trojano, M., Granella, F., Confalonieri, P., Radice, D., Solari, A(2009) The Multiple Sclerosis Knowledge Questionnaire: a self-administered instrument for recently diagnosed patients Volume 16, Issue 1
- 19. González, I., , -Rodríguez A., Conrad, R., Gregorio., M,(2020) Quality of life in adults with multiple sclerosis: BMJ Open 2020;10:e041249. doi:10.1136/bmjopen-2020-041249
- 20. Grau-López, L, Sierra, S E. Martínez-Cáceres, E. Ramo-Tello, C(2011) Analysis of the pain in multiple sclerosis patients NEUROLOGÍA;26(4):208-213
- 21. Habibi, H., Sedighi, B., Jahani, Y., Hasani, M., Iranpour, A. (2021) Self-Care Practices and Related Factors in Patients with Multiple Sclerosis (MS) Based on the Health Belief Model
- 22. Hassan, M (2021) Fatigue in A sample of Egyptian Multiple Sclerosis Patients: A Cross Sectional Study International Journal of Medical Arts 2021; 3 [3] July-September: 1681-1688
- 23. Hohol MJ, Orav EJ, Weiner HL (1999) Disease steps in multiple sclerosis: alongitudinal study comparing disease steps and EDSS to evaluate diseaseprogression. Mult Scler 5: 349–354
- 24. Homayuni, A., Abedini, S., Hosseini, Z., Etemadifar, M., & Ghanbarnejad, A. (2021) Explaining the facilitators of quality of life in patients with multiple sclerosis: a qualitative study BMC Neurology Article number: 193
- 25. Javdan, T., IMAN, E., NEGAH, A., TESHNIZ, S., (2021) Evaluation the effect of progressive muscle relaxation technique on fatigue and daily living activities in patients with Multiple Sclerosis P J M H S Vol. 15, NO. 6, JUN 2021

- 26. Kan, F., Hoseinipalangi, Z., Ahmadi, N., Hosseinifard, H., Dehnad, A., Hoseini, B., Tohidi, M., Ghashghaee, A(2020) Global, regional and national quality of life in patients with multiple sclerosis: a global systematic review and meta-analysis BMJ Supportive & Palliative Care 2020;0:1–9.
- 27. Kim, Y., Lai, B., Mehta, T., Thirumalai, M., Padalabalanarayanan, S., Rimmer, J., and Motl, R.,(2020) Exercise training guidelines for multiple sclerosis, stroke, and Parkinson's disease: Rapid review and synthesis Am J Phys Med Rehabil. 2019 Jul; 98(7): 613–621.
- 28. Kołtuniuk, A., Przestrzelska, M., Karnas, A., Rosińczuk, J (2020) The Association Between Sexual Disorders and the Quality of Life of Woman Patients With Multiple Sclerosis: Findings of a Prospective, Observational, and Cross-Sectional Survey Sex Med Jun;8(2):297-306. doi: 10.1016/j.esxm
- 29. Koziarska, D., Król, J., Nocoń, D., Kubaszewski, P., Rzepa, T., Przemysław Nowacki, P. (2018) Prevalence and factors leading to unemployment in MS (multiple sclerosis) patients undergoing immunomodulatory treatment in Poland
- 30. Krupp LB, LaRocca NG, Muir-Nash J, Steinberg AD., (1989) The Fatigue Severity Scale: application to patients with multiple sclerosis and systemic lupus erythematosis. Arch Neurol; 46: 1121–3.
- 31. Maloni, H and Hillman, L (2015) Multidisciplinary Management of a Patient With Multiple Sclerosis Part two Nurses' Perspective
- 32. Maniscalco, G., Ferrara, A., Liotti, A., Valentino Manzo, V., Battista, M., Salvatore, S (2022) Long term persistence of SARS-CoV-2 humoral response in multi, ple sclerosis subjects Multiple Sclerosis and Related Disorders Volume 62, June 2022, 103800
- 33. Momenabadi V., Kaveh, M., Nakhaee, N., Shirazi, K., Sedighi, B., Tabatabaei., S., 2020 Health Promoting Self-care Behaviors in Patients With Multiple Sclerosis in the Southeast of Iran: Developing a Model for Practice Basic and Clinical Neuroscience, 11(5), 687-700.
- 34. Mustafa, W., Elgendy, N., Samer Salama, S., Jawad, M., and Eltoukhy, K (2021) The Effect of Cannabis on the Clinical and Cytokine Profiles in Patients with Multiple Sclerosis Hindawi Multiple Sclerosis International Volume 2021, Article ID 6611897, 10 pages
- 35. Negaresha, R., .Mot.,R, Mokhtarzade, M., Dalgas, U., Patel, D., Shams, M., Majdinasab, N., Ranjbarg, R., Zimmerhi, P., Bakerj, J (2018) Effects of exercise training on cytokines and adipokines in multiple Sclerosis: A systematic review Multiple Sclerosis and Related Disorders Volume 24, August 2018, Pages 91-100

- Lamiaa Zaki Ahmed et. al
- Assessment of Fatigue, Pain, Disability and Quality of life for Patients with Multiple Sclerosis
- 36. Ochoa-Morales A, Hernández-Mojica T, Paz-Rodríguez F, et al. (2019) Quality of life in patients with multiple sclerosis and its association with depressive symptoms and physical disability. Mult Scler Relat Disord;36:101386
- 37. Olek, M. J. (2021). In the Clinic Multiple Sclerosis. ANNALS OF INTERNAL MEDICINE, 174(6), https://doi.org/10.7326/AITC202106150
- 38. Ozer, D., Altun, O.,(2022) The Relationship between Disability Levels and Psychological States of Multiple Sclerosis Patients International Journal of Caring Sciences May-August 2021 Volume 14 Issue 2 Page 1352
- 39. Öztürk, P., Vural, G., Öztürk, M., Gümüşyayla, S (2018) The Relationship between Quality of Life and Disability in Multiple Sclerosis Patients and Pain, Sleep Quality, Mood and Fatigue
- 40. Reina-Gutiérrez, S., Cavero-Redondo, I., Martínez-Vizcaíno, V., Arenas-Arroyo, S., López-Muñoz, P., Álvarez-Bueno, C., Guzmán-Pavón, M., Torres-Costoso, A (2022) The type of exercise most beneficial for quality of life in people with multiple sclerosis: A network meta-analysis Ann Phys Rehabil Med. 2022 May;65(3):101578.
- 41. Sagawa, Y., Watelain, E., Moulin, T., and Decavel, P. (2021) Physical Activity during Weekdays and Weekends in Persons with Multiple Sclerosis Sensors 2021, 21, 3617. <a href="https://doi.org/10.3390/s21113617">https://doi.org/10.3390/s21113617</a>
- 42. Salime, R., Elzehiri, D., Ibrahim, R.(2022) Effect of Nursing Intervention on Fatigue for Multiple Sclerosis Patients Tanta Scientific Nursing Journal Vol. 24 No. 1 (Suppl)
- 43. Salter, A., J.Fox, R., Tyry, T., Cutter, G., Ann Marrie, R.(2019) The association of fatigue and social participation in multiple sclerosis as assessed using two different instruments Multiple Sclerosis and Related Disorders Volume 31, June 2019, Pages 165-172
- 44. Sandroff, B.,. Jones, D., Baird, J., Motl, R.,(2020) Systematic Review on Exercise Training as a Neuroplasticity-Inducing Behavior in Multiple Sclerosis Volume 34, Issue 7 <a href="https://doi.org/10.1177/1545968320921836">https://doi.org/10.1177/1545968320921836</a>
- 45. Shawli, A., Abdulmutalib, I., Al Nagshabandi, E. (2019) Fatigue and Self-management among Multiple Sclerosis Patients American Journal of Nursing Research. 2019, 7(4), 550-560. DOI: 10.12691/ajnr-7-4-17
- 46. Stanikić, M., Salmen, A., Chan, A., Kuhle, J., Kaufmann, M., Ammann, S., Schafroth, S., et al (2022) Association of age and disease duration with comorbidities and

- disability: A study of the Swiss Multiple Sclerosis Registry Multiple Sclerosis and Related Disorders Volume 67
- 47. **Tabrizi**, **F.**, **Radfar**, **M** (2015) Fatigue, Sleep Quality, and Disability in Relation to Quality of Life in Multiple SclerosisInternational Journal of MS Care;17:268–274.
- 48. Valentine, T. Alschuler, K., Kratz, A. (2021) Prevalence, co-occurrence, and trajectories of pain, fatigue, depression, and anxiety in the year following multiple sclerosis diagnosis Multiple Sclerosis Journal Volume 28, Issue 4
- 49. Visser, L., Louapre, C., Groot, U., and Redekop, W(2020) Health-related quality of life of multiple sclerosis patients: a European multi-country study Archives of Public Health (2021) 79:39
- 50. Wallace, V., Cotterell, S., Nicholas, Z., Blain, C.(2020) The evaluation of pain and pain management in patients with multiple sclerosis Journal of Neurology, Neurosurgery and Psychiatry Volume 93, Issue 6
- 51. Ware JE Jr, Snow KK, Kosinski M, Gandek B., (1993) SF-36 Health Survey manual and interpretation guide. Boston (MA): Nimrod Press
- 52. Y.Ng., J &Kishimoto., V 2021 Multiple sclerosis clinical practice guidelines provide few complementary and alternative medicine recommendations: A systematic review Complementary Therapies in Medicine Volume 56
- 53. Yalachkova.,Y., Soydaşa., D., Bergmanna, J, Frischab,S., Behrensa, M., Foercha,. c Gehriga, J (2019) Determinants of quality of life in relapsing-remitting and progressive multiple sclerosis Multiple Sclerosis and Related Disorders Volume 30, May 2019, Pages 33-37
- 54. Yilmazer, C., Lamers, I., and Peter Feys, P. (2020) Clinical perspective on pain in multiple sclerosis Multiple Sclerosis Journal Volume 28, Issue 4

Table 1: Frequency and Percentage Distribution of Sociodemographic Characteristics of the Studied Patients with MS (n=60)

Demographic characteristics	(n=60)		
	Frequency	Percent	
Age:	49	81.7	
	11	18.3	

Scierosis		T
20-		
40-		
Mean ± SD	32.32 ± 8.1	
(range)	(20-52)	
sex:		
Male	18	30.0
Female	42	70.0
Marital status:		
Married	30	50.0
Un married [single/ divorced]	30	50.0
Education level :		
Illiterate	1	1.7
Read & write	2	3.3
Secondary education	34	56.7
University or Higher	23	38.3
occupation:		
Employee	19	31.7
Not Employee	41	68.3
Residence:		
Rural	25	41.7
Urban	35	58.3
Income:		
Enough	23	38.3
Not Enough	37	61.7

Table (2) Frequency and Percentage Distribution of medical History of the Studied Patients with MS (n=60).

Medical history	(n=60)		
	No	%	
Diagnosis of MS:*			
MRI	42	70.0	
Spinal fluid	22	36.7	

Lamiaa Zaki Ahmed et. al Assessment of Fatigue, Pain, Disability and Quality of life for Patients with Multiple Sclerosis

Excited voltage test	4	6.7	
Duration of MS:			
Less than 5 years	44	73.3	
From 5-10 years	8	13.3	
More than 10 years	8	13.3	
Mean ± SD	4.23 ± 1.8	l	
Types of MS			
Isolated Clinical Syndrome	4	6.7	
Relapsing multiple sclerosis	26	43.3	
Primary progressive multiple sclerosis	21	35.0	
Secondary progressive multiple sclerosis	8	13.3	
No type identified	1	1.7	
had an attack			
Yes	49	81.7	
No	11	18.3	
Frequency of MS attack			
Less than 5 times			
From 5-10 times	38	63.3	
More than 10 times	15	25.0	
	7	11.7	
Mean ± SD	4.22 ± 4.22		
First clinical manifestation.			
Sensory manifestation	7	11.7	
Optic Neuritis	13	21.7	
Motor weakness	24	40.0	

Ataxia	9	15.0
Cognitive Affection	3	5.0
Oculomotor Affection	4	6.6

Table (3): Total Patient's knowledge and practice level regarding multiple sclerosis

Parameter	Satisfactory		Unsatisfacto		
	No	%	No	%	Mean SD
Total knowledge score 60%+:	1	1.7	59	98.3	2.53±.43
Total practices score 60%+:	0	0.0	60	100	1.08 ±1.2

Figure (1) f Frequency and Percentage Distribution of fatigue level of studied patients with MS.



Table (4): Frequency and Percentage Distribution of pain characteristic of Studied Patients with MS (n=60)

Pain characteristics	(n=60)		
	No	%	

Lamiaa Zaki Ahmed et. al Assessment of Fatigue, Pain, Disability and Quality of life for Patients with Multiple Sclerosis

Do you have pain now		
Yes	46	76.7
No	14	23.3
Location of pain (no=46)		
Thigh, leg and foot	16	34.8
Arm, forearm and hands	5	10.9
Neck	6	13.0
Back	4	8.7
Knee	9	19.6
A large area of the body	6	13.0
the Nature of the pain		
Continuous	11	23.9
Intermittent	22	47.8
With the occurrence of an attack	10	21.7
Without an attack	3	6.6
pain wake up from sleep		
Yes	25	54.3
No	21	45.7
Pain description?		
Burning sensation	4	8.7
Numbness	6	13.0
Spasm	10	21.8
Wrench / ache	25	54.3
tightness	1	2.2

Figure (2): Frequency and Percentage Distribution of pain severity of studied patients with MS

Lamiaa Zaki Ahmed et. al Assessment of Fatigue, Pain, Disability and Quality of life for Patients with Multiple Sclerosis

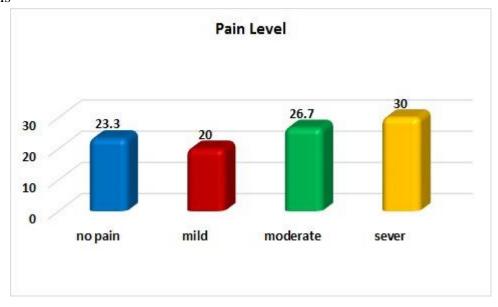


Table (5) Frequency and Percentage Distribution regarding disability (PDDS) grade among studied Patient with MS

Disability level	(n=60)		
	No	%	
Normal	3	5.0	
Mild disability	2	5.0	
Moderated disability	9	13.3	
Gait disability	24	38.3	
Early cane	7	11.7	
Late cane	8	13.3	
Bilateral support	4	6.7	
Wheelchair	3	6.7	

Figure (3) Frequency and distribution of regarding Level of Disability of Patient with MS



Table(6)Total mean score of fatigue, pain , disability and quality of life among studied patients with MS

Parameter	Mean ± SD
Total knowledge score	2.53±.43
Total practice score	1.08± 1.2
Fatigue (FSS)	54.37±10.21
Pain (NRS)	5.30± 3.71
Disability (PDDS)	3.46±1.71
Physical impact (QOL)	61.47 ± 12.95
Psychological impact(QOL)	31.38 ±5.74

Table (7): Correlation matrix of knowledge, practices, Fatigue, pain, disability and quality of life Scores & patient characteristic .

	Total mean score						
Scores	Knowled ge	Practice s	Fatigue	Pain	Disabilit y	Physical QOL	Psychologi cal QOL
Knowledge							
Practices	.227						
Fatigue	.024	091					
Pain	.244	.046	.028				
Disability	.070	218	.379**	.011			
Physical QOL	052	259*	.384**	.101	.564**		
Psychological QOL	109	212	.152	040	024	.295**	
Age	-	-	489**	.142	.464**	345*	
Duration of MS	-	-	.396**	.024	.356**	.451**	
Occupation	-	-	298**	.025	495**	321	