

Quality of Life Needs for Patients with Multiple Sclerosis

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Abstract: Multiple sclerosis is a chronic, inflammatory demyelinating disease of the central nervous system that represents one of the major causes of neurological disability, impairing quality of life during patients' productive life. Aim of the study was to assess the quality of life needs for patients with multiple sclerosis. Design: A descriptive exploratory study. Settings: Multiple Sclerosis Unit of Qasr Al-Aini at Cairo University Hospitals. Study subjects: A purposive sample of 70 adult patients from both genders admitted to multiple sclerosis unit. Data collection tools: Tool I. Interview Questionnaire Sheet. Tool II. Multiple Sclerosis Quality of Life -54 Instrument. Results: Regarding patients' knowledge, nearly three quarters of studied patients had poor total knowledge regarding multiple sclerosis, while more than one quarter of them had average total knowledge. Regarding patients' quality of life, nearly three quarters of studied patients had poor total quality of life regarding multiple sclerosis whenever, more than one quarters of them had average total quality of life regarding multiple sclerosis. There is a highly statistically significant relation between demographic characteristics and patients' total knowledge. There was statistically significant relation between patients' total knowledge and their total quality of life related to multiple sclerosis Conclusion: Regarding patients' knowledge, nearly three quarters of studied patients had poor total knowledge regarding multiple sclerosis. Regarding patients' quality of life, nearly three quarters of studied patients had poor total quality of life regarding multiple sclerosis. Recommendations: Investigators should continuously create educational programs for multiple sclerosis patients' and their families about the disease, management, complication & treatment. Ensuring of adequate assessment of nurses during their care and providing teaching with motivation and feedback for patients with multiple sclerosis.

Keywords: Multiple Sclerosis, Needs, Patients, Quality of life.

I. INTRODUCTION

Multiple sclerosis (MS) is one of the most common nervous system diseases, affecting people in many parts of the world, although it has a special preference for young people, for women, and for those in northern latitudes. MS has a genetic susceptibility, but it is not directly inherited, it is a potentially disabling disease of the brain and spinal cord (central nervous system), In MS, the immune system attacks the protective sheath (myelin) that covers nerve fibres and causes communication problems between the brain and the rest of body. Eventually, the disease can cause permanent damage or deterioration of the nerves (Santangelo et al., 2019).

The cause of multiple sclerosis is unknown. It's considered an autoimmune disease in which the body's immune system attacks its own tissues, this immune system malfunction destroys the fatty substance that coats and protects nerve fibers in the brain and spinal cord (myelin) whenever., risk factors of MS include young age between 20&40 years, being female, heavy smokers, exposure to certain infectious viruses such as Epstein-Barr virus (Kingwell et al., 2020).

Signs and symptoms of MS often affect movement, such as numbness or weakness in one or more limbs that typically occurs on one side of body, electric-shock sensations that occur with certain neck movements, tremor, lack of coordination or unsteady gait, vision problems are also common, including partial or complete loss of vision, prolonged

double vision, blurring vision in addition slurred speech, fatigue, dizziness, tingling or pain in parts of body & problems with sexual, bowel and bladder function (**Freiha et al., 2020**).

Quality of life is a subjective measure of a patient's life satisfaction that is affected by mood, coping mechanisms, life experiences, emotional support as well as disease state. according to the National Multiple Sclerosis Society (NMSS), MS diminishes QOL by interfering with ability to work, perform leisure activities, and carry on activities of daily living (ADLs), QOL domains include physical and occupational function, psychological state, spiritual, marital and social interaction, no cure for MS exists, so it is imperative that health care providers consider QOL on treatment program by focusing on physical role limitations, mental and emotional role limitations, and psychosocial impairments (**National Multiple Sclerosis Society., 2018**).

Nurses play an integral role in providing on-going support to the patient and participating in the prevention and management of symptoms, nurses can provide information, support and advice to patients during their disease progression, assist with fatigue management by reinforcing an energy conservation techniques learned from the occupational therapist. Moreover, nurses can also ensure that any mobility equipment is readily available and that the patient understands how to use it correctly, in addition nurses can assist in the management of bowel and bladder dysfunction by use of a toileting regime and education on continence management techniques (**Roman & Menning, 2017**).

Significance of the Study:

Multiple sclerosis (MS) is the commonest non-traumatic disabling disease affecting commonly young adults. There is increasing incidence and prevalence of MS in both developed and developing countries, the underlying cause of remains unknown, early diagnoses help patients to start treatment early and delay another attack, some studies suggest that damage caused by MS in the first year can be three times higher than subsequent years (**Simpson et al., 2019**).

Multiple sclerosis is a chronic disease, which causes 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, mental changes, such as forgetfulness or mood swings, depression, epilepsy, poor QOL, inappropriate coping skills and weak family relationships, and thus may cause a bad effect for both patients and their families, when MS patients have a better understanding of their illness, they manage their disease better and improve their health related quality of life (**Koltuniuk et al., 2020**).

According to WHO (2020), total of 2.8 million people are estimated to live with MS worldwide (35.9 per 100,000 population), Moreover, recent studies in Middle East indicates prevalence rates currently ranging between 55 and 85/100,000 cases.

According to MS international federation (2020), it was found that in Egypt about 59,671 people are living with MS. This equates to 1 in every 1,500 people, 9,244 new people are diagnosed each year. That's 770 diagnosed every month. 90% of people are initially diagnosed with relapsing-remitting MS and 10% have progressive MS, regarding age of diagnosis 27 years is the average age of an MS diagnosis and 75% of people with MS are women.

Aim of the study:

This study aimed to assess the quality of life needs for patients with multiple sclerosis through:

1. Recognizing patients with multiple sclerosis knowledge regarding multiple sclerosis.
2. Determine quality of life needs for multiple sclerosis patients.

Research Questions:

1. What is the level of knowledge among patients with multiple sclerosis regarding their disease?
2. What are quality of life needs for patients with multiple sclerosis?
3. Is there a relation between patients with multiple sclerosis socio- demographic characteristics and their knowledge?
4. Is there a relation between patients with multiple sclerosis socio- demographic characteristics and their quality of life?
5. Is there a relation between patients with multiple sclerosis knowledge and their QOL

II. SUBJECTS AND METHODS

- **Research design:** A descriptive exploratory design was utilized in this study. A research design is the arrangement of conditions for the collection and analysis of data in a manner that aims to combine relevance to the research purpose with economy and procedure (Akhtar, 2018).

- **Setting:** The study was carried at Multiple Sclerosis Unit, which is a part of neurology department at Qasr Al-Aini at Cairo University Hospitals.

- **Subjects:** A purposive sample of 70 adult patients from both genders admitted to multiple sclerosis units.

Inclusion criteria:

- Adult Patients with confirmed diagnosis of multiple sclerosis
- Ages of patients range from 18 to 60 years old.

Exclusion criteria:

- Patients with other critical values such as:
 - Systemic lupus erythematosus.
 - Rheumatoid arthritis.
 - Congenital neurovascular disorder.

Tools of data collection: The required data was collected through the following tools::

I. Interview Questionnaire Sheet: it was designed by the investigator based on literature review (Chen, Liu & Zhang, 2016) and was written in simple Arabic language to gather data regarding the following parts:

First part: It was concerned with socio-demographic characteristics of the patient, it included age, gender, marital status, qualification, place of residence, work nature, number of family members and income.

Second part: It concerned with past medical history such as (DM, Hypertention, renal failure, anaemia, malignancy ..., etc) and surgical interventions.

Third part: Knowledge Assessment form: it was used to assess the knowledge of patients about multiple sclerosis (definition, Popularity of MS, causes, manifestation, diagnosis, types of MS, Type of MS that the patient diagnosed, treatment, aim of the treatment, prevention and living with the disease) and was adapted from (Chen, Liu & Zhang, 2016).

The total scoring system of patients' knowledge:

Three levels of scoring for each question as the following:

- Correct and complete answer was scored (2).
- Correct and incomplete answer was scored (1).
- Incorrect answer or don't know was scored (0).

So, the total score of 11 questions were 22 degree.

The total scoring system of patients' knowledge was calculated and classified in three levels as following:

- For 75-100% was considered good level of knowledge (17-22 degree).
- For 60- <75% was considered average level of knowledge (14- < 17 degree).
- For less than 60% was considered poor level of knowledge (<14 degree).

II. Multiple Sclerosis Quality of Life (MSQOL)-54 Instrument: this tool was adapted from (Samohyl, 2014). was used to assess quality of life for patients with multiple sclerosis. It was modified by the investigator. Its' domains evaluated problems such as physical domain (10 items), psychological domain (15 items), Family & Social domain (10 items), spiritual domain(10 items) and marital domain (9items).

The total scoring system of patients' quality of life:

The items were rated on a 5-point Likert-type scale from "Never" to "always" and vice versa for the negative statement. These items were scored as Never= 0, Rarely=1, Sometimes =2, 'Usually=3, Always=4.

Quality of life for patients with multiple sclerosis was classified according to their response into good ($\geq 75\%$) equal to ≥ 160 degree, average (50- <75%) equal to (108- <160) degree and poor (<50%) equal to < 108 degree.

Validity:

It was ascertain by a jury of five experts in the field of critical care to test its content validity by reviewing the tools clarity, relevance, comprehensives, simplicity, minor modification were done.

Reliability:

The tool was measured to ensure that an assessment tool produces stable and consistent result overtimes. To assess reliability, the study tools were tested by Cronbach's alpha which was 0.725 for knowledge questionnaire regarding MS and 0.89 for multiple sclerosis QOL questionnaire.

Ethical Considerations:

An approval was obtained from Scientific Ethical Committee of Faculty of Nursing at Helwan University and the study subjects individually using an oral and written informed consent obtained from each participant prior to data collection. They was assured that anonymity and confidentiality would be guaranteed and the right to withdraw from the study at any time. Ethics, values, culture, and beliefs were respected.

II- Operational Design:

The operational design includes preparatory phase, Pilot study and fieldwork.

The Preparatory Phase:

It was included reviewing related literature and theoretical knowledge of various aspects of the study using books, articles, internet periodicals and magazines.

Pilot Study:

A pilot study was carried out on 10% (not less than 7 patients) of the sample under study to test applicability, clarity and efficiency of the tools, than the tools was modified according to the results of the pilot study. Patients shared in the pilot study was not involved in the sample.

Field Work

Interviewing with (70) multiple sclerosis patients' in the previously mentioned setting, the started data collection by introducing himself to the patients , explaining the aim of the study, the effect of this study on their quality of life and take their approval to participate in the study prior to any data collection:

- Assessing patients' knowledge, health needs, physical health problems and their quality of life regarding multiple sclerosis patients' by using questionnaire sheets.
- Patients filled the questionnaires in the morning and afternoon shifts but regarding the illetrate patient, the investigator ask the patient and filled the questionnaire; it took about 30 minutes for each patient to complete the questionnaire.
- Data collection was done 2 days per week (Sunday &Tuesday), as the invesigator was available. It took three months starting from the 15 September 2019 up to 15 December 2019, it took 4 hours from (9 am to 1 pm and from 3pm to 7 pm) in the previously mentioned setting in morning and afternoon shifts.

III- Administrative Design:

- An Issued litter from the Dean of Faculty of Nursing at Helwan University and official permission was obtained from The Head of Multiple Sclerosis Unit in which the study was conducted.

IV- Statistical Analysis:

The data obtained were synthesized, analyzed, and presented in the form of tables and figures using the Statistical Package for Social Sciences version 20 (SPSS). Qualitative variables was presented in the form of frequencies and percentages, quantitative variables was presented in the form mean and SD. Test of significance were used to find out associations between study variables. Chi-square (χ^2) test of significance was used in order to compare proportions between two qualitative parameters. Spearman's rank correlation coefficient (r) was used to assess the correlation between two variables. The confidence interval was set to 95% and the margin of error accepted was set to 5%. So, the p-value was considered significant as the following:

P value <0.05 was considered significant.

P value <0.001 was considered as highly significant.

P value >0.05 was considered insignificant.

III. RESULTS

Regarding Sociodemographic Characteristics of the Studied Patients, Table (1) shows that, the mean age of studied patients is (34.235 ± 7.65) years old whenever, 57.1% of them have university education and from urban area, regarding working nature 71.4% aren't working.

Regarding Multiple Sclerosis Domains Scores according to their Total Quality of Life among Studied Patients, Table (2) illustrates that, (68.6% & 71.4%) of studied patients have a poor quality of life regarding physical and social domains respectively and 85.7% of them have poor quality of life regarding psychological domain, whenever 30.0% of studied patients have average QOL regarding spiritual domain.

Regarding Relation between Total Knowledge of Studied Patients' and their Demographic Characteristics , Table (3) indicates that, there is a highly statistically significant relation between total knowledge of studied patients' and their age, gender, qualification, place of residence and working nature (p<0.001**).

Regarding Relation between Total Quality of Life of Studied Patients' and their Demographic Characteristics, Table (4) indicates that, there is a highly statistically significant relation between total QOL of studied patients' and their (age, gender & qualification) with P value (.000) while there is statistically significant relation between total QOL and working nature with P value (.01) and there is no statistically significant relation between total QOL & place of residence with P value (.240) .

Regarding Relation between Total Knowledge and Total Quality of Life of Studied Patients, Table (5) indicates that, there is statistically significant relation between patients' total knowledge and their total QOL related to multiple sclerosis with P value (.005).

Table (1): Frequency and Percentage Distribution of the Studied Patients according to their Demographic Characteristic (n=70).

Characteristics of Studied Patients	No	%
Age/years		
18-30	19	27.1
31-40	40	57.1
41-50	9	12.9
51-60	2	2.9
Mean ±SD	34.235 ± 7.65	
Gender		
Male	40	57.1
Female	30	42.9
Qualification		

Illiterate	1	1.4
Secondary education	29	41.4
University education	40	57.1
Place of residence		
Urban	40	57.1
Rural	30	42.9
Work nature		
Working	20	28.6
Not working	50	71.4
Number of family members		
1<3	10	14.3
3<5	60	85.7

Table (2): Frequency and Percentage Distribution of Studied Patients according to their Total Quality of Life regarding Multiple Sclerosis Domains (n=70).

Domains	Good		Average		Poor	
	No	%	No	%	No	%
Physical domain	5	7.1	17	24.3	48	68.6
Psychological domain	1	1.4	9	12.9	60	85.7
Social domain	3	4.3	17	24.3	50	71.4
Spiritual domain	19	27.1	21	30.0	30	42.9
Marital domain	18	25.7	22	31.4	30	42.9
Total QOL	2	2.9	18	25.7	50	71.4

Table (3): Frequency and Percentage Relation between Total Knowledge of Studied Patients' and their Demographic Characteristics (n=70).

Demographic Characteristics	Total Knowledge						R	P-value	Sig
	Good		Average		Poor				
	No	%	No	%	No	%			
Age/years									
18-30	0	0.0	0	0.0	19	38.8	30.500	.000	HS
31-40	2	66.7	18	100	20	40.8			
41-50	0	0.0	0	0.0	9	18.4			
51-60	1	33.3	0	0.0	1	2			
Gender									
Male	3	100	16	88.9	21	42.9	13.741	.000	HS
Female	0	0	2	11.1	28	57.1			
Qualification									
Illiterate	1	33.3	0	0.0	0	0.0	42.881	.000	HS
Secondary education	0	0.0	0	0	29	59.2			
University education	2	66.7	18	100	20	40.8			
Place of residence									
Urban	2	66.7	17	94.4	21	42.9	14.421	.001	HS
Rural	1	33.3	1	5.6	28	57.1			
Working nature									
Working	2	66.7	16	88.9	2	4.1	48.622	.000	HS
Not working	1	33.3	2	11.1	47	95.9			

on sig. >0.05 Sig. <0.05* High sig. <0.001**

(Statistical significant difference).

Table (4): Frequency and Percentage Relation between Total Quality of Life of Studied Patients' and their Demographic Characteristics (n=70).

Demographic Characteristics	Total Quality of Life						R	P-value	Sig
	Good		Average		Poor				
	No	%	No	%	No	%			
Age/years									
18-30	1	50	8	44.4	10	20	24.332	.000	HS
31-40	0	0	10	55.6	30	60			
41-50	0	0	0	0	9	18			
51-60	1	50	0	0	1	2.0			
Gender									
Male	2	100	18	100	20	40	21.000	.000	HS
Female	0	0	0	0	30	60			
Qualification									
Illiterate	1	50.0	0	0.0	0	0.0	35.322	.000	HS
Secondary education	1	50	8	44.4	20	40			
University education	0	0	10	55.6	30	60			
Place of residence									
Urban	0	0	10	55.6	30	60	2.852	.240	NS
Rural	2	100	8	44.4	20	40			
Working nature									
Working	0	0.0	10	55.6	10	20	9.022	.01	S
Not working	2	100	8	44.4	40	80			

Non sig. >0.05 Sig. <0.05* High sig. <0.001**

(Statistical significant difference).

Table (5): Frequency and Percentage Relation between Total Knowledge and Total Quality of Life of Studied Patients (n=70).

Total Knowledge	Total Quality of life						R	P-value	Sig
	Good		Average		Poor				
	No	%	No	%	No	%			
Good	1	50	0	0	2	4	15.046	.005	Sig
Average	0	0	8	44.4	10	20			
Poor	1	50	10	55.6	38	76			

Non sig. >0.05 Sig. <0.05* High sig. <0.001**

(Statistical significant difference)

IV. DISCUSSION

Multiple sclerosis (MS) is a chronic, inflammatory, immune-mediated disease of the central nervous system that usually strikes young adults, this chronic demyelinating disease involves unpredictable episodes of inflammatory demyelination and axonal transection that result in lesions along axons of nerve fibres in the brain and spinal cord, the symptoms of MS are weakness, sensory loss, and ataxia, which are directly related to demyelination and axonal loss, along with other symptoms such as reactive depression or social isolation which can result in functional limitations, disability and reduced quality of life (Wendebourg *et al.*, 2017).

The treatment of MS is divided into treatment of MS relapses, prevention of new relapses, disease progression, and symptomatic treatment of the disease, symptom management includes medications, and nonpharmacological methods such as rehabilitation and psychosocial support. Health-related quality of life is a multidimensional concept that includes self-reported measures of physical, mental, emotional and social functioning. These measures have become very important as clinical trial outcome measures in MS, multiple sclerosis has a major negative impact on patients health related quality of life (HRQoL) (*Fasczewski et al., 2017*).

Regarding the demographic characteristics of studied patients, the findings of the current study revealed that the mean age of studied sample was 34.235 and nearly three fifth of them had university education, this may be interpreted that the disease usually strikes young adults and the onset of disease usually occur over 25 years old, the study was conducted in urban area in which people interested in education more than rural area. These findings were supported by **Bertado-Cortés et al., (2016)** whose study entitled, (Clinical and Demographic Characteristics of Patients with Multiple Sclerosis), they revealed that the mean age in their study sample was 41.22 years old and more than half of their study sample were highly educated.

In relation to the place of residence, nearly three fifth of studied patients are from urban area, this may be interpreted that the study was conducted at Al-Qasr Elieny hospital in Cairo, so that most patients were from urban area, the study is congruent with **Brola et al., (2017)** whose study entitled (Multiple Sclerosis: Patient-Reported Quality of Life in The Świętokrzyskie Region), they revealed that more than half of studied patients were from town.

Concerning working nature and marital status, the current study illustrated that nearly three quarters of studied patients were not working and the majority of studied patients are married, this may be interpreted that multiple sclerosis patients usually suffering from motor skills abnormalities, easy fatigability and cognitive impairment which affect their working abilities, the study is agreed with **Brola et al.,(2017)** whose study entitled (Multiple sclerosis: patient-reported quality of life in the Świętokrzyskie Region) whose study results illustrated that more than three quarters of their study sample were unemployed due to their physical and cognitive health problems and nearly three quarters of their study sample were married and also agreed with **Aulaban et al., (2019)** whose study entitled(Multiple Sclerosis Patients Knowledge in Saudi Arabia), they revealed that nearly half of studied patients are unemployed.

In relation to income of studied patients, the current study revealed that nearly three fifth of studied patients had insufficient 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 study is agreed with **Rezapour et al.,(2017)** whose study entitled (The Impact of Disease Characteristics on Multiple Sclerosis Patients' Quality of Life), they revealed that more than three fifth of study sample didn't have sufficient income, moreover the study is disagreed with **Hudaif et al., (2014)** whose study entitled (Assessment of multiple sclerosis awareness and knowledge among Saudi population in Riyadh City) they revealed that more than three fifth of studied patients had sufficient family income .

Pertaining to the quality of life of studied patients regarding physical domain, the current study revealed that more than half of studied patients were sometimes unable to perform work and need care till the end of life, may be related to the physical impairment caused by the disease, frequent fatigue and disabilities, the study is agreed with **Brola et al., (2017)** entitled (Multiple sclerosis: patient-reported quality of life in the Świętokrzyskie Region), they revealed that only less than two fifth of their study sample were economically active, able to work and the rest of them were unable to work and need care until the end of life due to their disease, fatigue and weakness, they relied on their families to help them and meet their needs.

Regarding physical domain the current study also revealed that more than half of studied patients always feeling exhausted and tired and always suffering from weakness in the muscles of extremities, the study is agreed with **Fasczewski et al., (2017)**, whose study entitled (Assessing self-report physical activity behaviour and quality of life in individuals with multiple sclerosis), they revealed that more than half of studied patients had fatigue and always feeling exhausted and tired and nearly half of their studied sample had improper gait coordination and muscle weakness due to pain, muscle atrophy and lack of strength.

Regarding sleep satisfaction, the current study revealed that more than one quarter of studied patients never feel satisfied with sleep may be related to pain, fatigue which cause insomnia, the study is agreed with **Hughes et al., (2017)**, whose

study entitled (Sleep and its associations with perceived and objective cognitive impairment in individuals with multiple sclerosis), they revealed that nearly three quarters of studied patients never feel satisfied with sleep and had a poor sleep quality which increase their fatigue, affect their ADLs and cause cognitive impairment.

In relation to patients' quality of life regarding psychological domain, the current study revealed that nearly half of studied patients never feeling enjoyed with life moreover., nearly three quarters of them always feeling alone and more than half of them always feeling nervous, depression and sadness, these results interpreted that patients always feeling fatigue, impaired mobility, inability to perform activities of daily living and dependence on others so that they suffer from sadness and depression.

The study supported by **Calandri et al., (2016)**, whose study entitled (Depression, Positive and Negative Affect, Optimism and Health-Related Quality of Life in Recently Diagnosed Multiple Sclerosis Patients: The Role of Identity, Sense of Coherence, and Self-efficacy), they revealed that more than one third of their studied participants always feeling dissatisfied with their life whenever nearly one half of studied participants always had depression and feeling sadness, psychological distress, low self-efficacy and unpleasant emotions usually due to the disease process and impaired social relation.

Concerning patients' satisfaction with their appearance, the current study revealed that more than one quarter of participants were never satisfied with their appearance, this may be interpreted that they always had change in motor function, weakness, tingling and numbness of extremities also they some-times had change in vision which affect their self-esteem and satisfaction with appearance, the study is agreed with **Bass et al., (2020)** whose study entitled (Effect of Multiple Sclerosis on Daily Activities, Emotional Well-being, and Relationships), they revealed that more than one third of their study sample always had low self-esteem and not satisfied with their appearance related to physical, psychological and cognitive impairment.

Pertaining to patients' quality of life regarding their family& Social domain, the current study revealed that more than two fifth of studied patients never feeling satisfied with relationships with others and always don't interested with recreational activities which may be related to impaired physical mobility, psychological depression and mood swing or the load that put on caregivers due to completely dependence on them to meet the patient basic needs.

The study is consistent with **Cattaneo et al., (2017)**, whose study entitled (Participation Restriction in People With Multiple Sclerosis: Prevalence and Correlations With Cognitive, Walking, Balance, and Upper Limb Impairments), they revealed that more than one third of studied sample had problems with their relation with others and diminished their interesting activities due to their motor impairment and preferring social isolation, moreover, the study is incongruent with **Mattarozzi et al., (2015)** whose study entitled (Assessing subjective quality of life domains after multiple sclerosis diagnosis disclosure), they revealed that most of studied patients had apposite relationship with their families and more than half of studied patients adhere to simple recreational activities such as reading and walking.

The current study also revealed that nearly one quarter of studied patients usually feeling inability to help others and more than two fifth of them always feeling that family is suffering because of disease condition, the study is congruent with **Brola et al., (2017)** whose study entitled (Multiple sclerosis: patient-reported quality of life in the Świętokrzyskie Region), they revealed that nearly half of studied patients always feeling that their family is suffering due to their disease condition.

Regarding patients' quality of life regarding their spiritual domain, the current study revealed that more than one quarter of studied patients suffered from loss of hope, also more than two fifth of them lacked desire, sense of stability and feeling that religious and spiritual activities have been affected moreover, more than half of studied patients always feeling unhappy, this may be interpreted that they sometimes had cognitive impairment, social and physical impairment that increase their frustration and depression.

The result of the current study is agreed with **Niyazmand et al., (2018)**, whose study entitled (The relationship between spiritual health and hope in multiple sclerosis patients: A descriptive-correlational study), they illustrated that most of studied patients had inadequate spiritual activities, more than half of study sample impaired religious activities and more than three fifth of them had loss of hope related to lifelong chronic disease that affect their psychological health status.

Pertaining to patients' quality of life regarding marital domain, the current study revealed that more than one quarter of studied sample always feeling that their husband or wife suffers from dependence on him and more than half of studied patient always suffer from Loss of emotional support from his partner also more than half of them sometimes feeling that their partner unhappy and more than two fifth of them some-times feeling that their partner was dissatisfied with their appearance, this may be interpreted that patients had low self-esteem, physical impairment and decreased the mobility so that feeling dependent on his partner .

The study is in the line with **Bass et al., (2020)** whose study entitled (Effect of Multiple Sclerosis on Daily Activities, Emotional Well-being, and Relationships), they revealed that nearly half of studied patients reported that they some-times feel that their partner is unhappy with them due to decrease sexual attractiveness and more than one quarter of participants had lack of support from their partner and feeling fear that partner may leave them due to their impaired health condition, unemployment, insufficient income and frequent mood change.

Pertaining to patients' total quality of life regarding physical domain, the current study revealed that more than three fifth of studied patients 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 **Bass et al., (2020)** whose study entitled (Effect of Multiple Sclerosis on Daily Activities, Emotional Well-being, and Relationships), 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.

Pertaining to patients' total quality of life regarding social domain, the current study revealed that nearly three quarters of studied patients had a poor social support may be related to lack of emotional support from family and friends or impaired physical activities which lead to lack of socialization and family visits, the study is agreed with **costa et al., (2017)**, whose study entitled (Social support network and quality of life in multiple sclerosis patients), they revealed that more than half of studied patients had poor total quality of life related to social domain the participants mentioned that they did not have a family member with whom they could talk to about almost everything, they could not trust friends and most patients did not participate in sports groups , meetings or in voluntary work.

The study was disagreed with **Zengin et al., (2017)** whose study entitled (Quality of Life, Coping, and Social Support in Patients with Multiple Sclerosis: A Pilot Study), they revealed that the majority of their study sample have good social support as they received social and emotional support from their family, relatives, neighbours and from other patients in group therapy.

Pertaining to patients' total quality of life regarding psychological domain, the current study showed that, the majority of studied patients had poor quality of life, from the invesigator point of view this may be related to poor socialization, recurrent mood change, life-long impaired mobility, dependence on others to meet their daily needs and certain medication side effects that may cause depression.

The study is agreed with **Algahtani et al., (2017)** whose study entitled (Quality of life among multiple sclerosis patients in Saudi Arabia), they revealed that more than half 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.

The study also is in the same line with **Soundy et al., (2016)** whose study entitled (The Psychological Processes of Adaptation and Hope in Patients with Multiple Sclerosis) they showed that more than half of studied patients had poor psychological status related to depression , loss of hope, unstable income moreover., lack of social support and coping mechanism, the patients improved their psychological status after adaptation because hope has been associated with less depression, being positive and optimistic is associated with better mental well-being, and also that positive adjustment is aided by coping strategies such as benefit finding, positive re-appraisal, and seeking social support.

Pertaining to patients' total quality of life regarding spiritual domain, the current study revealed that more than one quarter of studied patients had average quality of life, the study is disagreed with **Niyazmand et al., (2018)**, whose study

entitled (The relationship between spiritual health and hope in multiple sclerosis patients: A descriptive-correlational study), they revealed that most of study sample had adequate spiritual and religious activities as Iranian society is a community with Islamic beliefs and teachings and spirituality is rooted in the lives of the nation, therefore, such a research result was not away from expectation. According to Islamic beliefs and teachings, remembering god pacifies the hearts and this pacification in life is one of the most important variables of life expectancy.

Pertaining to patients' total quality of life regarding multiple sclerosis, the current study revealed that nearly three quarters of studied patients had a poor quality of life related to immobility, social problems, patients' dependence on others, psychological problems and depression.

The study is agreed with **Algahtani et al., (2017)** whose study entitled (Quality of life among multiple sclerosis patients in Saudi Arabia), they revealed that more than half of studied patients had a poor quality of life regarding all dimensions of multiple sclerosis, they mentioned that MS affects the patient in a variety of aspects including the psychological state, pain, vitality, sexual dysfunction, fatigue, financial problems, employment difficulties, and the perception of MS within their community. Depression and loss of cognitive function usually affect the employment status and social functioning of the patient, these two symptoms were reported by patients with MS as important determinants of their quality of life, and some patients believe that these symptoms are more important than their physical impairments.

The study also supported by **Brola, (2017)** whose study entitled (Multiple sclerosis: patient-reported quality of life in the Świętokrzyskie Region), they revealed that more than three fifth of study sample had a total poor quality of life regarding all items of MS related to long-lasting disease, reduced mobility, poor coping mechanism, sexual dysfunction and psychological health problem.

Pertaining to the relation between demographic characteristics and total patients' knowledge, the current study revealed that there were highly statistically significant relation between patients' age and total knowledge of studied patients may be related to that with aging the patients increased years of experiencing the disease and may be exposed to educational program or inpatient training program about multiple sclerosis.

The study was agreed with **Roy et al., (2017)** whose study entitled (Differential effects of aging on motor and cognitive functioning in multiple sclerosis), they revealed that there were statistically significant relation between patients' age and their total knowledge about causes, types, diagnosis and management of the disease, this may be related to reading and understanding about the disease and related prognosis moreover, the study is incongruent with **Aulaban et al., (2019)**, whose study entitled (Multiple Sclerosis Patients' Knowledge in Saudi Arabia), they revealed that there were no statistically significant relation between patients' age and their knowledge regarding multiple sclerosis questionnaire.

Regarding the relation between total patients' knowledge and educational level, the current study revealed that there were highly statistically significant relation, this may be interpreted that high level of education help patients to read and understand more about the disease, the study is agreed with **Rimkus et al., (2018)** whose study entitled (The protective effects of high-education levels on cognition in different stages of multiple sclerosis), Low-education attainment is associated is associated with worse knowledge and performance in (MS) patients.

Regarding the relation between patients' total knowledge and place of residence, the current study revealed that there were highly statistically significant relation, patients live in urban areas had adequate knowledge than those in rural areas, may be related to different culture and adequate facilities, the study is inconsistent with **Aulaban et al., (2019)** whose study entitled (Multiple Sclerosis Patients Knowledge in Saudi Arabia), they illustrated that there were no statistically significant relation between patients' place of residence and level of knowledge.

Regarding the relation between patients' total knowledge and working nature, the current study revealed that there were statistically significant relation, working patients had adequate knowledge than non- working, may be related to that working patients associated with high level of education and may be more reading than no working patients, the study agreed with **Aulaban et al., (2019)** whose study entitled (Multiple Sclerosis Patients Knowledge in Saudi Arabia), they illustrated that there were statistically significant relation between patients work and level of knowledge, employed patients had a satisfactory knowledge than unemployed patients.

Regarding the relation between patients' demographic characteristics and total patients' quality of life, the current study illustrated that there were a highly statistically significant relation between patients' age and quality of life, elderly patients had poor quality of life than younger patients, this may be interpreted that older patients had greater disabilities, psychological depression, lack of socialization and greater dependence on others than young patients so that they had poor quality of life, the study is agreed with **Brola et al., (2017)** whose study entitled (Multiple sclerosis: patient-reported quality of life in the Świętokrzyskie Region), 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 total quality of life and patients' gender and qualification, the current study illustrated that there were highly statistically significant relation, from the investigator point of view this may be related to the effect of patients' education on their perception, understanding of coping strategies and adherence to follow-up and treatment.

The study was agreed with **Alhazzani, (2018)** whose study entitled (Quality of life assessment among multiple sclerosis patients in Saudi Arabia), they revealed that there were statistically significant relation between patients' gender and qualification regarding total quality of life, the mean score for males is higher than the mean score for females in all quality of life subscales due to better emotions higher energy and less fatigue, they also showed that patients with a high level of education (for instance, secondary level or above) scored higher in every measurement than those who had the lowest level of education.

Regarding the relation between patients' total quality of life and place of residence, the current study revealed that there were no statistically significant relation between place of residence and patients quality of life, the study is consistent **Brola et al., (2017)** whose study entitled (Multiple sclerosis: patient-reported quality of life in the Świętokrzyskie Region), they revealed that there were no statistically significant relation in quality of life between patients who live in country and town.

Pertaining to the relation between patients' total quality of life and work nature, the current study revealed that there were statistically significant relation between patients' total quality of life and their work 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 **Mattarozzi et al., (2015)**, whose study entitled (Assessing subjective quality of life domains after multiple sclerosis diagnosis disclosure) whose study showed that there were statistically significant relation between patients' employment status and quality of life regarding multiple sclerosis.

Pertaining to the correlation between patients' total knowledge and total quality of life regarding multiple sclerosis, the current study revealed that there were statistically significant relation between, high education associated with good quality of life, may be related to adequate understanding of the disease result in adequate coping with physical impairment, managing psychological problems, improving social relation and improving spiritual and religious activities.

The study was supported by **Brola et al., (2017)** entitled (Multiple sclerosis: patient-reported quality of life in the Świętokrzyskie Region), they revealed that there were highly statistically significant correlation between patients' knowledge and their quality of life, knowledgeable patients associated with adequate coping, managing physical impairment and dealing with frustration and depression.

V. CONCLUSION

Based on the results of the present study, it can be concluded that, regarding patients' knowledge, nearly three quarters of studied patients had poor total knowledge regarding multiple sclerosis, while more than one quarter of them had average total knowledge. In addition, nearly three quarters of patients had poor total QOL regarding multiple sclerosis whenever, more than one quarters of them had average total QOL regarding MS. Moreover, there were a highly statistically significant relation between patients' demographic characteristics and their total knowledge. Regarding the relation between patients' demographic characteristics and their QOL, the study revealed that there were a highly statistically significant relation between total QOL of studied patients' and their (age, gender & qualification), while there were statistically significant relation between total QOL and working nature. The study also concluded that, there were statistically significant relation between patients' total knowledge and their total quality of life regarding multiple sclerosis.

VI. RECOMMENDATIONS

Based on the study result, it could be recommended that:

Investigators Recommendations:

- Investigators should continuously create educational programs for multiple sclerosis patients' and their families about the disease, management, complication & treatment.
- Encourage investigators to conduct the study on a large sample size and different hospitals setting in order to generalize the results.
- Provide additional research efforts for young adults with MS to undertake plan interventions to achieve health outcomes while living with the disease.
- Developing a simplified and comprehensive booklet including guidelines about MS management.

Patients Recommendations:

- Patients should adhere to medication program and physiotherapy to improve their quality of life.
- Recommend patients for frequent follow-up appointments for early detection and prevention of complications.
- Instruct the patients to use assistive devices to help in movement and decrease their dependence.
- Recommend the patients to adhere to exercise program according to doctor order to improve their mobility.
- Instruct the patients to avoid stress, anxiety and depression.

Nurses Recommendations:

- Recommend nurses to improve patients' care in out-patients clinics to provide more comfort and decreasing number of hospitalization by improving self-care measures.
- Nurses should provide additional program for in-home management with the training of cognitive and behavioural techniques to deal with patients with impaired mobility.
- Ensuring of adequate assessment of nurses during their care and providing teaching with motivation and feedback for patients with MS.
- Create recreational environment in neurology departments by using methods that can help patients in improving their self-care & self-efficacy such as videos and coloured boosters.

Community Recommendations:

- Encouraging social agencies to support patients with chronic diseases such as multiple sclerosis.
- The study provides recommendations for the healthcare system to facilitate a reduction in the financial burdens of this critical disease.

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