

## Effects of Self-Care Education Program on Quality of Life of Patients with Multiple Sclerosis

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**Abstract: Background:** Multiple sclerosis is a chronic and progressive disease of the central nervous system with debilitating symptoms and complications. Therefore, appropriate interventions, including self-care education are necessary to increase the quality of life in these patients.

**Aim:** The aim of the study was to determine the effect of self-care education program on quality of life of patients with multiple sclerosis.

**Design:** A quasi-experimental research design was used.

**Setting:** The study was conducted at the Out Patient Neuromedicine Clinic in Bab Elshaeria University Hospital affiliated to El-Azhar University, Cairo Governorate, Egypt.

**Sample:** A purposive sample of 80 patients was selected.

**Tools:** Tool I) A structured designed interviewing questionnaire which covers two parts: Part one: Demographic characteristics of studied sample as age, gender, marital status, level of education. Part two: Knowledge of studied sample about multiple sclerosis. Tool II: Multiple sclerosis quality of life. **Results:** The study sample had poor knowledge scores (67.5%) about multiple sclerosis at pre self-care education program, which improved to 88.7% having good knowledge at post self-care education ( $p < 0.001$ ). There was statistically significant improvement between total quality of life scores at pre and post self-care education, at pre, only 12.5 % of study sample had good quality of life scores which improved to 62.5% having good scores of quality of life at post self-care education.

**Conclusion:** The study findings revealed improvements in patients' knowledge and quality of life after implementation of self-care education program.

**Recommendations:** Counseling to enhance strategies of coping with the disease and regular follow-up should be carried out for reducing or preventing complications among patients with multiple sclerosis.

**Keywords:** Multiple Sclerosis, Quality of Life, Self-Care

Date of Submission: 10-06-2019

Date of acceptance: 26-06-2019

### I. Introduction

Multiple sclerosis (MS) is the most common disabling disease of young adults. It occurs due to the inflammatory process of demyelination of the central nervous system [1]. The prevalence rate of MS was reported to be 2.5 million individuals worldwide [2].

Multiple sclerosis (MS) is a long-lasting, incapacitating and chronic infection that affects different parts (e.g., brain, spinal cord) of the central nervous system (CNS) at different intervals. At its preliminary stages, MS is often categorized by vital set backs in its neurological pivotal deficits, which is gradually followed by a substantial degree of recovery referred to as the relapsing-remitting stage. The progress in the "relapsing-remitting" MS stage goes on for a period of about 10 years and then it is followed by another MS stage known as a secondary progressive stage [3, 4].

Multiple sclerosis (MS) is a chronic progressive disease, associated with a wide range of symptoms, which decrease the individual and social performance of patients [5]. The primary symptoms of this disease include visual disturbance, pain, urinary incontinence, weakness, fatigue, apprehension and anxiety [6]. The severity of multiple sclerosis symptoms differs from one patient to another and may range from almost unnoticeable to severe. The outcome of MS on these patients' lives is consequently wide-ranging and thereby a challenge to foresee, which have a significant impact on the independence and ability of individuals for active cooperation in the family and society and finally the quality of life [7].

Risk factors which increase developing of multiple sclerosis includes age (most commonly affects people between the ages of 15 and 45), gender (women are two to three times more likely than men to become diagnosed with MS), family history (If one of your parents or siblings has had MS), vitamin D deficiency, certain infections (the virus that causes infectious mononucleosis), certain autoimmune diseases and smoker

persons[8]. People with multiple sclerosis suffer from many 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 and depression [9].

Quality of life (QoL) 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 multiple sclerosis [10].

Quality of life (QoL) assessment has many apparent merits in multiple sclerosis outcome measurement. It can be used to measure incremental improvement rather than complete cure, considering a wide range of aspects of daily living and centered on the patient care [11]. The principle of self-care for patients complain from MS involves patient will become physically and mentally healthy as well as stay fit and uphold healthy lifestyle which includes exercise, cognitive health, eating well-balanced (healthy meals) and practicing good hygiene [12].

Self-care deficit are among the reasons leading to frequent hospitalizations of MS patients. Thus, self-care education has an important role since it will prevent frequent hospitalizations, reduce frustration and increase confidence in MS patients [13,14]. Education should focus on the patients' physical, emotional, psychological and social needs. Main goals of care, such as controlling the disease, improving personal performance and reducing complications [15].

Nurse can deliver multidimensional role for patient with MS such as providing information and education to patients about their condition at different stages of the disease, advising patients on relapse management, the management of symptoms such as; fatigue, incontinence and cognitive problems and other conditions associated with disease [16].

Nurses play a key role in patient education, helping patients and their families to better understand the disease process. Self-care can empower patients to feel more active in the management of their disease and therefore enhance their motivation to improve quality of life [17].

### **Significance of the study**

Multiple sclerosis (MS) is the second cause of disability among 20 to 40 year-old people which is the most active and productive period of human life with an increase in the incidence and prevalence especially among women. This disease causes a negative impact on long-term career and job prospects and relationships. This can lead to financial hardships, strained family relations and feelings of social isolation [18].

The MS causes wide range of symptoms and problems faced by patients with the disease, so a comprehensive care is required to provide the support needed for effective disease management to prevent or at least reduce the complications of the disease [19].

In **Egypt**, there are 120,000 case registered sufferers multiple sclerosis, who face a number of particular challenges. The condition can often be wrongly diagnosed and they're often unable to afford proper treatment or obtain the necessary medical, social, emotional or psychological support. Multiple sclerosis was found to be 14.1/100,000 of other neurological diseases [20].

### **Aim of the study**

This study aimed to determine the effect of self-care education program on quality of life of patients with multiple sclerosis. This aim was achieved through:

1. Assessing patient's knowledge regarding multiple sclerosis
2. Designing and implementing a self-care education program to improve QOL in patient with multiple sclerosis
3. Evaluating the effect of self-care education program on QOL in patient with multiple sclerosis

### **Research Hypotheses**

**H1:** Self-care education program will improve patients' knowledge regarding multiple sclerosis in post-program than pre-program.

**H2** Self-care education program will improve patients' quality of life regarding multiple sclerosis in post-program than pre-program.

### **Subjects and Methods**

**Design:** A quasi-experimental research design was utilized in this study to achieve the desired aim.

#### **Setting:**

The study was conducted at the Outpatient Neuromedicine Clinic in Bab Elshaeria University Hospital affiliated to El-Azhar University, Cairo Governorate Egypt.

#### **Sampling**

A purposive sample of 80 patients, diagnosed with multiple sclerosis was selected under the following criteria:

**Inclusion criteria include:-**

- Patient age ranges from 20 to 50 years from both sexes
- Able to communicate
- Patient who is willing to participate in the study

**Exclusion criteria**

- Having any psychological and mental disease.
- Unconscious patient

**Sample size:** the sample size was calculated using the following formula:

$$n = [(Z_{\alpha/2} + Z_{\beta})^2 \times \{2(SD)^2\}] / (\text{mean difference between the two groups})^2$$

Where:

SD = standard deviation

$Z_{\alpha/2}$ : This depends on level of significance, for 5% this is 1.96

$Z_{\beta}$ : This depends on power, for 80% this is 0.84

Therefore,

$$n = [(1.96 + 0.84)^2 \times \{2(16.92)^2\}] / (7.2)^2 = 80.$$

Based on the above formula, the sample size required is 80.

**Tools of Data Collection:**

**Tool I: A Structured designed interviewing questionnaire:**

Designed by the researchers after reviewing previous and recent available related literatures, it was written in simple Arabic language to collect the required data and includes the following:

**Part one:** Demographic characteristics of studied patient which includes age, gender, marital status, level of education, occupation and monthly income.

**Part two:** Knowledge of studied patient about multiple sclerosis. It consisted of 10 closed-ended questions to assess the knowledge about multiple sclerosis which includes: meaning, signs and symptoms, causes, risk factors, high risk group, complications, diagnostic test for MS, importance of nutrition for MS, types of exercise should be practiced and management of MS.

**Scoring system for knowledge:**

Knowledge obtained from the studied patient was checked with a model key answer. For each closed-ended question a score of “one” was given for a correct answer and score of “zero” was given for an incorrect answer.

The total score was converted into percentage and interpreted as follows:

- Poor knowledge (< 50%) scored from 0-4
- Fair knowledge (50-75%) scored from 5-7.
- Good knowledge (>75%) scored from 8-10).

**Tool II: Multiple sclerosis quality of life (MSQOL-54 instrument:** Including 54 questions in three main

sections of the questionnaire, these were physical, mental health of quality of life, and overall quality of life. Adapted from **Giordano(21)** the questionnaire was translated to simple Arabic language by the researchers.

There are 12 subscales, which include: Physical health consists of 10 questions, role limitation due to physical problems consists of 4 questions; role limitations due to psychological reasons consists of 3 questions; pain: consists of 3 questions, emotional well-being consists of 5 questions, energy consists of 8 questions, health perception consists of 7 questions, social function consists of 3 questions, cognitive function consists of 2 questions, health distress consists of 2 questions, sexual function and satisfaction with sexual function consist of 3 questions and overall quality of life consists of 4 questions. The total score of quality of life equals 100 scores. The total score was converted into percentage and interpreted as follows:

- Low quality of life (< 50%)
- Moderate quality of life (50-75%)
- Good quality of life (>75%).

**Data collection procedure:**

- Data were collected during a period of 6 months starting from the beginning of July 2018 to the beginning of January 2019

- **Approval:** The present study was carried out after an official letter was issued from the Dean of the Faculty of Nursing, Helwan University and delivered to the Director of the previously mentioned setting, Bab elshaeria university hospital, in order to obtain their approval for conduction of the research after explaining its purpose.

- Reviewing the available literature related to disease of multiple sclerosis and quality of life domains and self-care education for multiple sclerosis patients covering various aspects of the research problems using books, articles, magazines and internet search to develop the study tools for data collection.

**Ethical considerations:**

An explanation of the aim of the study was given to patients before their enrollment in the study. An informed oral consent was obtained. Each study subject was individually interviewed using the previously mentioned study tools. They were assured that all the collected data will be used for research purpose only. Participants' anonymity, confidentiality, privacy, safety and protection were secured.

**Validity & reliability of tools:**

The study tools were tested for validity by a panel of 5 experts in Adult and Community Health Nursing. Modifications were done accordingly to ascertain relevance and completeness.

The researchers assessed reliability of the study tools, the patient's knowledge tool, and multiple sclerosis quality of life tool were tested using Cronbach's Alpha these were 0.893 and 0.917 respectively.

**Pilot study:**

A pilot study was carried out on 10% (8 patients) of study sample to test tools for clarity, applicability and to determine the time required for filling in the tools. Data obtained from the pilot study were analyzed and the necessary modifications and rearrangements on the study tools were done. Patients who participated in the pilot study were excluded from the main study sample

**Field work:**

The researcher was available in the previously mentioned setting two days/week (Sundays&Thursdays) from 9.00 a.m. to 12.00 noon from the beginning of July 2018 to the beginning of January 2019. The researchers met each patient individually, introduced themselves and explained the purpose of the study. They implemented the program in a waiting area at the Outpatient Clinic of the Neuromedicine .

**Construction of self-care education program:**

The study was achieved through four phases, assessment, planning, implementation and evaluation.

**Assessment phase:**

In this phase, each patient recruited in the study sample was interviewed by the researchers using sociodemographic questionnaire and knowledge assessment tool about multiple sclerosis disease.

**Planning phase:**

The self-care education program for patients with multiple sclerosis was developed based on the finding of the assessment and in the light of related literatures. The self-care education program was designed to improve the quality of life of patients with multiple sclerosis. Knowledge regarding multiple sclerosis disease included meaning, signs and symptoms, risk factors, high risk group, complications, different methods of diagnostic test importance of nutrients, types of exercise should be practiced and management of multiple sclerosis.

**Implementation phase:**

During this phase, the researchers implemented the self-care education program sessions for patients with multiple sclerosis. Simple questions regarding multiple sclerosis and its causes, self-care skills in mobility, skills in reducing physical symptoms "fatigue" and improving nutrition, skills in reducing emotional and psychological symptoms were answered. In addition on education pamphlet on all physical, emotional, psychological and social aspects of multiple sclerosis was distributed. The self-care education program was implemented over 6 months. The total number of patients with multiple sclerosis was 80 patients, divided into 5 groups; each group consisted of 16 patients, the study groups attended 4 sessions for theory and 2 sessions for practices. The duration of each session ranged between 30-45 minutes. At the beginning of each session, the researchers started by giving summary about the previous session and explaining the objective of the new one. Different teaching strategies were used including instructions, lectures, brain storming and demonstration, using illustrative media such as: computer, video, pictures. The sessions included the following:

**Session 1:** This session includes clarification of the aim of the study and presentation of the time table designed for self-care education. The researchers applied brain storming about multiple sclerosis disease, by providing general introduction about disease, definition, signs and symptoms, causes and diagnostic methods.

**Session 2:** it started by a revision of first session, after that an explanation of the complications and management of multiple sclerosis was given stressing on self-care aspects for those patients.

**Session 3:** This session includes physical self-care education that explains healthy diet, suitable exercise, period of rest and sleep, improved physical activity, decreased muscle weakness, staying away from stressful technology and self-care skills related to fatigue.

**Session 4:** This session includes mental self-care education that explains steps to reduce stress, identify reassuring activities, spiritual self-care items, and emotional self-care items and reviewing the contents of previous sessions and answering the questions of the participants.

#### **Evaluation phase:**

Evaluation of the self-care-education program for patients with multiple sclerosis was done immediately after the self-care-education implementation through using the same tools of pre-test as post-test.

#### **Statistical Design**

All statistical analyses were performed using the Statistical Package for Social Sciences (SPSS) for windows, version 20.0 (SPSS, Chicago, IL). Continuous data were normally distributed and were expressed in mean  $\pm$  standard deviation (SD). Categorical data were expressed in number and percentage. The comparisons were determined using independent sample Student's t-test for variables with continuous data. Chi-square test was used for comparison of variables with categorical data. Statistical significance was set at  $p < 0.05$ .

## **II. Results**

**Table (1)** displays demographic characteristics of the study sample. It shows that 46.2% of studied sample, their age ranged between 30-<40 years with a mean  $33.5 \pm 8.2$ . Regarding gender, 58.7% were female and 60% of them were married. Concerning level of education, 45.0% of them had secondary education, and 47.5% of the sample was employed. In relation to monthly income, for 45.0% of the patients under study, it was insufficient.

**Table (2)** presents the studied sample knowledge related to multiple sclerosis at pre/post self education program. It demonstrates that, highly statistically significant improvements were found in knowledge of the studied sample between pre/post self-care education program at all items ( $p < 0.001$ )

**Figure (1)** shows the total knowledge level scores of the studied sample at pre/post program it illustrates that 67.5% of studied sample had poor level knowledge scores about multiple sclerosis at pre self-care training, which improved to be good level for 88.7% of studied sample at post self-care education program ( $\chi^2 = 111.281$ ,  $p < 0.001$ )

**Table (3)** It reveals statistically significant differences between physical domain items of quality of life of studied sample at pre/post self-care education as regards improvements in the following areas: physical health, health perception, energy, problems in working due to physical reasons, pain, sexual activities, social activities, health distress, and overall physical health at ( $p < 0.001$ ).

**Table(4)** shows statistically significant differences detected between mental domain items of quality of life of the studied sample at pre/post self-care education program as regards improvements in the following areas: changes in mental health, reduced problems in working due to psychological reasons, emotional well-being, emotional role limitation, cognitive activities and overall mental health ( $p < 0.001$ ).

**Figure (2)** illustrates that there are statistically significant differences between total QOL scores at pre and post self-care training program, where only 12.5 % of studied sample had good level of QOL scores at pre test compared to 62.5% had good level of QOL scores at post self-care education program ( $\chi^2 = 64.444$ ,  $p < 0.001$ ).

**Table (5)** indicates that, there are statistically significant associations between total knowledge score and QOL score levels at pre self-care education program ( $\chi^2 = 81.754$  at  $p < 0.001$ ).

**Table (6)** shows that there are statistically significant associations between total knowledge score and QOL score level ( $p < 0.001$ ) post self-care education. It also indicates that 70.4% had good QOL score ( $\chi^2 = 71.197$  at  $p < 0.001$ ).

**Table (7):** indicates that there were statistically significant relationships between demographic characteristics as age, gender and level of education at post educational program and total knowledge level scores, where  $P = 0.018$ ,  $0.039$  and  $0.003$  respectively. Regarding patients' age, more than half (52.1%) of the sample who had good knowledge their age ranged between 30-<40 years. Concerning gender, less than two thirds (63.4%) who had good knowledge were female, As for educational level, approximately half (49.3%) of the sample who had good knowledge were secondary educated, while pre education there were statistically significant relationships between demographic characteristics as gender and level of education as p-values were  $P = 0.022$  and  $< 0.001$  respectively.

**Table (8)** reveals that there were statistically significant relationship between demographic characteristics and total QOL score post education program regarding age, gender, level of education and monthly income as p-values were  $P = 0.025$ ,  $< 0.001$ ,  $< 0.001$  and  $< 0.001$  respectively. Concerning patients' age, more than half (54%)

of the sample who had good level of quality of life their age ranged between 30-<40 years. Regarding gender, approximately three quarter (74%) who had good level of quality of life were female. Concerning educational level, more than half (58%) of the sample who had good level of quality of life were secondary educated, and in relation to monthly income, more than half (52%) of the sample who had good level of quality of life had sufficient monthly income. While at pre education, there were statistically significant relationships between demographic characteristics as age, level of education and monthly income and total quality of life scores as p-value was <0.001.

**Table 1.** Demographic Characteristic of Studied Subjects (n=80)

Variables	No	%
<b>Age (years)</b>		
20 – <30	25	31.2
30 – <40	37	46.2
40 – 50	18	22.6
Mean ±SD	33.5±8.2	
<b>Gender</b>		
Female	47	58.7
Male	33	41.3
<b>Marital status</b>		
Single	8	10.0
Married	48	60.0
Divorced	17	21.3
Widowed	7	8.7
<b>Level of education</b>		
Illiterate	9	11.3
Read/write	10	12.5
Basic education	15	18.7
Secondary education	36	45.0
University	10	12.5
<b>Occupation</b>		
Employed	38	47.5
Housewife	20	25.0
Dealer	10	12.5
Handicraftsman	12	15.0
<b>Monthly income</b>		
Insufficient	36	45.0
Sufficient	29	36.3
Sufficient and save	15	18.7

**Table 2.** Knowledge of Studied Sample at Pre and Post Self-Care Education Program (n=80)

Items of knowledge	Pre- education		Post-education		$\chi^2$	P
	No	%	No	%		
<b>Meaning of multiple sclerosis</b>						
Incorrect	45	56.3	15	18.7	24.000	<0.001*
Correct	35	43.7	65	81.3		
<b>Signs and symptoms</b>						
Incorrect	57	71.3	19	23.7	36.190	<0.001*
Correct	23	28.7	61	76.3		
<b>Causes</b>						
Incorrect	52	65.0	26	32.5	16.911	<0.001*
Correct	28	35.0	54	67.5		
<b>Risk factors</b>						
Incorrect	52	65.0	16	20.0	33.146	<0.001*
Correct	28	35.0	64	80.0		
<b>High risk group for MS</b>						
Incorrect	49	61.3	24	30.0	15.746	<0.001*
Correct	31	38.7	56	70.0		
<b>Complications</b>						
Incorrect	55	68.8	29	36.3	16.942	<0.001*
Correct	25	31.3	51	63.7		
<b>Diagnostic test for MS</b>						
Incorrect	53	66.3	31	38.7	12.130	<0.001*
Correct	27	33.8	49	61.3		
<b>Importance of nutrients for MS</b>						
Incorrect	50	62.5	28	35.0	12.108	<0.001*
Correct	30	37.5	52	65.0		
<b>Types of exercise should be practiced by MS patient</b>						
Incorrect	52	65.0	25	31.3	18.251	<0.001*

Correct	28	35.0	55	68.7		
<b>Management of MS</b>						
Incorrect	44	55.0	21	26.3	19.318	<0.001*
Correct	36	45.0	59	37.7		

\*Significant (P<0.05)

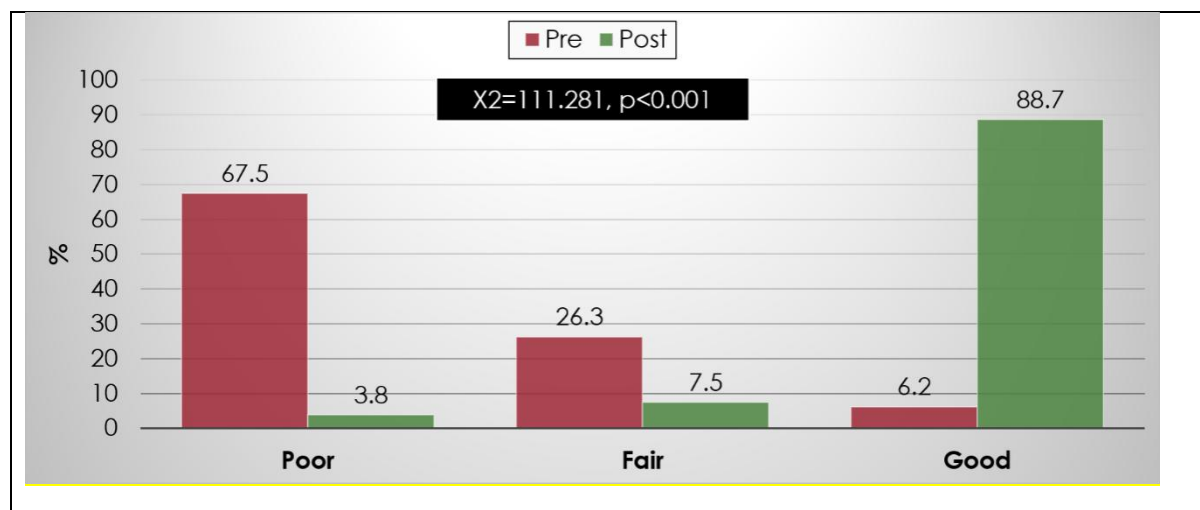


Figure 1. Total Knowledge Level Scores of Studied Sample at Pre and Post Self -Care Education Program

Table 3. Comparison Between the Physical Domain of Quality of Life Among the Studied Sample at Pre and Post Self-Care Education Program (n=80)

Physical domain of quality of life	Pre-education	Post education	Mean difference	t	p
	Mean ± SD	Mean ± SD			
Physical health	10.3 ±4.2	11.8±4.0	1.48	2.262	0.025 *
Health perception	10.3 ±2.3	11.6 ±2.1	1.26	3.678	<0.001*
Energy	8.1 ±2.4	9.1 ±2.4	1.04	2.707	0.008 *
Problems in working due to physical reasons	7.4 ±3.0	6.3 ±3.2	1.10	2.223	0.028 *
Pain	6.6 ±2.5	8.1 ±2.4	1.51	3.893	<0.001*
Sexual activities	1.3 ±1.2	1.7 ±1.1	0.40	2.263	0.025 *
Social activities	5.8 ±3.4	6.9 ±3.1	1.09	2.131	0.035*
Health distress	6.9 ±2.0	8.2 ±2.0	1.23	3.869	<0.001*
Overall physical health	55.6 ±8.2	64.7±7.3	9.10	7.443	<0.001*

\*Significant (P<0.05)

Table 4. Comparison Between the Mental Domain of Quality of Life among Studied Sample at Pre and Post- Self-Care Education Program (n=80)

Mental domain of quality of life	Pre- education	Post- education	Mean difference	t	p
	Mean ± SD	Mean ± SD			
Changes in mental health	8.9 ±1.4	10.3 ±1.4	1.35	6.095	<0.001*
Problems in working due to psychological reasons	9.6 ±3.5	11.4 ±3.6	1.83	3.253	<0.001*
Emotional well-being	15.3 ±5.9	17.5 ±6.1	2.21	2.350	0.020*
Role limitation	9.1 ±6.2	11.9 ±6.0	2.80	2.905	0.004*
Cognitive activities	9.8 ±3.7	11.0 ±3.7	1.26	2.147	0.033*
Overall mental health	52.7 ±9.0	62.1 ±9.5	9.45	6.439	<0.001*

\*Significant (P<0.05)

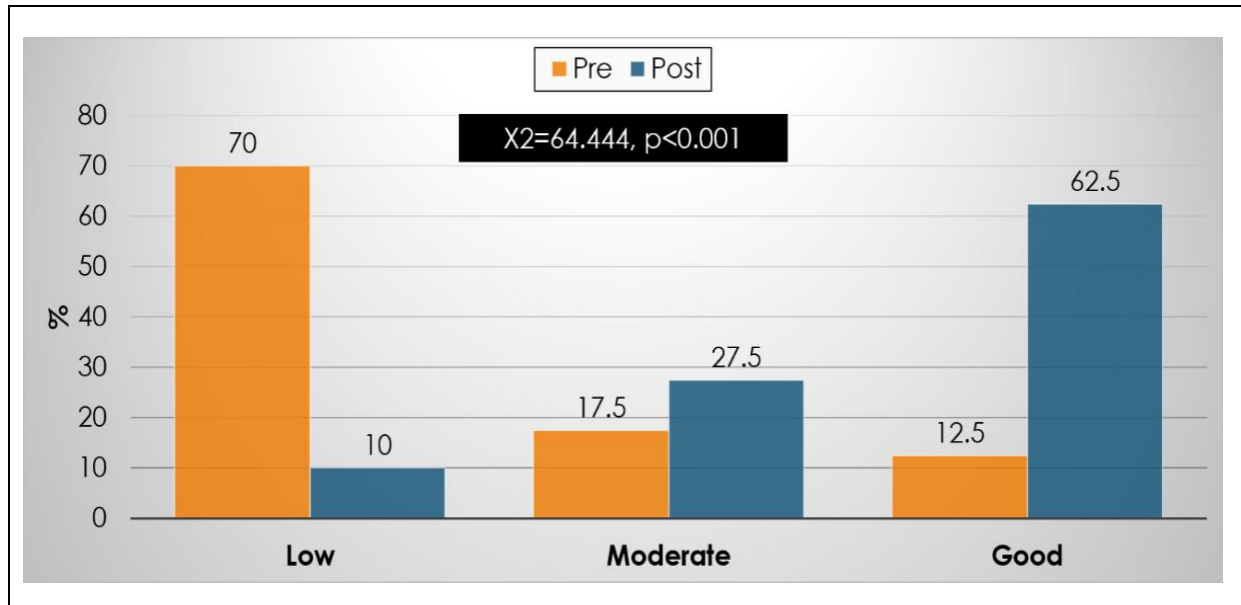


Figure 2. Total QOL Scores of Studied Sample Pre/Post Self-Care Education Program

Table 5. Associations between Total Knowledge Scores and Total QOL Scores at Pre Self-Care Education Program (n=80)

Total QOL scores at post-education	Total knowledge scores pre- education						X <sup>2</sup>	p
	Poor (no=54)		Fair (no =21)		Good (no =5)			
	No	%	No	%	No	%		
Low	50	92.6	6	28.6	0	0.0	81.754	<0.001*
Moderate	4	7.4	10	47.6	0	0.0		
Good	0	0.0	5	23.8	5	100.0		

\*Significant (P<0.05)

6. Associations between Total Knowledge Scores and Total QOL Scores at Post Self-Care Education Program (n=80)

Total QOL scores at post-training	Total knowledge scores post-education						X <sup>2</sup>	p
	Poor (no=3)		Fair (no=6)		Good (no=71)			
	No	%	No	%	No	%		
low	3	100.0	5	83.3	0	0.0	71.197	<0.001*
Moderate	0	0.0	1	16.7	21	29.6		
Good	0	0.0	0	0.0	50	70.4		

\*Significant (P < 0.05)



**Table 7.** Relationships Between Selected Demographic Characteristics of Studied Subjects and Total Knowledge Scores at Pre/Post-Education Program (n=80)

Variables	Pre-education						Post-education						X <sup>2</sup>	p		
	Poor (no=54)		Fair (no=21)		Good (no=5)		Poor (no=3)		Fair (no=6)		Good (no=71)					
	No	%	No	%	No	%	No	%	No	%	No	%				
<b>Age (years)</b>																
20-<30	15	27.8	9	42.9	1	20.0			2	66.7	2	33.3	21	29.6		
30-<40	27	50.0	9	42.9	1	20.0			0	0.0	0	0.0	37	52.1		
40-50	12	22.2	3	14.2	3	60.0	6.034	0.197	1	33.3	4	66.7	13	18.3	11.879	0.018*
<b>Gender</b>																
Female	34	63.0	8	38.1	5	100.0			0	0.0	2	33.3	45	63.4		
Male	20	37.0	13	61.9	0	0.0	7.603	0.022*	3	100.0	4	66.7	26	36.6	6.500	0.039*
<b>Level of education</b>																
Illiterate	9	16.7	0	0.0	0	0.0			2	66.7	1	16.7	4	5.6		
Read/write	8	14.8	2	9.5	0	0.0			0	0.0	1	16.7	9	12.7		
Basic	12	22.2	3	14.3	0	0.0			1	33.3	1	16.7	13	18.3		
Secondary	24	44.4	11	52.4	1	20.0			0	0.0	3	50.0	35	49.3		
University	1	1.9	5	23.8	4	80.0	33.071	<0.001*	0	0.0	0	0.0	10	14.1	22.989	0.003*

\*Significant (P<0.05)

**Table 8.** Relationships Between Selected Demographic Characteristics of Studied Subjects and Total QOL Scores at Pre/Post- Education Program (n=80)

Variables	Pre-education						Post-education						X <sup>2</sup>	p		
	Low (no=56)		Moderate (no=14)		Good (No=10)		Low (no=8)		Moderate (no=22)		Good (no=50)					
	No	%	No	%	No	%	No	%	No	%	No	%				
<b>Age (years)</b>																
20-<30	21	37.5	3	29.1	1	10.0			3	37.5	7	31.8	15	30.0		
30-<40	28	50.0	0	43.6	9	90.0			0	0.0	10	45.5	27	54.0		
40-50	7	12.5	11	27.3	0	0.0	37.663	<0.001	5	62.5	5	22.7	8	16.0	11.108	0.025*
<b>Gender</b>																
Female	34	60.7	8	57.1	5	50.0			0	0.0	10	45.5	37	74.0		
Male	22	39.3	6	42.9	5	50.0	0.420	0.811	8	100.0	12	54.5	13	26.0	17.797	<0.001*
<b>Level of education</b>																
Illiterate	9	16.1	0	0.0	0	0.0			4	50.0	3	13.6	2	4.0		
Read/write	9	16.1	1	7.1	0	0.0			2	25.0	5	22.7	3	6.0		
Basic	13	23.2	2	14.3	0	0.0			1	12.5	7	31.8	7	14.0		
Secondary	25	44.6	10	71.4	2	20.0			1	12.5	6	27.3	29	58.0		
University	0	0.0	2	14.3	8	80.0	55.914	<0.001	0	0.0	1	4.5	9	18.0	29.044	<0.001*
<b>Monthly income</b>																
Insufficient	34	60.7	1	7.1	1	10.0			7	87.5	19	86.4	10	20.0		
Sufficient	21	37.5	6	42.9	2	20.0			1	12.5	2	9.1	26	52.0		
Sufficient and save	1	1.8	7	50.0	7	70.0	41.070	<0.001	0	0.0	1	4.5	14	28.0	33.812	<0.001*

Significant (P<0.05)

### III. Discussion

Multiple sclerosis (MS) is a complex neurological disease with a far-reaching impact on patients and families throughout a lifetime with the disease. It has physical, emotional, financial and psychosocial implications throughout its course [22].

Concerning demographic characteristics of studied sample, the present study results revealed that slightly more than two fifths of the studied sample were in the age group of 30-<40 years with a mean of  $33.5 \pm 8.2$ , more than half of the sample are female, three fifths of sample were married, less than half had secondary education, were employed and had insufficient monthly income (**Table 1**). These results are to some extent similar to those of **Ashjazadeh et al., [23], in Iran**, whose study entitled "Assessment of health-related quality of life in patients with multiple sclerosis living in the Fars Province of Iran", reported that 80% of sample were women and 20% were men with a mean age of  $35.1 \pm 9.5$  years, 68% of the patients were married, 37% of the patients were employed, 30% of the patients had completed primary school, 46.3% of the patients had completed secondary school and 57% of sample had insufficient income. These findings may be due to that this disease is common in young adults and more often affecting women than men.

Regarding knowledge of studied sample, the present study result showed highly statistically significant improvements in all items of knowledge at post self-care education program. As well, this study showed statistically significant improvements among the studied sample concerning total knowledge scores, the results revealed that more than two thirds had poor knowledge scores at pre-education, while at post-education, the majority of them had good knowledge scores (**Table 2 & Figure 1**). This result is congruent with that of **Köpke et al. [24], in Germany**, who studied "Patient education program to enhance decision autonomy in multiple sclerosis relapse management", they found improvement in knowledge after implementation of an education program to the study when compared to the control group. This result was in the same line with that of a study done by **Dahmardeh et al. [25] in Iran** who studied "Effect of Orem-based self-care education program on disease-related problems in patients with multiple sclerosis", which stated that the program had its impact on improving the level of knowledge about multiple sclerosis among the intervention group than the control group. This may be related to the implementation of self-care education program that was effective for acquiring the study sample with knowledge about multiple sclerosis.

Concerning the physical domain of quality of life among the studied sample at pre and post self-care education program, the present study result revealed that statistically significant differences were detected between the domain of physical quality of life of the studied sample at pre/post self-care education program as regards improvement in the following areas: physical health, health perception, energy, the ability to reduce problems in working due to physical reasons, pain, sexual activities, social activities, health distress which improved at post-education program in all cases resulting in an overall physical health improvement ( $p < 0.001$ ) (**Table 3**). These results agree with those of **Montel and Bungener [26], in France** who studied "Coping and quality of life in one hundred and thirty five subjects with multiple sclerosis" and reported that, a significant difference in overall physical health after training ( $p = 0.002$ ). Similarly, this result is in accordance with that of the study conducted by **Tworck et al. [27], in Germany** entitled "chronical illness and maternity: Life conditions, quality of life and coping in women with multiple sclerosis" and reported that the values of health perception before and after the training showed statistically improvement which can indicate, that the training was effective on improving health perception and effective on physical health improvement ( $p = 0.003$ ). As well, these results were in agreement with those of **Sutherland et al. [28] in Australia** who studied "Relaxation and health related quality of life in multiple sclerosis", which revealed that most of the study group improved in overall physical health than control group. This may be related to self-care education program that was an effective method on improving the overall physical health.

Regarding comparison of the mental domain of quality of life among the studied sample at pre and post self-care education program, the present study finding revealed that, statistically significant differences were found between domain of mental quality of life of the studied sample at pre/post self-care education program as regards improvement in the following areas: changes in mental health, reduction of problems in working due to psychological reasons, emotional well-being, role limitation, cognitive activities and overall mental health ( $p < 0.001$ ) (**Table 4**). These results agree with those of **Montel and Bungener [26]**, who found improvement in cognitive functions and overall emotional and psychological health. These results are similar to those of **Lufei et al. [29], in USA** who studied "A home-based comprehensive care model in patients with multiple sclerosis". This study used a randomized controlled design to evaluate providing care during 24-months and quality of life. They concluded that home-based comprehensive care program helped in improving overall quality of life in mental aspect more than physical aspect and reduce complications related to disease. These results are in agreement with those of **Kidd [30], in USA**, who studied "A systematic review of the effectiveness of self-management interventions in people with multiple sclerosis at improving depression, anxiety and quality of life" and stated that, significant improvement in mental composite QOL items was the most common outcome and the physical composite QOL items to a lesser degree. As well, this study results are congruent with those of the

study of **Sahebalzamani et al.[5], in USA**, who studied "The effects of self-care training on quality of life in patients with multiple sclerosis" and found that, there were significant differences in values of mental health before and after training. This may be due to that the patients became knowledgeable about the importance of self-care and its impact on mental quality of life.

In relation to total quality of life scores, this study results revealed that a statistically significant difference was detected between pre and post of self-care education program regarding total QOL scores (**Figure2**). This study finding is in accordance with that of the study of **Rashvand et al. [15], in Iran**, who studied "Educational, psycho mental and socio economical needs of an Iranian Cohort with multiple sclerosis". They found that self-care training was effective on physical, emotional and psychological domains of quality of life in patients with MS. Similarly, these results are consistent with those of **Dahmardeh et al.[25], in Iran**, which indicated effectiveness of self-care training on all aspects of quality of life.

The current study result revealed a statistically significant association between total knowledge scores and total QOL scores at pre and post self-care education program **Tables (6&7)**. This result agree with that of the study of **Miller et al. [31], in USA**, whose study entitled "Web-based self-management for patients with multiple sclerosis: A practical, randomized trial. " Which mentioned the impact of SMI (self-management intervention) on QOL in people with MS and reported significant improvement in QOL over time in the study group than the control group. In a similar study **Samgelaji et al. [32], in Tehran**, studied "The effect of rehabilitation on quality of life of people with MS", and noticed that there is a significant difference between the pre-post test mean scores regarding quality of life. This may be due to the positive effect of self-care education program on all aspects of quality of life for patients with multiple sclerosis.

Additionally, the current study results showed statistically significant relationships between selected demographic characteristics as; age, gender and level of education and total knowledge score at post self-care education program. Regarding to patients' age, more than half of the study sample who had good knowledge were in the age group between 30-<40 years. This study finding is similar to that of the study of **Algahtani et al. [33], in Riyadh** who studied "Quality of life among multiple sclerosis patients in Saudi Arabia", Which stated that, older patients with a progressive and long-term disease had poor knowledge compared to younger patients. This indicates that younger patients gain knowledge faster than older ones.

Regarding to gender, the current study result revealed that less than two third who had good knowledge were female, this study result agree with that of the study of **McCullagh et al. [34] in, Ireland**, who studied "Information and long-term benefits of exercising on quality of life and fatigue in multiple sclerosis patients with mild disability: A pilot study" and mentioned that, significant difference was found between gender as females had good level of knowledge than males .This may be due to that more half of study sample were female patients, also it refers to that the females are more interested in their health than males.

Concerning the educational level, approximately half of the study sample who had good knowledge were secondary educated, this finding agrees with that of the study of **Samgelaji et al. [32], in Tehran**, who stated that both physical and mental health components of QoL showed a positive correlation with the educational level and employment status. The current study result may be due to that the highest percentage of the study sample had secondary education which allows them to better follow instructions related to their disease than illiterate patients

Similarly, the current study results revealed statistically significant relationships between selected demographic characteristics as age, gender, level of education and monthly income post self-care education, and total QOL score. Regarding to patients' age, more than half of the study sample who had good level of QOL their age ranged between 30-< 40 years, have secondary education and have sufficient monthly income. This study results agree with those of the study of **Fernández et al., [35], in France**, who studied " Patient characteristics and determinants of quality of life in an international population with multiple sclerosis: Assessment using the MusiQoL and SF-36 questionnaires", which stated that, significant differences were found with the gender, age, education level and occupation in QoL level among their study sample. This may be due to that the younger age, patients was the greater their responses and the greater their motivation than older age patients. The higher the level of education, of patients the greater their interest in self-care, so the quality of life improved.

#### **IV. Conclusion**

Self-care education program had improved knowledge and quality of life among patients with multiple sclerosis.

#### **V. Recommendations**

- Regular follow-up should be carried out for reducing or preventing complications among patients with multiple sclerosis.
- Counseling to enhance strategies of coping with multiple sclerosis.
- Further research on a larger sample and in other settings is needed using a multidisciplinary approach.

## References

- [1]. **Fauci, A.S., Eugene, B., Hauser, S.L., Longo, D.L., Loscalzo, J.L., & Harrison, S. (2015):** Principles of internal medicine. (17th ed.) New York: McGraw-Hill; pp. 375–7.
- [2]. **Smeltzer, S.C. (2014):** Textbook of medical-surgical nursing. (9th ed.). Philadelphia: Lippincott Williams & Wilkins;
- [3]. **Madan, S., & Pakenham, K. I. (2014):** The stress-buffering effects of hope on adjustment to multiple sclerosis. *International Journal of Behavioral Medicine*; 21(6):877-90.
- [4]. **Chruzander, C. (2014):** A ten year follow up of people with multiple sclerosis- aspects of disability and health, use of and satisfaction with care and feasibility of cognitive behavioral therapy. *Karolina Institute, Stockholm. J Neurol Sci.*; 332:121–127.
- [5]. **Sahebalzamani, M., Zamiri, M., & Rashvand, F. (2016):** The effects of self care training on quality of life in patients with multiple sclerosis. *Iranian Journal of Nursing and Midwifery Research*; 17(1): 7-11.
- [6]. **Omran, S., Mirzaei, B., Aghabagheri, H., Hassanzadeh, R., & Abedini, M. (2015):** Effectuality of cognitive-behavioral therapy on the life expectancy of patients with multiple sclerosis. *Journal of Mazandaran University of Medical Sciences* 2; 22(93): 58- 65. [Persian]
- [7]. **Hamidizadeh, S., Masoodi, R., Ahmadi, F., Mohammadi E. (2016):** Evaluation of the effect of self- care program based on the Orem framework on the physical quality of life in multiple sclerosis patients. *The Journal of Shahid Sadoughi University of Medical Sciences*; 17(2): 153-62. [Persian]
- [8]. **Lauer, K. (2015):** Risk factors for multiple sclerosis. *Expert Review of Neurotherapeutics, New Engl. J Med*; 343:938-952.
- [9]. **Kister, I., Bacon, T.E., Chamot, E., Salter, A.R., Cutter, G.R, Kalina, J.T. (2014):** Natural history of multiple sclerosis symptoms and complications *International Journal of MS Care*; 15(3): 146-56.
- [10]. **Al-Tahan, A.M., Al-Jumah, M.A., & Bohlega, S.G., (2014):** The importance of quality-of-life assessment in the management of patients with multiple sclerosis. Recommendations from the Middle East MS Advisory Group. *Neurosciences (Riyadh)*; 16:109-13.
- [11]. **Moore, F., Vickrey, B., Fortin, K., & Lee, L. (2015):** Two multiple sclerosis quality-of-life measures: comparison in a national sample. *Can J Neurol Sci*; 42(1):55–63.
- [12]. **Baumann, L.C., & Dang, T.T.N: (2013) :** Helping patients with chronic conditions overcome barriers to self-care. *The Nurse Practitioner*; 37(3):32-38.
- [13]. **McGuinness, S.D., & Peters, S. (2014):** The diagnosis of multiple sclerosis: Peplau's Interpersonal Relations Model in practice. *Rehabil Nurs*; 24(1):30–3. [PubMed]
- [14]. **Sutherland, M., & Rashvand, F. (2015):** The study of training demands of patients afflicted with MS, members to Iran's MS Society and presenting a proper training model for these patients. *Medical Science Journal of Islamic Azad University Tehran Medical Branch*; 18(3):195–200.
- [15]. **Rashvand, F., Aliloo, L., Sahebalzamani, M., & Rahmani, A. (2016):** Educational, psycho mental and socio economical needs of an Iranian cohort with multiple sclerosis. *Oman Medical Journal*; 25(1):22–5. [PMC free article] [PubMed]
- [16]. **Corry, M., McKenna, M., & Duggan, M., (2015):** The role of the clinical nurse specialist in MS: A literature review. *British Journal of Nursing*; 20(2): 86-93.
- [17]. **Halper, J., & Holland, N. (2015):** An overview of multiple sclerosis. *Comprehensive Nursing Care in Multiple Sclerosis. (2nd ed.)* .New York, NY: Demos Medical Publishing.
- [18]. **Al-Shimmery, E.K. & Bzaini A.S. (2013):** Multiple sclerosis in Jordan and Iraq. *Clinical and social overview. Neurosciences (Riyadh)*; 13: 276–282.
- [19]. **Khodaveisi, M., Ashtarani, F., Mohammadi, N., Beikmoradi, A., Mahjub, H., & Mazdeh, M., (2014):** The effect of continuous care on quality of life in multiple sclerosis patients. *Scientific Journal of Hamadan Nursing & Midwifery Faculty*; 22:64-73.
- [20]. **Hashem, S., El-Tamawy, M., & Hamdy, S. (2017):** Epidemiology of multiple sclerosis in Egypt. *Egypt J Neurol Psychiat Neurosurg*; 47(4):625–632.
- [21]. **Giordano, A., Uccelli, M., Pucci, E., Martinelli, V., Borreani, C., Lugaresi, A., Trojano, M., Granella, F., Confalonieri, P., Radice, D., & Solari, A. (2010).** The multiple sclerosis quality of life questionnaire: Multiple Sclerosis Quality of Life (MSQOL)-54 Instrument, 16(1): 100-111.
- [22]. **Ross, A.P. (2015):** The evolution of disease management: Advanced concepts in multiple sclerosis nursing, (2<sup>nd</sup> Ed.) New York: Demos Medical Publishing; pp.53–68.
- [23]. **Ashjzadeh, N., Hadianfard, H., Feridoni, S., & Farjam, E. (2016):** Assessment of health-related quality of life in patients with multiple sclerosis living in the Fars Province of Iran. *Neuro immuno InNeuroinflammation*; 3:57-62.
- [24]. **Köpke, S.J., Kasper, A., Flachenecker, P., Meißner, H.A., Brandt, M.B., Hauptmann, B., Bender, G., Backhus, A., Rahn, A., Pöttgen, J., Vettorazzi, E., & Heesen, N. (2017):** Patient education program to enhance decision autonomy in multiple sclerosis relapse management, University Medical Center, Hamburg-Eppendorf, Hamburg, Germany, *Clinical Rehabilitation*; 31(2): 250–261.
- [25]. **Dahmardeh, H., Kianian, T., & Vagharseyyedin, S.A. (2017):** Effect of Orem-based self-care education program on disease-related problems in patients with multiple sclerosis, Zahedan University of Medical Sciences, Zahedan, Iran, *Medical-Surgical Nursing Journal*; 6(1): 14-20. <https://neoscriber.org/cdn/.../1622ad4a-1a12-11e8-a33e-6f0925cad8...>
- [26]. **Montel, S.R., & Bungener, C. (2013):** Coping and quality of life in one hundred and thirty five subjects with multiple sclerosis. *Neuropsychology, University of Paris Descartes, Paris, France: Mult Scler*; 13(3): 393-401.
- [27]. **Tworok, S., Wirtz, M., Schipper, S., Klewer, J., Bergmann, A., & Kugler, J., (2014):** Chronical illness and maternity: Life conditions, quality of life and coping in women with multiple sclerosis. *Qual Life Res Dresden, Germany*, 16(10): 1587-94.
- [28]. **Sutherland, G., Andersen, M.B., & Morris, T. (2014):** Relaxation and health related quality of life in multiple sclerosis: The example of autogenic training. *J Behav Med*; 28 (3): 249-56.
- [29]. **Lufei, K.H., Charlton, M., Schmid, K., Zabad, R., & Wester, R. (2015):** "A home-based comprehensive care model in patients with multiple sclerosis. *Journal of Nursing, University of Nebraska Medical Center, USA*; 18 (2): 1–11.
- [30]. **Kidd, T., Carey, N., Mold, F., Westwood, S., Miklaucich, M., Konstantara, E., Sterr, A., & Cooke, D. (2017):** A systematic review of the effectiveness of self-management interventions in people with multiple sclerosis at improving depression, anxiety and quality of life. *National Center for Biotechnology Information, U.S. National Library of Medicine PLoS One*; 12(10): e0185931.
- [31]. **Miller, D.M., Moore, S.M., Fox, R.J., Atreja, A., Fu, A.Z., & Lee, J.C., et al. (2011):** Web-based self-management for patients with multiple sclerosis: A practical, randomized trial. *Telemedicine and e-Health. USA*, ;17(1):5–13. doi: 10.1089 /tmj .2 0 10.0133 [PMC free article] [PubMed]
- [32]. **Samgelaji, B., HatamiZadeh, N., Rashvand, F., & KazemNejad, A. (2014):** The effect of rehabilitation on quality of life of people with MS. *Journal of Nursing & Midwifery, ShahidBeheshti , Tehran, University of Medical Sciences and Health Services*; 20(71): 36-41.

- [33]. **Algahtani, H.A., Shirah,B.H., Alzahrani,F.A., Abobaker, H.A. , Algha naim ,N.A., and Manlangit, J.S. ( 2017):** Quality of life among multiple sclerosis patients in Saudi Arabia. *Neurosciences (Riyadh)*. Oct; 22(4): 261.[https:// www. ncbi. nlm. nih. Gov /pmc /article s / PM C5946374/](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5946374/)
- [34]. **McCullagh, R., Fitzgerald, A.P., Murphy, R.P., & Cooke, G. (2016):** Information and long-term benefits of exercising on quality of life and fatigue in multiple sclerosis patients with mild disability: A pilot study. *Clin Rehabil* Trinity College Dublin, St James' Site, Dublin, Ireland; 22: 206–214.
- [35]. **Fernández, O., & Baumstarck- Barrau,K., Simeoni, M.C., &Auquier, P. (2017):** Patient characteristics and determinants of quality of life in an international population with multiple sclerosis: Assessment using the Musi QoL and SF-36 questionnaires, France, *Multiple Sclerosis Journal*: 17 (10): 1238-1249. First Published May 16. Research Article [https:// doi. org/ 10.11 77/ 135 24 5 8 5 1140795](https://doi.org/10.1177/135245851140795) [https:// www .ncbi.nlm.nih.gov/pubmed/21669936](https://www.ncbi.nlm.nih.gov/pubmed/21669936) *Multiple Sclerosis Journal*

Badria Abd Elshahed Ahmed El-Kattan. " Effects of Self-Care Education Program on Quality of Life of Patients with Multiple Sclerosis" .IOSR Journal of Nursing and Health Science (IOSR-JNHS), vol. 8, no.03 , 2019, pp. 76-88.