Effect of Educational Guideline on Self-Management and Clinical Outcomes for Patients with Multiple Sclerosis

Ahmed Mohamed Abozeid[1], Ola Abd Elaty Ahmed[2], Jackleen Faheem Gendy[3], Arzak Mohamed khalifa[4].

Assistant lecturer [1], Professor [2], Assistant professor[3], [4]Assistant professor of Medical Surgical Nursing, Faculty of Nursing, Ain Shams University, Egypt.

Abstract

Background: Multiple sclerosis (MS) is a chronic progressive degenerative disease that affects the myelin sheath of the neurons in the central nervous system. Self-management is essential for people with MS because it helps them improve their prognosis by learning about the different elements of the condition and regularly monitoring their health with their caregivers. **The study was aimed** to evaluate the effect of educational guideline on self-management and clinical outcomes for patients with MS. **Study design**: A quasi-experimental design was utilized to conduct this study. **Setting**: This study was conducted at Multiple Sclerosis Outpatient Clinic affiliated to Ain Shams University Hospital, Egypt. **Sample**: A purposive sample of 80 adult patients were selected based on inclusion criteria. **Tools of data collection**: An interview questionnaire to assess patient's demographic characteristics and patient's clinical data. Patients' knowledge assessment. Multiple Sclerosis Self-Management Scale. Clinical Outcomes Assessment Questionnaire. **Results**: The mean age of the studied patients was 36.75 ± 5.63; females were more prevalent and constituted 68.8% of the studied patients. Also, 88.8% and 87.5% of them had satisfactory level of total knowledge and total self-management practices post implementation of educational guideline, respectively. Moreover, there was a significant reduction in impact of fatigue, pain, visual impairment and psychological distress among the studied patients post implementation of educational guideline. Furthermore, there was a significant improvement in patients' bladder, bowel control, sexual activity and satisfaction post implementation of educational guideline. **Conclusion**: The implementation of educational guideline has a statistically significant positive effect on self-management and clinical outcomes for patients with MS. **Recommendations:** Self-management guideline should be included in the routine nursing care and rehabilitation process for patients with MS and should be updated periodically in order to enhance their knowledge and self-management practices. Establishment of Web site under medical and nursing supervision to provide information about the disease.

Keywords: Multiple sclerosis, Self-Management, Clinical outcomes, and Educational guideline.

Introduction:

Multiple sclerosis (MS) is a progressive disease in which scattered patches of the protective myelin covering the nerve fibers in the brain and spinal cord are damaged or destroyed. MS is also a chronic disease of the central nervous system (CNS) characterized by inflammation and the loss of myelin sheath surrounding the axon **(Janice & Hinkle, 2018).**

Multiple sclerosis is the third most common neurological diagnosis cited as the cause of disability and it affect young adults. The estimated number of people with MS worldwide has increased to 2.8 million in 2020. The 2020 global prevalence is 35.9 per 100,000 people. Females are twice as likely to have MS as males. However, the ratio of women to men is as high as 4:1 in some countries. Although all races are affected, MS is primarily a disease of people of northern European ancestry **(Walton et al., 2020).**

The course of MS is varied widely and characterized by uncertain; unpredictable relapsing and remitting episodes; and often interferes with activities of daily living. People with MS typically develop symptoms in their late 20 years experiencing fatigue, pain, visual and sensory disturbances, limb

weakness, gait problems, bladder and bowel symptoms. Disability, moving limits, low personal activity-related self-effectiveness and limitation of self-regulatory concepts **(Farran et al., 2021).**

Multiple sclerosis has a high prevalence of clinically significant symptoms, with estimated rates of 29–86% for pain **(Aboud & Schuster, 2019)** and 80% for fatigue **(Capone et al., 2020).** Patients' daily living activities are significantly impacted by these symptoms. Patients with MS report that pain affects their ability to sleep, work and enjoy leisure activities. Fatigue which many people describe as their most incapacitating symptom, relates to difficulties associated with physical or intellectual function and reduces social participation **(Valentine et al., 2022).**

Bladder and bowel dysfunction are very common in patients with MS and in some patients can be present early in the course of disease. As disease progresses, impairment of elimination is a problem for the majority of patients with MS **(Sakakibara, 2019).** The reported incidence of bladder voiding dysfunction in people with MS ranges between 30% and 50%, and appears to be related to disease disability status **(Al Dandan et al., 2020).** Among patients with MS, faecal incontinence affects 24% to 66% and constipation is reported at 24 to 40% **(Preziosi et al., 2018).** Sexual dysfunction (SD) is a significant, but often underestimated, symptom of MS. Prevalence ranges from 50 to 90% in men and 40 to 80% in women, depending on the severity of disability and duration of their illness **(Drulovic et al., 2020).**

Visual impairment is the first symptom of MS for many patients. The sudden onset of double vision, eye pain or blurring can be terrifying, and the knowledge that vision may be compromised makes people with MS anxious about the future. **(Dobson & Giovannoni, 2019).** Individuals and families may experience intense feelings of loss in the face of changes brought about by the disease, anxiety about the unpredictable future, and tension and resentment about changes over which they feel little if any

control. Although stress doesn't cause the disease, it can worsen the symptoms of MS; stress can precipitate the onset of the disease or trigger exacerbations. Almost everyone with MS can cite some emotionally stressful event that took place just before an attack **(Santos et al., 2019).**

A self-management is a key strategy for improving the physical, psychological health and quality of life in patients with chronic conditions through positive health and rehabilitation outcomes. Moreover, effective self-management maximizing clinical outcomes and minimizing health care costs and utilization **(Shawli et al., 2019).**

Health care professionals should focus on empowering patients with skills and knowledge that helps patients to achieve optimal MS management. Lifestyle modifications and self-management are essential to manage symptoms, so nurses have a valuable role providing knowledge and support to patients transitioning to independent self-management **(Ghahari et al., 2019).**

Similar to many other chronic conditions in patients with MS, self-management skills can improve the quality of patients' lives. Through patient education and coordination of specialty care, specifically physical therapy and occupational therapy, this quality improvement initiative aimed to improve self-management skills in patients with MS **(Castro, 2021).**

Nurses play an important role in monitoring clinical outcomes in terms of relapses and disease progression, and are therefore well position to advise patients on the risks that they may face as a result of no adherence. This construct comprises outcomes from the patient perspective **(Cohan et al., 2018).**

Significance of the study:

Multiple sclerosis produces profound effects on patients 'physical, social, and psychological well-being, which are form vital segments of health-related self-management and may be exacerbated by disease uncertainty. In Egypt, there were

about 50,000 patients in Egypt diagnosed with MS **(Ibrahim et al., 2016).** More than 500 Patients with MS come to Multiple Sclerosis Unit at Ain Shams University hospitals (**Essawy et al., 2020).**

Patients with MS experience a high level of fatigue, pain, bowel and bladder dysfunction, sexual dysfunction and stress caused by the disease and treatment processes. Dealing with patients using more beneficial practices and coping styles can effectively improve the general health status and reduce the side effects of MS, and its treatment, so educational guideline is important for improving self-management especially in patients with MS as building knowledge, treatment adherence, emotional health and social support and health maintenance behavior (**Faraji et al., 2018**).

Operational definitions

Self-management has been broadly defined as learning and practicing the skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition. Self-management for patients with MS including that, healthcare provider-patient relationship, treatment adherence, emotional health and social support, communication about symptoms/changes, health and symptom awareness and health maintenance behavior.

Clinical outcomes are the impacts of disease and treatment on the lives of patients. Clinical outcomes for patients with MS including that, patients' fatigue level, pain, bowel and bladder control, sexual satisfaction, impact of visual impairment level and mental level on MS patients.

Aim of the Study

The study was aimed to evaluate the effect of educational guideline on self-management and clinical outcomes for patients with multiple sclerosis through the following:

1. Assessing patients' self-management regarding multiple sclerosis pre implementation of educational guideline.

2. Assessing patients' clinical outcomes regarding multiple sclerosis pre implementation of educational guideline.

3. Developing and implementing educational guideline based on patients' assessment.

4. Evaluating the effect of educational guideline on self- management and clinical outcomes for patients with multiple sclerosis post implementation of educational guideline.

Research Hypotheses

The study hypothesized that:

1- Implementation of educational guideline will improve self-management for patients with multiple sclerosis.

2- Implementation of educational guideline will improve clinical outcomes for patients with multiple sclerosis.

Subject and methods:
Research design:

One group quasi‑ experimental research with pre‑ test post‑ test design.

Study Setting:

The study was conducted at Multiple Sclerosis Outpatient Clinic at Ain Shams University Hospital affiliated to Ain Shams University; Egypt. The working days were five days weekly according hospital policy (from Saturday to Wednesday) from 8:30 am to 1pm. About 15-20 patients visit the clinic daily. The Multiple Sclerosis Outpatient Clinic presents in the second floor and consisted of one room with one bed.

Subjects

A purposive sample of 80 patients who visited the Multiple Sclerosis Outpatient Clinic at the time of data collection. The calculation of sample size done based on power analysis. As about 500 patients in the year 2019 visited the previous mentioned setting (**Essawy et al., 2020).**

The sample size was calculated based on:

$$\frac{N \times p\,(1-p)}{\{N-1 \times (d^2 \div z^2)\} + p\,(1-P)\}}$$

- Type I error with significant level (α) = 0.05.
- Type II error by power test (1-B) = 95%.

The minimum sample were 80 cases (**Suresh & Chandrashekara, 2012**).

Inclusion criteria:

The subjects included in the present study were selected according to the following criteria:

1- Adult patients 18 ≤ 65 years old.
2- Both genders (male and female).
3- Patients with different educational level and able to comprehend instructions.
4- Patients who were in clinical remission or after 3 weeks of acute relapse, to avoid the effect of steroids given for treatment of acute relapse, on mood.
5- Patients who didn't receive any educational guideline about self-management and agreed to participate in the study.

Exclusion criteria:

1- Patients with history of head trauma or central nervous system disorders other than MS, to avoid overlapping of these disorders with the effect of MS lesion.
2- Having drug addiction.
3- Patients with psychiatric disorders.

Tools of data collection:

Four tools were used for data collection:

Tool I: Patients' interviewing questionnaire

This tool was developed by the researcher in Arabic language based on reviewing the related literatures (**Linton, 2015; Potter et al., 2016; Lewis et al., 2016; Debska et al., 2020; McGinley et al., 2021**). It included two parts to assess patients' demographic characteristics and clinical data as the following:

Part (1): Patients' demographic characteristics assessment:

This part was used to assess demographic characteristics of patients under study. It consisted of eight questions regarding age, gender, marital status, level of education, working status, residence, living condition and monthly income.

Part (2): Patients clinical data assessment:

This part concerned with assessment of patients' clinical data. It included:

- **Present history**: It consisted of four closed ended questions regarding time of diagnosis, type of MS, history of relapse and signs of MS.

- **Past history**: It consisted of three closed ended questions regarding chronic diseases, previous hospitalization and surgical history.

- **Family history**: It consisted of one closed ended question regarding family history of MS.

- **Smoking history**: It consisted of two closed ended questions regarding time of starting smoking and passive smoking.

Tool II: Patients' knowledge assessment tool:

This tool was developed by the researcher in Arabic language based on reviewing the related literatures (**Lewis et al., 2016; Hinkle & Cheever, 2017; Timby & Simth, 2017; DeLaune et al., 2019; Linton & Matteson, 2019**). It was used to assess patients' knowledge about MS and written in the form of (yes or no). It was composed of 44 questions grouped under 8 sections.

❖ Scoring system for patients' knowledge:

Patients' answers were compared with model key answers. Each question was assigned a score (1) given when the answer was correct and a score (zero) was given when the answer was incorrect; the total score of each section was calculated by summation of the scores of its items. The total knowledge score was calculated by the addition of the total score of all sections and ranged from (0-44). The mean and standard deviation was calculated. These scores were summed and converted into a percent score and classified into 2 levels as the following:

- Satisfactory level of knowledge considered at score ≥ 70% (31-44 grades).
- Unsatisfactory level of knowledge considered at score <70% (0-30 grades).

Tool III: Multiple Sclerosis Self-Management Scale (MSSM-S):

It was adapted from **Bishop and Frain, (2007)** and translated into Arabic language then back translation was done. It was used to assess patients' self-management regarding MS. It composed of 95 statements grouped under 6 subscales.

❖ **Scoring system for self-management scale:**

The response of each statement was judged according to three-point Likert scale continuum from never (1), sometimes (2), and always (3); the total score of each subscale was calculated by summation of the scores of its statements. The total score of self-management practices was calculated by the addition of the total score of all subscales and ranged from (95-285 grades). The mean and standard deviation was calculated. These scores were summed and converted into a percent score and classified into 2 levels as the following:

▪ Satisfactory level of self-management practices considered at score ≥ 70% (≥ 200 grades).
▪ Unsatisfactory level of self-management practices considered at score <70% (<200 grades).

Tool IV : Clinical Outcomes Assessment Questionnaire :

It was concerned with assessment of patients' clinical outcomes. It was translated into Arabic language and back translation was done and included the following:

A- Modified Fatigue Impact Scale (MFIS): It was adapted from **Mills et al., (2010)** and was used to assess the impact of fatigue on physical, cognitive, and psychosocial functions for patients with MS in the past four weeks. It composed of 21 statements grouped under 3 subscales that included: physical subscale (9 statements), cognitive subscale (10 statements) and psychosocial subscale (2 statements).

❖ **Scoring system:**

The response of each statement was judged according to three-point Likert scale continuum from never (1), sometimes (2), and always (3); the total score of each subscale was calculated by summation of the scores of its items. The total score of fatigue impact scale was calculated by the addition of the total score of all subscales and ranged from (21-63 grades). The mean and standard deviation was calculated. Higher total scores indicated a greater impact of fatigue on the patient's physical, cognitive, and psychosocial functions.

B- Pain Effects Scale (PES): It was adapted from **Ferreira-Valente et al., (2011)** and was used to assess the pain level and its effect on patients' mood and behavior in the last four weeks. Six statements were used to assess the effects of pain on mood and behavior such as mood, ability to walk or move around, sleep, normal work both outside home and at home, recreational activities and enjoyment of life.

❖ **Scoring system:**

The response of each item was judged according to three-point Likert scale continuum from never (1), sometimes (2), and always (3). The total score of pain effects scale ranged from (6-18). The mean and standard deviation was calculated. Higher total scores indicated a greater impact of pain on a patient's mood and behaviour.

C- Bladder Control Scale (BLCS): It was adapted from **Marrie and Goldman, (2007)** and was used to assess the bladder control level for patients with MS in the last four weeks. It was composed of 4 statements.

❖ **Scoring system:**

The response of first 3 statements were judged according to five-point Likert scale continuum ranged from not at all (0), once (1), two to four times (2), more than weekly but not daily (3) to daily (4); The 4th statement was judged according to Likert scale ranged from not at all (0) to severely (10). The total score of bladder control scale was ranged from (0-22 grades). The mean and standard deviation was calculated. Higher total scores indicated poor bladder control.

D- Bowel Control Scale (BWCS): It was adapted from **Marrie and Goldman,**

(2007) and was used to assess the bowel control level for patients with MS in the last four weeks. It was composed of 5 items.

❖ **Scoring system:**

The response of first 4 statements were judged according to five-point Likert scale continuum ranged from not at all (0), once (1), two to four times (2), more than weekly but not daily (3) to daily (4); The 5th statement was judged according to Likert scale ranged from not at all (0) to severely (10). The total score of bowel control scale was ranged from (0-26 grades). The mean and standard deviation was calculated. Higher total scores indicated poor bowel control.

E- The Multiple Sclerosis Intimacy and Sexuality Questionnaire (**MSISQ**): It was adapted from **Monti et al., (2020).** The MSISQ is a self- report questionnaire composed of 15 statements to evaluate the sexual activity and satisfaction in the last four weeks.

❖ **Scoring system:**

The response of each statement was judged according to three-point Likert scale continuum from never (1), sometimes (2), and always (3). The total score of MSISQ ranged from (15-45 grades). The mean and standard deviation was calculated. Higher total scores indicated poor level of sexual activity and satisfaction.

F- Impact of Visual Impairment Scale (IVIS): It was adapted from **Pawar et al., (2010)** and was used to assess the impact of visual impairment level on patients with MS in the last four weeks. It was composed of 28 statements grouped under 3 subscales that included: reading and accessing information subscale (9 statements), mobility and independence subscale (11 statements) and emotional well-being subscale (8 statements).

❖ **Scoring system:**

The response of each statement was judged according to three-point Likert scale continuum from never (1), sometimes (2), and always (3); the total score of each subscale was calculated by summation of the scores of its items. The total score of visual impairment scale was calculated by the addition of the total score of all subscales and ranged from (28-84 grades). The mean and standard deviation was calculated. The mean and standard deviation was calculated. Higher total scores indicated high impact of visual impairment on reading, accessing information, mobility, independence and emotional well-being.

G- Mental Health Inventory (MHI): It was adapted from **Meybodi et al., (2011).** It was used to assess psychological distress for patients with MS in the last four weeks. It was composed of 18 statements as feel depressed felt, emotionally stable and able to relax without difficulty…etc.

❖ **Scoring system:**

The response of each statement was judged according to three-point Likert scale continuum from never (1), sometimes (2), and always (3) for negative statements, while items number 1, 3, 5, 7, 8, 10, 13, and 15 were positive statements in which never (3), sometimes (2), and always (1). The total score of mental health scale was calculated by the addition of the total score of all subscales and ranged from (18-54 grades). The mean and standard deviation was calculated. The mean and standard deviation was calculated. Higher total scores indicated high level of psychological distress.

Educational guideline construction

It was designed by the researcher based on recent related literatures **(Timby & Simth, 2017; Linton & Matteson, 2019; Dobson, & Giovannoni, 2019; Bowen, 2021; Chintamani, & Mani, 2021).** The contents were prepared according to patients' level of understanding in simple, organized and scientific Arabic language.

The booklet composed of three chapters: First chapter aimed to provide information to patients with MS about nature, causes, risk factors, types, symptoms, diagnose and the different ways to treat the disease. Second chapter aimed to provide self-management guideline for patients with MS to relieve fatigue, pain, bowel and bladder problems, sexuality, visual impairment and psychological stress. Also, this chapter

provide information to patients about proper healthy nutrition, taking medications, follow-up, improving mental health, dealing with social, family and occupational problems and improving spirituality. Third chapter aimed to train the patients on hand washing, aerobic exercises, pelvic exercises and progressive relaxation exercises.

Validity and Reliability

Validity of the study tools

Tools of data collection were investigated for their content validity by panel of five experts 4 professors from Medical Surgical Nursing department at the Faculty of Nursing, Ain Shams University, and one assistant professor from Neurology department at the Faculty of Medicine, Ain Shams University, who are selected to test content validity of the tools and to judge its clarity, relevance, comprehensiveness, understanding and applicability. The opinion was elicited regarding the layout, format and sequence of the questions and all of their remarks were taken into consideration and the tools were regarded as a valid from the experts' point of view.

Reliability of the study tools

Reliability of tools was applied by the researcher for testing the internal consistency of the tools by administrating of the same tool to the same subjects under similar condition. Internal consistency reliability of all items of the tools was assessed using Cronbach's alpha coefficient. It was (0.951) for Patients' Knowledge Assessment Tool, (0.984) for Multiple Sclerosis Self-Management Scale, (0.959) for Modified Fatigue Impact Scale, (0.937) for Pain Effects Scale, (0.791) for Bladder Control Scale, (0.727) for Bowel Control Scale, (0.955) for The Multiple Sclerosis Intimacy and Sexuality Questionnaire, (0.969) for Impact of Visual Impairment Scale and (0.967) for Mental Health Inventory.

Ethical Considerations

The ethical research considerations included the following:

- The research approval was obtained from the Faculty of Nursing Ethical Committee before starting the study.

- The researcher clarified the objectives and aim of the study to patients before obtaining their consent to participate in the study.
- The researcher assured maintaining anonymity and confidentiality of subjected data.
- Patients were informed that they are allowed to choose either to participate or withdraw from the study at any time.
- Values, cultures and benefits were respected.

Pilot Study

A pilot study was conducted on 10% (8) patients of the total sample. In order to test the applicability of the constructed tools and the clarity of the included questions. The pilot has also served to estimate the time needed for each subject to fill in the questions and to identify the problems that may be encountered during the study. All participants in the pilot study were included into the sample.

Fieldwork

The collection of data and application of educational guideline lasted over a period of nine months; starting at September 2021 up to the end of June 2022, through the following phases:

Assessment Phase

Assessment phase involved interview with patients to collect baseline data. The researcher visited the Multiple Sclerosis Outpatient Clinic at Ain Shams University Hospital affiliated to Ain Shams University in Saturday, Sunday and Wednesday during morning shifts (9.00 am to 2.00 pm). The patients who fulfilled the inclusion criteria were selected. Number of patients taken every day was ranged from 3-5 patients.

At the beginning of interview; the researcher welcomed patients, explained the purpose, duration, activity of the study and take their oral approval to participate in the study prior to data collection. An individual interview was conducted for every patient to collect the necessary data using the tools of data collection. Filling the tools took about 60 minutes distributed as the following: patient's demographic characteristics clinical data took

about 5 minutes, patients' knowledge assessment tool took about 10 minutes, multiple sclerosis self-management scale took about 20 minutes and patients' clinical outcomes assessment took about 25 minutes.

Planning phase

All information collected through data collection tools were interpreted for identifying individualized teaching needs. The researcher set up teaching plan covering all objectives. These objectives were categorized into general and specific objectives. The guideline resources and facilities were allocated (printed material and location of session that best serve the patients). The researcher determined the time table of sessions, teaching methods, media used and learner's activities. After data collection, the appointment for starting guideline sessions was detected and scheduled with the patients for the following weeks.

Implementation phase

General and specific objectives of educational guideline were stated and implemented to satisfy the actual needs of the studied sample. The studied patients were 80 divided into 20 groups; each group consisted of 4 patients. The implementation phase was achieved through 10 sessions, covered in 10 hours approximately, (8 theoretical hours and 2 practical hours) at period of five days, 2 sessions / day, the time of each session was 60 minutes. The teaching sessions were conducted in the room at Multiple Sclerosis Outpatient Clinic. The rooms were conditioned, quiet, had adequate lighting, well ventilated and furnished, and had adequate spacing for the place for implementing educational guideline activities.

Different methods of teaching were used as modified lecture, group discussion, brain storming, group activities, demonstration, and redemonstration, suitable teaching media were included videos, real object, colored posters and handouts (booklet) to help proper understanding of the content by patients.

Evaluation phase:

The evaluation phase emphasized on determining the effect of the educational guideline on knowledge, self-management and clinical outcomes for patients with MS by comparing the results pre and post implementation of educational guideline using the previously mentioned tools. Concerning knowledge, self-management and clinical outcomes were assessed pre and one month after implementation of the educational guideline and comparing the collected data before and after application of educational guideline.

III. Administrative Design

An official approval was taken from the Dean of the Faculty of Nursing, Ain Shams University to the director of Ain Shams University hospital, affiliated to Ain Shams University. A clear explanation was given about the nature, importance and expected outcomes of the study to carry out the study with minimal resistance.

IV- Statistical Design:

The statistical analysis of data was done by using the computer software of Microsoft Excel Program and Statistical Package for Social Science (SPSS) version 25. Data were presented using descriptive statistics in the form of frequencies and percentage for categorical data, the mean (X) and standard deviation (SD) for quantitative data. Qualitative variables were compared using chi square test (X^2) and parried t test (t) was used to compare mean score, P-value to test association between two variables and Pearson correlation test (R- test) to the correlation between the study variables. Reliability of the study tools was done using Cronbach's Alpha.

Degrees of significance of results were considered as follows:

- P-value > 0.05 Not significant (NS)
- P-value < 0.05 Significant (S)
- P-value < 0.01 Highly Significant (HS).

Results:

Table (1): displays that, 60.0% of the studied patients their age ranged between 30-<40 years old, the mean ± SD of age was 36.75 ± 5.63 years. Also, 100.0% of them were married. Regarding educational level,

50.0% of them had secondary level of education. Moreover, 41.2% of the studied patients were employed, as 63.6% of them had work that required muscle effort. Furthermore, 63.7% and 100.0% of the studied patients live in urban areas and with their family, respectively. Meanwhile, 76.2% of them stated that their monthly income was insufficient to cover medical expenses.

Figure (1): shows that, 68.8% of the studied patients were female. While, 31.2% of them were female.

Table (2): presents that, 51.2% of the studied patients were diagnosed with MS from 5-10 years ago with mean ± SD 7.66 ± 3.50. Relapsing–remitting MS was more prevalent and constituted 81.3% of the studied patients. Also, 91.3% of the studied patients had previous relapses, as 67.1% of them had 1-3 relapses. Moreover, 97.5% of the studied patients suffered from fatigue, anxiety and stress.

Table (3): demonstrates that, there was a significant improvement in all subscales of patients' knowledge regarding MS post implementation of educational guideline compared to pre intervention phase with a highly statistically significant difference (P < 0.01). As evidence, 15.0% of the studied patients had satisfactory level of total knowledge regarding MS pre implementation of educational guideline which improved to 88.8% post intervention phase.

Table (4): shows that, there was a significant improvement in all items of patients' self-management practices regarding MS post implementation of educational guideline compared to pre intervention phase with a highly statistically significant difference (P < 0.01). As evidence, 18.7% of the studied patients had satisfactory level of total self-management practices regarding MS pre implementation of educational guideline which changed to 87.5% post intervention phase.

Table (5): reveals that, there was a statistically significant improvement in all items of patients' outcomes post implementation of educational guideline compared to pre intervention phase with a highly statistically significant difference (P < 0.01).

Table (6) illustrates that, there was a highly statistically positive correlation between total patients' self-management and total knowledge, total bladder control, total bowel control and total sexual activity and satisfaction pre and post implementation of educational guideline at (P= < 0.01). While, there was a highly statistically negative correlation between total patients' self-management and total impact of fatigue, total pain, total impact of visual impairment and total psychological distress pre and post implementation of educational guideline at (P= < 0.01).

Table (1): Frequency and percentage distribution of the studied patients regarding demographic data **(n=80).**

Items	No.	%
Age (years)		
20-< 30	10	12.5
30-< 40	48	60.0
≥ 40	22	27.5
Mean ± SD= 36.75 ± 5.63 **Max= 53** **Min=** 27 **Range=**26		
Marital status		
Married	80	100.0
Education level		
Illiterate	4	5.0
Read and write	19	23.8
Secondary education	40	50.0
High education	17	21.2
Occupation		
Employed	33	41.2
Unemployed	47	58.8
If the answer is employed, what is the nature of the work?? (n=33)		
Work that requires muscle effort	21	63.6
Office work	12	36.4
Residence		
Rural	29	36.3
Urban	51	63.7
Living pattern		
Live with family	80	100.0
Monthly income		
Sufficient for medical expenses	19	23.8
Insufficient for medical expenses	61	76.2
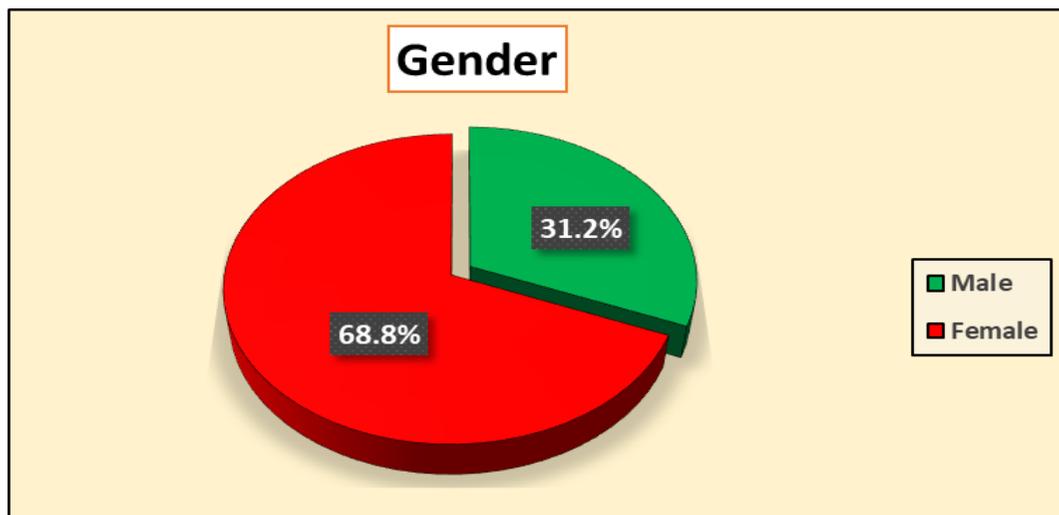
Figure (2): Percentage distribution of the studied patients according to their gender **(n = 80).**

Table (2): Frequency and percentage distribution of the studied patients regarding present history **(n=80).**

Items	No.	%
Duration of diagnosis with MS / Years		
<5	11	13.8
5-<10	41	51.2
≥ 10	28	35.0
Mean ± SD= 7.66 ± 3.50 **Max= 15** **Min= 3** **Range**=12		
Type of multiple sclerosis		
Relapsing–remitting MS	65	81.3
Secondary progressive MS	10	12.5
Primary progressive MS	3	3.7
Progressive relapsing MS	2	2.5
Previous relapses		
Yes	73	91.3
No	7	8.7
If the answer is yes, how often? (n=73)		
1-3 times	49	67.1
4-6 times	19	26.0
≥ 7 times	5	6.9
*Symptoms of multiple sclerosis		
Weakness of the extremities	56	70.0
Lack of coordination and balance	35	43.7
Fatigue when doing any simple work	78	97.5
Numbness, burning in the limbs, trunk or face	62	77.5
Pain in a limb, trunk or face.	71	88.8
Disturbance of vision	70	87.5
Partial or complete loss of vision	21	26.2
Urinary system impairment	76	95.0
Bowel dysfunction	72	90.0
Dizziness	36	45.0
Sexual problems	68	85.0
Anxiety and stress	78	97.5
Depression	8	10.0
Sleep disorders	62	77.5
Mood disorders	76	95.0
Memory problems	43	53.8
Concentrating problems	43	53.8

(*) Responses are not mutually exclusive

Table (3): Comparison between the studied patients regarding knowledge about multiple sclerosis pre and post implementation of educational guideline **(n=80).**

Items	Pre				Post				X²	P-value
	Satisfactory		Unsatisfactory		Satisfactory		Unsatisfactory			
	No.	%	No.	%	No.	%	No.	%		
Nature of MS	27	33.7	53	66.3	72	90.0	8	10.0	53.65	0.000**
Types of MS	6	7.5	74	92.5	66	82.5	14	17.5	90.90	0.000**
Causes and risk factors for MS	8	10.0	72	90.0	68	85.0	12	15.0	90.22	0.000**
Clinical manifestations of MS	33	41.2	47	58.8	75	93.8	5	6.2	50.25	0.000**
Complications of MS	10	12.5	70	87.5	66	82.5	14	17.5	78.59	0.000**
Diagnosis of MS	19	23.7	61	76.3	74	92.5	6	7.5	77.67	0.000**
Treatment of MS	11	13.7	69	86.3	69	86.3	11	13.7	84.10	0.000**
Total	**12**	**15.0**	**68**	**85.0**	**71**	**88.8**	**9**	**11.2**	**87.14**	**0.000**
Range	**8-41**				**20-44**					
Mean ± SD	**20.16 ± 7.95**				**39.55 ± 6.11**				**t=19.68**	**0.000**

t= Paired-t test.   **X²:** Chi Square Test. **(**) Highly statistically significant at p < 0.01.

Table (4): Comparison between the studied patients regarding total self-management practices regarding multiple sclerosis pre and post implementation of educational guideline **(n=80).**

Items	Pre intervention				Post intervention				X²	P-value
	Satisfactory		Unsatisfactory		Satisfactory		Unsatisfactory			
	No.	%	No.	%	No.	%	No.	%		
Fatigue	10	12.5	70	87.5	71	88.8	9	11.2	93.04	0.000**
Pain	18	22.5	62	77.5	72	90.0	8	10.0	74.05	0.000**
Bladder problems	19	23.7	61	76.3	72	90.0	8	10.0	71.57	0.000**
Diarrhea	15	18.7	65	81.3	70	87.5	10	12.5	75.92	0.000**
Constipation	18	22.5	62	77.5	70	87.5	10	12.5	65.85	0.000**
Sexual problems	16	20.0	64	80.0	69	86.3	11	13.7	70.50	0.000**
Vision problems	15	18.7	65	81.3	67	83.8	13	16.2	67.64	0.000**
Psychological distress	15	18.7	65	81.3	70	87.5	10	12.5	75.92	0.000**
Health and symptom awareness	13	16.2	67	83.8	69	86.3	11	13.7	78.44	0.000**
Health maintenance behavior	24	30.0	56	70.0	72	90.0	8	10.0	60.00	0.000**
Treatment adherence	37	46.3	43	53.7	76	95.0	4	5.0	45.82	0.000**
Communication about symptoms / changes	23	28.7	57	71.3	72	90.0	8	10.0	65.33	0.000**
Emotional health and social support	33	41.2	47	58.8	74	92.5	6	7.5	47.42	0.000**
Healthcare provider-patient Relation	18	22.5	62	77.5	67	83.8	13	16.2	60.26	0.000**
Total self-management practices	**15**	**18.7**	**65**	**81.3**	**70**	**87.5**	**10**	**12.5**	**65.11**	**0.000**
Range	**118-268**				**134-279**					
Mean ± SD	**169.62 ± 42.06**				**249.18 ± 36.28**				**t=15.36**	**0.000**

t= Paired-t test.   **X²:** Chi Square Test. **(**) Highly statistically significant at p < 0.01.

Table (5): Comparison between the mean ± SD of self-management practices regarding multiple sclerosis pre and post implementation of educational guideline **(n=80).**

Variables	No. of items	Pre Mean ± SD	Post Mean ± SD	t	p-value
Total impact of fatigue	21	46.33 ± 10.55	28.47 ± 9.24	13.05	0.000**
Total pain effects	6	14.44 ± 3.48	7.70 ± 3.02	14.13	0.000**
Total bladder control	4	12.97 ± 4.16	4.68 ± 5.24	12.41	0.000**
Total bowel control	5	14.45 ± 4.35	6.02 ± 5.89	12.15	0.000**
Total sexual activity and satisfaction	15	35.48 ± 8.13	19.96 ± 6.84	15.82	0.000**
Total impact of visual impairment	28	59.16 ± 12.78	37.40 ± 11.76	12.05	0.000**
Total psychological distress	18	41.06 ± 8.36	22.80 ± 7.70	15.16	0.000**

SD: Standard Deviation; **t**= Paired-t test; (******) Highly statistically significant at p < 0.01.

Table (6): Correlation between total patients' self-management, total knowledge and their clinical outcomes pre and post implementation of educational guideline **(n=80)**.

Variables		Total self-management	
		Pre	Post
Total knowledge	r	0.873	0.922
	p	0.000**	0.000**
Total impact of fatigue	r	-0.793	-0.892
	p	0.000**	0.000**
Total pain	r	-0.745	-0.887
	p	0.000**	0.000**
Total bladder control	r	0.671	0.788
	p	0.000**	0.000**
Total bowel control	r	0.795	0.739
	p	0.000**	0.000**
Total sexual activity and satisfaction	r	0.850	0.847
	p	0.000**	0.000**
Total impact of visual impairment	r	-0.815	-0.855
	p	0.000**	0.000**
Total psychological distress	r	-0.820	-0.815
	p	0.000**	0.000**

r= Pearson correlation test.   **P**= p-value.   (******) Highly statistically significant at p < 0.01.

Discussion

Multiple sclerosis is a potentially disabling chronic neurological disease affecting the brain and the spinal cord. MS has a great influence on health-related quality of life, and the patient's health status. There's no cure for MS. However, treatments can improve speed recovery from attacks, modify the progress of the disease and manage symptoms **(Saadat et al., 2020).**

Self-management strategies help maintain and promote health and reduce the adverse outcomes of the disease using mechanisms such as having a better understanding of the disease, acquiring the necessary knowledge, adhering to appropriate diet and nutrition, and increasing knowledge and development of patient skills. Self-management is associated with positive clinical and rehabilitation outcomes **(Wilski et al., 2020).**

Regarding demographic data, the current study revealed that, three fifth of the studied patients, their age ranged between 30-<40 years old, the mean age ± SD 36.75 ± 5.63 years. Also, females were more prevalent

and constituted more than two thirds of the studied patients This may be interpreted that this disease usually strikes young adults and usually affects women two to three times as often as men. These results are similar to **Saad and Elsayed, (2021)** who found that, more than half of studied patients ranged in age between 30<40 with mean age ± SD was 34.16±5.99 years. Also, **Ibrahim et al., (2018)** and **Momenabadi et al., (2019)** reported that, most of the studied sample were females. On the other hand, a study carried out by **Hersche et al., (2019)** revealed that, mean/median (range) of the studied patients age was 45/51 (32-56) years old.

The present study clarified that, all of the studied patients were married. Also, half of them had secondary education. In the same line, a study in Turkey performed by **Efendi et al., (2022)** demonstrated that, most of the participants were married. As well as, **Hemmatpoor et al., (2018)** reported that, less than two thirds of the studied participants had diploma. Conversely, **Hersche et al., (2019)** reported that, most of the studied sample had university education.

Also, the current study declared that, more than half of the studied patients were unemployed. While, slightly more than two fifth of the studied patients were employed, as nearly two thirds of them had work that, required muscle effort. Also, more than three quarters of them reported that, monthly income was insufficient to cover medical expenses. Similarly, a study conducted by **Abulaban et al., (2019)** explained that, less than half of studied patients were employed. As well as, **Seifi and Moghaddam, (2018)** found that, the income of more than half of respondents was insufficient.

Concerning residence, the present study illustrated that, nearly two thirds of the studied patients live in urban areas and all of them live with their family. These results are in accordance with a study done by **Plow et al., (2019)** who mentioned most of the studied patients live in urban areas with their family.

Regarding the present history, the current study displayed that, slightly more than half of the studied patients were diagnosed with MS from 5-10 years ago with mean ± SD 7.66 ± 3.50 and relapsing–remitting MS was more prevalent and constituted most of the studied patients. These results agree with **Wilski et al., (2021)** who reported that, the mean disease duration was 11 years, and the majority of participants had a relapsing–remitting course.

As well, the current study demonstrated that, most of the studied patients had previous relapses, as more than two thirds of them had 1-3 relapses. These results are consistent with **Marck et al., (2018)** who reported that, nearly three quarters of the studied patients had previous relapses.

Moreover, the current study demonstrated that, the most of the studied patients suffered from fatigue, anxiety and stress. This result may be due to the fact that MS symptoms flare-up and subside, combined with the unpredictability of symptoms, has made MS a difficult disease to be recognized, and treated. This result agrees with **Sadeghi et al., (2019)** who reported that, most of the studied patients suffered from fatigue and psychological problems.

According to total patient's knowledge about MS, there was a significant improvement in all subscales of patients' knowledge post implementation of educational guideline. As evidence, less than one fifth of them had satisfactory level of total knowledge regarding MS with mean ± SD 20.16 ± 7.95 pre implementation of educational guideline which improved to the majority of them with mean ± SD 39.55 ± 6.11 post intervention phase. This may be due to the low educational level at pre intervention phase and improvement at post intervention phase may be due to the use of simple language during educational sessions which can clearly understood by the study sample, enhancing their knowledge about MS.

This finding is congruent with a study conducted by **Tkáčová, (2020)** in Iran to determine the influence of self-care education on quality of life in MS patients, who showed that, after the intervention, the average score of total knowledge was significantly higher in

the intervention group than in the control group.

Concerning total self-management practices, the current study declared that, there was a significant improvement in all domains of patients' self-management practices regarding MS post implementation of educational guideline. As evidence, less than one fifth of them had satisfactory level of total self-management practices regarding MS with mean ± SD 169.6 ± 42.0 pre implementation of educational guideline which improved to the majority of them with mean ± SD 249.2 ± 36.3 post intervention phase. This can be interpreted as educational guideline will lead to improve the self-management performance of MS patients. So self-management education can be an effective intervention for improving the performance of patients with MS.

Similarly, **Azizi et al., (2020)** conducted a study entitled "Comparison of the Effects of Peer-led and Nurse-led Self-management Programs on Self-management of Patients with MS", and stated that, the total score of self-management and its dimensions significantly increased in the two groups post intervention. In the same line, **Nabil and Abd Elsatar, (2022)** highlighted the same findings.

Regarding the total impact of fatigue on patients' physical, cognitive and psychosocial functions, the current study represented that, there was a statistically significant reduction in the total impact of fatigue post implementation of educational guideline. As evidence, the mean ± SD score of total impact of fatigue was 46.33 ± 10.55 pre implementation of educational guideline which decreased to 28.47 ± 9.24 post intervention phase. This may be due to educational guideline that, can be an effective intervention for decrease the total impact of fatigue on physical, cognitive and psychosocial functions of patients with MS.

This result is congruent with **Hugos et al., (2019)** who stated that, mean scores of total impact level of fatigue decreased in both groups after program completion. Also, a study by **Alzaghmouri et al. (2021)** on 95 patients diagnosed with MS revealed that,

progressive relaxation techniques play an effective role in fatigue reduction.

In terms of pain level and its effect on patients' mood and behavior, the present study illustrated that, there was a statistically significant reduction in pain level and its effect on mood and behavior among the studied patients post implementation of educational guideline. As evidence, the mean ± SD score of total pain effects was 14.44 ± 3.48 pre implementation of educational guideline which decreased to 7.70 ± 3.02 post intervention phase. This can be interpreted as educational guideline learned self-management practices as progressive relaxation techniques and exercises that, help the patients to manage their pain and its impact. This result is congruent with **Hadoush et al., (2021)** who found that, the majority of non-pharmacological rehabilitation interventions showed therapeutic effects in reducing pain intensity in patients with MS.

Concerning patients' bladder control, the current study portrayed that, there was a significant improvement in bladder control among the studied patients post implementation of educational guideline. As evidence, the mean ± SD score of total bladder control was 12.97 ± 4.16 pre implementation of educational guideline which changed to 4.68 ± 5.24 post intervention phase. This may be related to educational guidelines that, educated pelvic "Kegel" exercise to the studied patients. This result agrees with **Yavas et al. (2022)** who reported that, significant improvements were observed in urinary incontinence in the groups that received pelvic floor muscle training.

As regard patients' bowel control, the present study reflected that, there was a significant improvement in bowel control among the studied patients post implementation of educational guideline. As evidence, the mean ± SD score of total bowel control was 14.45 ± 4.35 pre implementation of educational guideline which decreased to 6.02 ± 5.89 post intervention phase. This improvement could be attributed to that, most patients were committed with the guidelines. Additionally, the role of attending sessions

and the lecture and positive reinforcement or the long-term retention of knowledge, as well as wide verities of used educational used methods. This result agrees with a study in Romania carried out by **Axelerad et al., (2021)** who examined the relationship between the physical exercise and the symptoms of MS patients and reported that, bowel control of the studied patients improved after intervention.

Regarding patients' sexual activity and satisfaction, the current study clarified that, there was a significant improvement in patients' sexual activity and satisfaction post implementation of educational guideline. As evidence, the mean ± SD score of total sexual activity and satisfaction was 35.48 ± 8.13 pre implementation of educational guideline which changed to 19.96 ± 6.84 post intervention phase. This may be due pelvic "Kegel" exercise that, was included in the education guideline that, can be useful in improving sexual activity in patients with MS. These results are in harmony with **Ghafoori et al., (2022)** who conducted a study in Iran about effectiveness of sexual counseling using better model to promote sexual function and satisfaction of married women with MS and mentioned that, the sexual function and satisfaction for the women in the intervention group improved at 8 and 12 weeks after the counseling compared to the control group.

In the same line, **Ghasemi et al., (2022)** conducted a study in Iran to assess the effect of sexual health promotion package on sexual life in women with MS and asserted that, there was a significant increase in the quality of sexual life score in the intervention group compared to control group.

In relation to impact of visual impairment among the studied patients, the present study showed that, there was a statistically significant reduction in the impact of visual impairment post implementation of educational guideline. As evidence, the mean ± SD score of total impact of visual impairment was 41.06 ± 8.36 pre implementation of educational guideline which changed to 22.80 ± 7.70 post intervention phase. This result is supported by **Jones et al., (2022),** who carried out a study

in UK to describe the type of telerehabilitation services available to people with vision impairment and summarize evidence on health-related outcomes; they confirmed that, the effect of vision deterioration can be prevented after vision optimization training in patients with MS.

Regarding to psychological distress of the studied patients, the current study clarified that, there was a statistically significant reduction in patients' psychological distress post implementation of educational guideline. As evidence, the mean ± SD score of total sexual activity and satisfaction was 41.06 ± 8.36 pre implementation of educational guideline which decreased to 22.80 ± 7.70 post intervention phase. This may because of the education guideline that, has a significant effect on patients' psychological distress through stress management guideline.

These findings are in harmony with **Simpson et al., (2019)** who conducted a study in UK to evaluate the efficacy of mindfulness-based interventions for improving mental well-being in patients with MS and declared that, mindfulness-based interventions were effective at improving mental well-being in patients with MS. Likewise, **Senders et al., (2019)** who studied the impact of mindfulness-based stress reduction for people with MS at 8 weeks and 12 months in USA and reported that, there was a significant improvement in level of emotional well-being among the patients after both mindfulness-based stress reduction and education.

Pertaining to correlation between total patients' self-management, total knowledge and their clinical outcomes, the present study highlighted that, there was a highly statistically positive correlation between total patients' self-management and total knowledge, total bladder and bowel control and total sexual activity and satisfaction pre and post implementation of educational guideline. This can be explained as level of patients' self-management increase when their level of knowledge increased. Also, bladder and bowel control and sexual activity and satisfaction improved when their level of self-management improved and vice versa.

Supporting the study findings, **Azizi et al., (2020)** they found that, there was positive correlation between patients' self-management and knowledge. Besides, a study conducted by **Wills and Probst, (2022)** they informed that, there was positive correlation between patients' self-management and bladder and bowel control and sexual activity before and after intervention.

As well, the current study declared that, there was a highly statistically negative correlation between total patients' self-management and total impact of fatigue, total pain, total impact of visual impairment and total psychological distress pre and post implementation of educational guideline. This can be interpreted as when level of patients' self-management increases their level of fatigue, pain, impact of visual impairment and psychological distress decreased and vice versa.

In the same line, **Akbar et al., (2018)** who conducted a study in Canada to determine a self-directed fatigue management resource for individuals with MS, was worth further, more rigorous evaluation and mentioned that, there was negative correlation between patients' self-management and impact of fatigue. Also, **Demaneuf et al., (2019)** there was negative correlation between patients' self-management and pain level.

Similarly, a study carried out by **Russell et al., (2020)** they studied the effectiveness of emotional wellness programs on mental health outcomes for adults with MS in Australia and found that, the studied patients' psychological distress correlates negatively with their self- management pre and post intervention.

Conclusion:

Based on the findings of the current study, it is concluded that: there was a significant improvement in patients' knowledge and self-management practices regarding MS post implementation of educational guideline. Also, there was a significant reduction in impact of fatigue, pain, visual impairment and psychological distress among the studied patients post implementation of educational guideline.

Moreover, there was a significant improvement in patients' bladder, bowel control, sexual activity and satisfaction post implementation of educational guideline. Hence the aim of the study was achieved and research hypotheses were accepted.

Recommendations:

In the light of the findings of the current study the following recommendations for future research and practice can be suggested:

➢ Self-management guideline should be included in the routine nursing care and rehabilitation program for patients with MS and should be updated periodically in order to enhance their knowledge and self-management practices.

➢ Conducted educational programs that provide the latest information about self-management approach in relation to MS to support patients to manage their disease effectively.

➢ Establishment of Web site under medical and nursing supervision to provide information about the disease, places of treatment, and psycho-social support. In addition, helping individuals with MS and their families to access available resources.

Implication for Future Research

➢ Further research is needed on a larger probability sample at different settings to generalize the results.

References:

Aboud, T., & Schuster, N., (2019). Pain management in multiple sclerosis: a review of available treatment options. *Current Treatment Options in Neurology*, *21*(12), 1-15.

Abulaban, A., Altowairqi, A., Altowairqi, H., Almutairi, A., Altalhi, S., Alotaibi, F., & Alabbadi, I. (2019). Multiple sclerosis patients knowledge in Saudi Arabia. *Neurosciences Journal*, *24*(4), 327-331.

Akbar, N., Turpin, K., Petrin, J., Smyth, P., & Finlayson, M. (2018). A pilot mixed-methods evaluation of MS INFoRm: a self-directed fatigue management resource

for individuals with multiple sclerosis. *International Journal of Rehabilitation Research, 41*(2), 114-121.

Al Dandan, H., Coote, S., & McClurg, D. (2020). Prevalence of lower urinary tract symptoms in people with multiple sclerosis: a systematic review and meta-analysis. *International journal of MS care*, *22*(2), 91-99.

Alzaghmouri, A. H., Masa'Deh, R., Al Jaberi, M., Masadeh, O., Al Smadi, A., & Alshawabkeh, G. A. (2021). The effect of Benson relaxation technique on fatigue of patients diagnosed with multiple sclerosis. *Journal of Health Sciences*, *11*(3), 154-159.

Axelerad, A., Sanda, J., Stroe, A., Axelerad, S., & Axelerad, D. (2020). The role of physical exercise in multiple sclerosis. *Ovidius University Annals, Series Physical Education & Sport/Science, Movement & Health*, *20*(1).

Azizi, M., Zarei, B., Rahimi, H., Mousavi Mirzaei, S., Javan, N., & Vagharseyyedin, S. (2020). Comparison of the effects of peer-led and nurse-led self-management programs on self-management of patients with multiple sclerosis. *Scientific Journal of Nursing, Midwifery and Paramedical Faculty, 6*(1), 58-71.

Bishop, M., & Frain, M. (2007). Development and initial analysis of multiple sclerosis self-management scale. *International Journal of MS Care*, *9*(2), 35-42.

Castro, A. (2021). Patient-centered education and care coordination initiative to improve self-management skills in latinos with multiple sclerosis (Doctoral dissertation, Texas A&M University-Corpus Christi).

Capone, F., Collorone, S., Cortese, R., Di Lazzaro, V., & Moccia, M. (2020). Fatigue in multiple sclerosis: the role of thalamus. *Multiple Sclerosis Journal*, *26*(1), 6-16.

Chintamani, M., & Mani, M. (2021). *Lewis's Medical-Surgical Nursing, Fourth South Asia Edition-E-Book: Assessment and Management of Clinical Problems*. Elsevier Health Sciences, Philadelphia, U.S.A. Pp.1410-1414.

Cohan, S., Moses, H., Calkwood, J., Tornatore, C., LaGanke, C., Smoot, K., & Mann, M. (2018). Clinical outcomes in patients with relapsing-remitting multiple sclerosis who switch from natalizumab to delayed-release dimethyl fumarate: a multicenter retrospective observational study (STRATEGY). *Multiple sclerosis and related disorders*, *22*, 27-34.

Debska, G., Milaniak, I., & Skorupska-Król, A. (2020). The quality of life as a predictor of social support for multiple sclerosis patients and caregivers. *Journal of Neuroscience Nursing*, *52*(3), 106-111.

DeLaune, S., McTier, L., Tollefson, J., Lawrence, J., & Ladner, P. (2019). *Fundamentals of Nursing: Australia & NZ Edition 2e*. Cengage AU. U.S.A. Pp. 869-899.

Demaneuf, T., Aitken, Z., Karahalios, A., Leong, T., De Livera, A., Jelinek, G., ... & Marck, C. (2019). Effectiveness of exercise interventions for pain reduction in people with multiple sclerosis: a systematic review and meta-analysis of randomized controlled trials. *Archives of physical medicine and rehabilitation*, *100*(1), 128-139.

Dobson, R., & Giovannoni, G. (2019). Multiple sclerosis–a review. *European journal of neurology*, *26*(1), 27-40.

Drulovic, J., Kisic-Tepavcevic, D., & Pekmezovic, T. (2020). Epidemiology, diagnosis and management of sexual dysfunction in multiple sclerosis. *Acta Neurologica Belgica*, 1-7.

Efendi, H., Ünal, A., Akçalı, A., Altunan, B., Bingöl, A., Altunrende, B., ... & Beckmann, Y. (2022). The effect of cognitive performance on self-management behavior of multiple sclerosis

patients. Multiple Sclerosis and Related Disorders, 103880.

Essawy, H., Elghonemy, S., Mahmoud, D., & Arafa, A. (2020). The relationship between disturbed eating behavior and substance abuse in an Egyptian sample. *QJM: An International Journal of Medicine*, *113*(Supplement_1), hcaa054-013.

Faraji, F., Khosravi, S., Sajadi, M., Farahani, Z., & Rafiei, F. (2018). Effect of self-care education on social adaptability in patients with multiple sclerosis. *Iranian Red Crescent Medical Journal*, *20*(1) e55634.

Farran, E., Waggas, D., Alkhunani, T., Almuwallad, S., & Aljohani, R. (2021). Assessment of multiple sclerosis awareness and knowledge among the community of Jeddah, Saudi Arabia. *Journal of Neurosciences in Rural Practice*, *12*(04), 733-738.

Ferreira-Valente, M., Pais-Ribeiro, J., & Jensen, M. (2011). Validity of four pain intensity rating scales. *Pain®*, *152*(10), 2399-2404.

Ghafoori, F., Bagheri, M., Dehghan-Nayeri, N., Khakbazan, Z., Haghani, H., Hedayatnejad, M., & Samadaee, K. (2022). Effectiveness of sexual counseling using better model to promote sexual function and satisfaction of married women with multiple sclerosis. *Sexuality and Disability*, 1-16.

Ghahari, S., Forwell, S., Suto, M., & Morassaei, S. (2019). Multiple sclerosis self-management model: Personal and contextual requirements for successful self-management. *Patient education and counseling*, *102*(5), 1013-1020.

Ghasemi, V., Nabavi, S. M., Simbar, M., Ozgoli, G., Alavi Majd, H., Mirshafaei, M. S., ... & Banaei, M. (2022). The effect of sexual health promotion package on sexual life in women with multiple sclerosis: Designed based on the results of a mixed method study. *Sexuality and Disability*, *40*(1), 57-75.

Hadoush, H., Alawneh, A., Kassab, M., Al-Wardat, M., & Al-Jarrah, M. (2022). Effectiveness of non-pharmacological rehabilitation interventions in pain management in patients with multiple sclerosis: Systematic review and meta-analysis. *NeuroRehabilitation*, 1-19.

Hemmatpoor, B., Gholami, A., Parnian, S., & Seyedoshohadaee, M. (2018). The effect of life skills training on the self-management of patients with multiple sclerosis. *Journal of medicine and life*, *11*(4), 387.

Hersche, R., Weise, A., Michel, G., Kesselring, J., Barbero, M., & Kool, J. (2019). Development and preliminary evaluation of a 3-week inpatient energy management education program for people with multiple sclerosis–related fatigue. *International journal of MS care*, *21*(6), 265-274.

Hinkle, J., & Cheever, K. (2017). *Brunner & Suddarth's textbook of medical-surgical nursing.* Assessment and Management of Patients with multiple sclerosis (10th Ed.) Ch. (40), U.S.A. Pp. 442-447.

Hugos, C. L., Chen, Z., Chen, Y., Turner, A. P., Haselkorn, J., Chiara, T., ... & VA MS Fatigue Study Group. (2019). A multicenter randomized controlled trial of two group education programs for fatigue in multiple sclerosis: Short-and medium-term benefits. *Multiple Sclerosis Journal*, *25*(2), 275-285.

Ibrahim, E., Gassoum, A., & Altom, S. (2020). The patterns of clinical presentation of multiple sclerosis in patients admitted to the national center of neurological sciences, Khartoum, Sudan 2018. *Multiple Sclerosis and Related Disorders*, *37*.

Ibrahim, F., Loutfi, Z., & Mourad, G. (2016). Psychosocial nursing intervention for improving quality of life of patient with multiple sclerosis. *Egyptian journal of health care Vol. 7, No. 3 September 2016.*

Janice, L., & Hinkle, K. (2018). Brunner & Suddarth's text book of medical surgical nursing 14th edition, New York, U.S.A, Pp. 2073:2078.

Jones, L., Lee, M., Castle, C. L., Heinze, N., & Gomes, R. S. (2022). Scoping review of remote rehabilitation (telerehabilitation) services to support people with vision impairment. *BMJ open*, *12*(8), e059985.

Lewis, S., Bucher, L., Heitkemper, M., Harding, M., Kwong, J., & Roberts, D. (2016). *Medical-Surgical Nursing-E-Book: Assessment and Management of Clinical Problems,* Single Volume. Elsevier Health Sciences. U.S.A. Pp. 1294-1299.

Linton, A. (2015). Introduction to medical-surgical nursing (6th, ed). Elsevier Health Sciences, Canada. Pp. 435-451.

Linton, A., & Matteson, M. (2019). *Medical-Surgical Nursing E-Book*. Elsevier Health Sciences. U.S.A. Pp. 386-388.

Marck, C. H., De Livera, A. M., Brown, C. R., Neate, S. L., Taylor, K. L., Weiland, T. J., ... & Jelinek, G. A. (2018). Health outcomes and adherence to a healthy lifestyle after a multimodal intervention in people with multiple sclerosis: Three-year follow-up. *PLoS One*, *13*(5), e0197759.

Marrie, R., & Goldman, M. (2007). Validity of performance scales for disability assessment in multiple sclerosis. *Multiple Sclerosis Journal*, *13*(9), 1176-1182.

McGinley, M., Goldschmidt, C., & Rae-Grant, A. (2021). Diagnosis and treatment of multiple sclerosis: a review. *Jama*, *325*(8), 765-779.

Meybodi, F., Saeedi, Z., Behjati, Z., Noorbala, F., Dastbaravardec, A., & Enjedany, E. (2011). Reliability and validity of a Farsi version of 18-item Mental Health Inventory. *Procedia-Social and Behavioral Sciences*, *30*, 1425-1429.

Mills, R., Young, C., Pallant, J., & Tennant, A. (2010). Rasch analysis of the modified fatigue impact scale (MFIS) in multiple sclerosis. *Journal of Neurology, Neurosurgery & Psychiatry,81*(9), 1049-1051. Available at: https://jnnp.bmj.com.

Momenabadi, V., Kaveh, M. H., Nakhaee, N., Shirazi, K. K., Dastoorpoor, M., & Sedighi, B. (2019). Effect of educational intervention based on health-promoting self-care behaviors model on quality of life, resilience, and sense of coherence in patients with multiple sclerosis: a randomized controlled trial. *Iranian Red Crescent Medical Journal, 21*(12).

Monti, M., Marquez, M., Berardi, A., Tofani, M., Valente, D., & Galeoto, G. (2020). The Multiple Sclerosis Intimacy and Sexuality Questionnaire (MSISQ-15): validation of the Italian version for individuals with spinal cord injury. *Spinal Cord*, 1-6.

Nabil, S., & Abd Elsatar, R. (2022). Self-management guidelines: effect on knowledge, fatigue, self-efficacy and medications adherence among patients with multiple sclerosis. *Egyptian Journal of Health Care*, *13*(1), 1008-1024.

Pawar, V., Pawar, G., Miller, L., Kalsekar, I., Kavookjian, J., Scott, V., & Madhavan, S. (2010). Impact of visual impairment on health-related quality of life in multiple sclerosis. *International Journal of MS Care*, *12*(2), 83-91.

Plow, M., Finlayson, M., Liu, J., Motl, R. W., Bethoux, F., & Sattar, A. (2019). Randomized controlled trial of a telephone-delivered physical activity and fatigue self-management interventions in adults with multiple sclerosis. *Archives of physical medicine and rehabilitation*, *100*(11), 2006-2014.

Potter, P., Perry, A., Stockert, P., & Hall, A. (2016). Fundamentals of nursing (9th ed.). Elsevier Health Sciences, St. Louis, U.S.A. Pp. 501-511.

Preziosi, G., Gordon-Dixon, A., & Emmanuel, A. (2018). Neurogenic bowel dysfunction in patients with multiple sclerosis: prevalence, impact, and management strategies. *Degenerative*

neurological and neuromuscular disease, *8*, 79.

Russell, R. D., Black, L. J., Pham, N. M., & Begley, A. (2020). The effectiveness of emotional wellness programs on mental health outcomes for adults with multiple sclerosis: a systematic review and meta-analysis. *Multiple sclerosis and related disorders, 44*, 102171.

Saad, A. M., & Elsayed, E. E. (2021). Self-management program to adapt with multiple sclerosis problems and enhance quality of life. *Assiut Scientific Nursing Journal*, *9*(26), 34-54.

Saadat, S., Kajbaf, M. B., Kalantari, M., & Hosseininezhad, M. (2020). The Multiple Sclerosis Self-Management Scale–Revised (MSSM-R) Persian Version and Psychometric Analysis. *International Journal of MS Care*, *22*(1), 37-42.

Sadeghi Bahmani, D., Kesselring, J., Papadimitriou, M., Bansi, J., Pühse, U., Gerber, M., ... & Brand, S. (2019). In patients with multiple sclerosis, both objective and subjective sleep, depression, fatigue, and paresthesia improved after 3 weeks of regular exercise. *Frontiers in psychiatry*, 10, 265.

Sakakibara, R. (2019). Neurogenic lower urinary tract dysfunction in multiple sclerosis, neuromyelitis optica, and related disorders. *Clinical Autonomic Research*, *29*(3), 313-320.

Santos, M., Sousa, C., Pereira, M., & Pereira, M. (2019). Quality of life in patients with multiple sclerosis: A study with patients and caregivers. *Disability and health journal*, *12*(4), 628-634.

Seifi, K., & Moghaddam, H. E. (2018). The effectiveness of self-care program on the life quality of patients with multiple sclerosis in 2015. Journal of the National Medical Association, 110(1), 65-72.

Senders, A., Hanes, D., Bourdette, D., Carson, K., Marshall, L. M., & Shinto, L. (2019). Impact of mindfulness-based stress reduction for people with multiple sclerosis at 8 weeks and 12 months: A randomized clinical trial. *Multiple sclerosis journal*, *25*(8), 1178-1188.

Shawli, A., Abdulmutalib, I., & Al Nagshabandi, E. (2019). Fatigue and Self-management among Multiple Sclerosis Patients. *American Journal of Nursing*, *7*(4), 550-560. Available at: http://article.scinursingresearch.com.

Simpson, R., Simpson, S., Ramparsad, N., Lawrence, M., Booth, J., & Mercer, S. W. (2019). Mindfulness-based interventions for mental well-being among people with multiple sclerosis: a systematic review and meta-analysis of randomised controlled trials. *Journal of Neurology, Neurosurgery & Psychiatry*, *90*(9), 1051-1058.

Suresh, K., & Chandrashekara, S. (2012). Sample size estimation and power analysis for clinical research studies. *Journal of human reproductive sciences*, *5*(1), 7.

Timby, B., & Smith, N. (2017). Introduction Medical Surgical nursing, (12th ed.), Lippincott Williams & Wilkins, Philadelphia, U.S.A. Pp.642-644.

Tkáčová, Ľ. M. A. H. Ľ. (2020). Influence of self-care on quality of life in patients with multiple sclerosis. *CER Comparative European Research 2020*.

Valentine, T. R., Alschuler, K. N., Ehde, D. M., & Kratz, A. L. (2022). Prevalence, co-occurrence, and trajectories of pain, fatigue, depression, and anxiety in the year following multiple sclerosis diagnosis. *Multiple Sclerosis Journal*, *28*(4), 620-631. https://doi.org/10.1177/135245852110233 52

Walton, C., King, R., Rechtman, L., Kaye, W., Leray, E., Marrie, R. A., ... & Baneke, P. (2020). Rising prevalence of multiple sclerosis worldwide: Insights from the Atlas of MS. *Multiple Sclerosis Journal*, *26*(14), 1816-1821.

Wills, O. C., & Probst, Y. C. (2022). Understanding lifestyle self-management

regimens that improve the life quality of people living with multiple sclerosis: a systematic review and meta-analysis. *Health and Quality of Life Outcomes*, *20*(1), 1-28.

Wilski, M., Brola, W., Łuniewska, M., & Tomczak, M. (2021). The perceived impact of multiple sclerosis and self-management: The mediating role of coping strategies. *PloS one*, *16*(3), e0248135.

Wilski, M., Kocur, P., Brola, W., & Tasiemski, T. (2020). Psychological factors associated with self- management in multiple sclerosis. *Acta Neurologica Scandinavica*, *142*(1), 50-57.

Yavas, I., Emuk, Y., & Kahraman, T. (2022). Pelvic floor muscle training on urinary incontinence and sexual function in people with multiple sclerosis: A systematic review. *Multiple Sclerosis and Related Disorders*, *58*, 103538.