

▪ **Basic Research**

Effect of Self-management Guidelines on Health Practices of Patients with Multiple Sclerosis

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Abstract

Background: Multiple sclerosis (MS) is a chronic brain and spinal cord disorder that can lead to disability, causing distressing physical and psychosocial problems. Self-management is the patient's ability to manage those problems to live with this chronic condition. **Aim:** The study aimed to evaluate the effect of self-management guidelines on the health practices of patients with multiple sclerosis. **Setting:** Multiple Sclerosis Outpatient Clinic at Ain Shams University Hospital. **Sample:** A purposive sample includes 133 patients. **Design:** A quasi-experimental design was used. **Tools:** **First tool:** A structured interview questionnaire consisting of two parts was used. **Part I:** To assess the socio-demographic characteristics of the patients; **Part II:** To assess the patient's medical history; and **Part III:** To assess the patients' knowledge about multiple sclerosis disease. **Second tool:** To assess patients' self-management of multiple sclerosis disease. **Third tool:** observational physical exercise checklist **Fourth tool:** To assess patients' health practices about multiple sclerosis disease. **Results:** The mean age of the studied patients was 35.69 ± 5.97 ; females constituted 60.2% of the studied patients. Also, 81.2%, 80.5%, and 84.2% of them had satisfactory levels of knowledge, self-management, and health practices post-implementation of self-management guidelines, respectively. Moreover, there was a significant improvement in patients' bladder, bowel control, sexual activity, and satisfaction post-implementation of self-management guidelines. **Conclusion:** The implementation of self-management guidelines for patients with MS has a statistically positive effect on their health practices, which supports the stated hypothesis. **Recommendations:** Self-management guidelines should be included in the routine nursing care and rehabilitation process for patients with MS.

Introduction

MS is a chronic brain and spinal cord disorder. It can lead to disability. Although there is no cure for MS, treatments can help people with MS manage the symptoms of the disease and live a normal life. However, the effectiveness of these treatments requires that the patient has an active role in the management of the disease (level of adherence to medication). Furthermore, a variety of treatment side effects, a lack of obvious improvement in the condition of the patient, the progression of the medical conditions, or a curiously long period without a relapse all play a key role in the lack of regulation visits, medication non-compliance, diet non-adherence, and frequent changes to treatment plans, and medical staff. (*Mokhberdezfuli et al., 2021*).

Multiple sclerosis is one of the main causes of disability in young people. This condition often strikes young adults, between the ages of 20 and 50. It causes a variety of problems, such as difficulty moving, pain, tiredness, and emotional ups and downs. As a result, individuals with MS experience a daily struggle with physical, emotional, and mental difficulties. The presence and complexity of MS symptoms complicate their management, which can become an exhausting task for individuals with MS (*Salimzadeh et al., 2022*).

Self-management of chronic conditions can be understood as acquiring and applying skills to live a fulfilling life despite the presence of a chronic illness as well. This proactive approach is linked to improved quality of life, better health practices, and reduced healthcare costs and symptoms (*Saadat et al., 2022*).

Self-management in multiple sclerosis focuses on equipping patients to control their symptoms, adhere treatment plan, stay active, eat well, and handle the emotional challenges of the disease. Studies show these self-management programs improve overall well-being, knowledge of MS, treatment adherence, and physical, social and mental health in individuals with chronic conditions (*Wills & Probst, 2022*).

Health practices are one of the various ways to treat the complications of patients with MS disease. MS necessitates long-term care, and the health practices, skills, and these patients' empowerment have become more visible and important. Early education and guidance about health practices allow for early intervention if complications arise. Educational guidelines allow patients to take an active role early in their recovery. So, in all phases of the disease, nurses play an essential part in enhancing patients' knowledge and promoting their self-management and health practices (*Afrasiabifar et al., 2020*).

Nurses have a key role in interacting with patients and their families throughout supporting patients in selecting appropriate healthy behavior management. Also, nurses have an essential role in counseling patient with MS about treatment decisions and providing education on treatment initiation, as well as monitoring and managing any side effects, assessing treatment outcomes, and encouraging patients to adhere to their treatment regimens (*Shawli et al., 2021*).

Significance of Study

According to data from Egypt's Ministry of Health and Population (2020), 1.4% of all neurological diseases are cases of MS. Based on data from the World Health Organization, there may have been as many as 2.8 million MS patients globally (*Ragab & Hussein, 2022*). Egypt has the highest number of multiple sclerosis (MS) patients in the Middle East region, with an estimated number of 25,000 subjects (*Zakria et al., 2020*).

Multiple Sclerosis (MS) rarely occurs in children, getting more common after age 18. It is peaking between 20 and 40, with an average age of diagnosis around 30. Women tend to develop MS 2 to 5 years earlier than men, and the rate of new cases declines after age 50. In Egypt, 59 out of every 100,000 people have MS. Women make up about 75% of these cases, compared to 25% being men. Additionally, 65% of cases in Egypt are the relapsing-remitting type, followed by 25% of secondary progressive and 10% of primary progressive types (*El-Sherbiny et al., 2020*).

Multiple sclerosis comes with unpredictable and varied signs and symptoms, both physical and mental. To control these and improve well-being, studies show the importance of comprehensive self-management programs and proactive strategies to decline chronic disease symptoms (*Heidari-Soureshjani et al., 2023*).

Aim of the study

The study aimed to evaluate the effect of self-management guidelines on the health practices of patients with multiple sclerosis through the following:

1. Assessing patients' knowledge about multiple sclerosis disease.
2. Assessing patients' self-management about multiple sclerosis disease.
3. Assessing patients' health practices about multiple sclerosis disease.
4. Developing and implementing self-management guidelines for patients with multiple sclerosis disease.
5. Evaluating the effect of self-management guidelines on stated health practices for patients with multiple sclerosis disease.

Research Hypothesis

The current study hypothesized that the implementation of self-management guidelines would improve health practices for patients with multiple sclerosis.

Subjects and Methods

Study design:

A quasi-experimental design was utilized to collect the data relevant to this study.

I. Technical Design:

The technical design includes the settings, subjects, and tools used in the study.

Settings:

The study was conducted at the Multiple Sclerosis Outpatient Clinic at Ain Shams University Hospital.

Sampling:

Type:

A purposive sample was used.

Size:

The study sample included 133 patients.

The sample was calculated according to the power analysis formula, as follows:

The estimated sample size is 133 patients out of 700 patients who attended the previously mentioned setting in the year 2022, at a confidence level of 80% (Steven & Thompson, 2012).

$$n = \frac{N \times p(1-p)}{\left[N-1 \times \left(\frac{d^2}{z^2} \right) + p(1-p) \right]}$$

$$700 * (0.5 * 0.5) = 175$$

$$n = \frac{175}{699 * (.0025 / 1.6384) + 0.25} = 133$$

Which:

n= Sample size

N= Total size

Z = the standard value corresponding to a confidence level of 80% which is (1.28).

d= Error level 5%

p= 0.5.

Inclusion criteria:

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

1. Adult patients 25 ≥ 55 years old.
2. Both sexes (male and female).
3. Patients who did not receive instructions on self-management about MS.

Exclusion criteria:

1. Patients have psychiatric disorders.

Tools of the study

Data were collected through:

Tool I: A structured Interviewing Questionnaire:

This tool will be developed by the researcher based on reviewing the related literature. It will include three parts:

- **Part I: Patients' Demographic Characteristics Assessment:** This part consisted of seven questions used to assess age, gender, marital status, level of education, occupation, residence, and monthly income.
- **Part II: Patients' medical history:** This part is closed-ended questions consisting of ten questions used to assess history, past history, family history and current condition.
- ❖ **Part III: Patients' Knowledge pre-post Assessment Tool:** This tool was developed by the researcher based on reviewing the related literature (*Lewis et al., 2021; Hinkle & Cheever, 2020; Timby & Simth, 2022*). It was used to assess patients' knowledge about MS and written in the form of (yes or no). It was composed of 14 questions such as the definition of MS, clinical manifestations, risk factors, complications, diagnostic measures and treatment of multiple sclerosis

❖ **Scoring system:**

The researchers checked the patient's answers against their answer guide. They gave one point for each correct answer and zero points for the wrong ones. The total score of knowledge was 72 grades, as some questions allowed for multiple correct answers. Scores were then categorized into two performance levels: satisfactory (60% or higher, 43-72 points) and unsatisfactory (below 60%, 0-42 points).

Tool II: Multiple Sclerosis Self-Management Scale (MSSM-S): It was adapted from (*Bishop & Frain, 2019*). It was used to assess patients' reported self-management regarding multiple sclerosis disease, written in the form of (done or not done) and included eight subscales; nutrition, stress, health and symptom awareness, Health maintenance behavior, treatment adherence, communication about symptoms/changes, emotional health and social support and working effectively with health care professionals (**Pre/Post implementation of self-management guidelines**).

❖ **Scoring system:**

The researchers evaluated the patient's responses by comparing them to a pre-defined answer key. A single point was assigned for each done answer, while not done answers received no points. The total score for each subscale is calculated then divided in to categories; more than 60% were considered adequate and less than 60% were considered in adequate.

Tool III: Physical Exercise Observational Checklist:

It was adapted from (*Bishop & Frain, 2019*). It was used to assess patients' self-management about physical exercise regarding multiple sclerosis disease, written in the form of (done or not done) and included fifteen items.

❖ **Scoring system:**

A single point was assigned for each done answer, while not done answers received no points. The total score is 15, divided in to categories; (9-15) were considered adequate and (0-8) were considered in adequate.

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

The test awarded high scores (98) for total self-management, partly because some questions accepted multiple answers. The scores were then grouped into two performance levels: those

scoring 60% or higher (between 59 and 98 points) were considered adequate, while those below 60% (0 to 58 points) were considered inadequate.

Tool IV: Multiple Sclerosis Health Practices Scale: It was adapted from (*Potter et al., 2021*). It was used to assess patients' reported health practices regarding multiple sclerosis disease, written in the form of (done or not done) and included eight subscales; fatigue, pain, bladder problems, diarrhea, constipation, sexual problems, vision problems and psychological problems.

❖ **Scoring system:**

Researchers checked the patient's answers against their answer key. Each done answer received a point and not done answer received zero. The total health practices score reached 70 due to some questions having multiple correct answers. Scores were then categorized into two levels: those exceeding 60% (42-70 points) were considered adequate, while those below 60% (0-41 points) were considered inadequate."

II. Operational Design:

Preparatory phase:

The researcher conducted a comprehensive literature review. This review included both current and past resources, encompassing local and international articles, publications, textbooks, online searches and magazines to gain a deep understanding of the research problem and develop appropriate tools for the study

Content validity:

It was ascertained by a group of five experts (assistant professors and professors) from medical and surgical nursing and the Family and Community Health Nursing Department, Faculty of Nursing, Ain Shams University. Their opinions were elicited regarding the format, layout, consistency, accuracy, and relevancy of the tools' contents. The required modifications were carried out accordingly.

Reliability:

The tool's moderate to high reliability was determined by Cronbach's Alpha coefficient test, which also revealed that the tools' items were generally homogeneous. After the questionnaire was put to the test, the tools showed strong reliability, with Cronbach's alpha coefficients of 0.907 for Tool I, 0.884 for Tool II, and 0.857 for Tool III.

Pilot study:

In the previously described setting, it was carried out on 13 patients with MS, representing 10% of the sample, to assess the feasibility of the research process as well as the applicability and clarity of the included tools. Also, the pilot has served to estimate the time needed for every subject to fill in the questionnaires. The pilot test showed the tools did not need any change, so these patients were included in the main study. Also, these patients were in need for guidelines to improve their pre unsatisfactory knowledge, inadequate self-management and health practices regarding multiple sclerosis disease.

Fieldwork:

The researchers met with the (133) patients at the designated research setting twice a week, between 9:00 am and 2:00 pm. The researchers told the patients about the study before it began, explaining what it was for and why it was important.

The researchers met with about 2 to 3 patients per day. Data were collected over a period of four months and two weeks, from the beginning of August 2023 until the end of December 2023, from the patients through interviewing questionnaires. Every participant took approximately 15–30 minutes to complete the interview questionnaires.

After getting formal consent from the patients, the researchers involved them in the study. Questionnaires were distributed, and the researchers clarified each question with the patients before they answered them.

Patients involved in the study received the tools twice - once before and again after participating in the guidelines program to assess their knowledge, self-management, and health practices

Ethical considerations:

Approval was obtained from the Ethical Committee of the Faculty of Nursing at Ain Shams University. Issues of ethical consideration were discussed with the director of health units and then with the directors and head nurses of selected setting. The patients who selected to participate in the study were informed of its objectives before it's started by the researchers. The patients gave formal permission before being included in the study. The researchers kept participant data anonymous and confidential.

Self-management Guidelines Instruction:

It was implemented through four phases:

Phase I: Self-management guidelines development

An extensive review of relevant recent, current, national and international related literature was done. The sources were books, articles in periodicals and magazines, as well as, online search in various aspects of multiple sclerosis disease. Accordingly, the program was designed by the researchers as well, on the results obtained from the pre-test results.

Phase II: Assessment phase

A pre-test based on the patient's existing knowledge, stated self-management and health practices regarding multiple sclerosis disease was used to assess their needs which was carried out through two days/week of the setting previously selected and out for eight weeks (from beginning of the august to the end of September 2023). Filling in the tools took an average of twenty to twenty-five minutes for the questionnaire, self-management scale and health practices scale tool.

Phase III: Implementation phase

Implementation of self-management guidelines took ten weeks and was carried out for two months and two weeks (from the beginning of October to the half of December 2023). The self-management guidelines implementation was based on conducting a variety of sessions

planned using different diverse teaching methods such as discussion and lecture and multimedia resources such as guidelines and educational videos.

The sessions took place at the outpatient's reception. Researchers gave self-management guidelines to small groups of 2-3 patients over 10 sessions. Each session lasted roughly 15-30 minutes. The initial session focused on building a rapport with the patients. This helped ease their anxiety and establish trust, which is crucial for successful self-management. As well, the program also included an introduction to the self-management guidelines and why they're important. Starting from the second session, each meeting began with a review of the previous session's key points and a clear explanation of the upcoming session's goals, all presented in a way that was easy for the patients to understand. In addition, Patients received guidelines booklet on MS and watched educational videos. Summaries were provided at the end of each session. There was a dedicated questions and answers period, followed by planning for the upcoming session. However, the final session wasn't planned for since feedback on prior sessions would mark the program's end.

Supportive materials:

Patients received a clear and guidelines booklet in Arabic outlining the program's guidelines. This booklet included pictures and explanations to make the information easy to understand. In addition to the booklet, the program incorporated various teaching methods like lectures and discussions, along with visual aids like pamphlets and videos.

Phase IV: Self-management Guidelines Evaluation

This phase was done through posttest to assess how well patients learned about knowledge, self-management and health practices about MS disease and was done one week after they received guidelines (the last week of December 2023). The test looked for changes in knowledge, self-management, and health practices. It also helped identify areas where the program was successful and areas that could be improved.

III. Statistical Design:

The researchers transformed the collected data from the study participants into a format a computer could understand. They then used a software program called SPSS, version 22, to enter and analyze this data statistically. The researchers used basic statistics like counts, percentages, averages, and standard deviations to describe the data. They then employed a chi-square test to see if there were any differences between the groups before and after the program. Pearson's correlation coefficient was used to measure how well two continuous variables were related. A p-value less than 0.05 was considered statistically significant, and a p-value less than 0.001 was considered highly significant.

Results

Table (1): It reveals that the mean of patients' age included in the study was 35.69 ± 5.97 . Concerning patients' gender and Marital status, 60.2% & 72.9% of them were female and married, while 12% of them were illiterate. About their occupation, 47.4% of patients were working. As well, 51.1% had insufficient medical expenses.

Table (2): shows that 36.8% of patients had a chronic disease history and 19.5% of them had previous hospitalization and a family history of multiple sclerosis disease. Regarding

smoking 38.7% of them smoked. Of about 75.2% of patients who had Relapsing-remitting MS, 60.2% of them had a previous relapse and of these, 72.5% had 1-3 relapse

Table (3): clarifies that a significant improvement in patients' knowledge pre/post implementation regarding types of multiple sclerosis and complications of multiple sclerosis disease, 9.8 %, 67.7% & 12 %, 73.7% respectively. Regarding, knowledge about bladder and bowel problems and sexual problems 15%, 75.2% & 12%, and 72.9% respectively. There were highly statistically significant differences between pre/post-implementation ($p < 0.001$).

Table (4): illustrates a significant improvement in patients' self-management pre & post-implementation about physical activity, health and symptoms awareness and health maintenance behaviour (12%, 64.7%, 18%, 79.7% & 9.8%, & 78.9%) respectively. There were highly statistically significant differences between pre & post-implementation ($p < 0.001$).

Table (5): displays a significant improvement in patient health practices regarding pain, bladder problems, and sexual problems (10.5%, 7.5%, 16.5%) respectively in pre-implementation, while improved to (78.9%, 70.7%, and 73.7%) respectively in post-implementation. there were highly statistically significant differences between pre & post implementation ($p < 0.001$).

Table (6): detects that there is a positive correlation between patients' total knowledge, total self-management and total health practices with a highly statistically significant difference ($p < 0.001$).

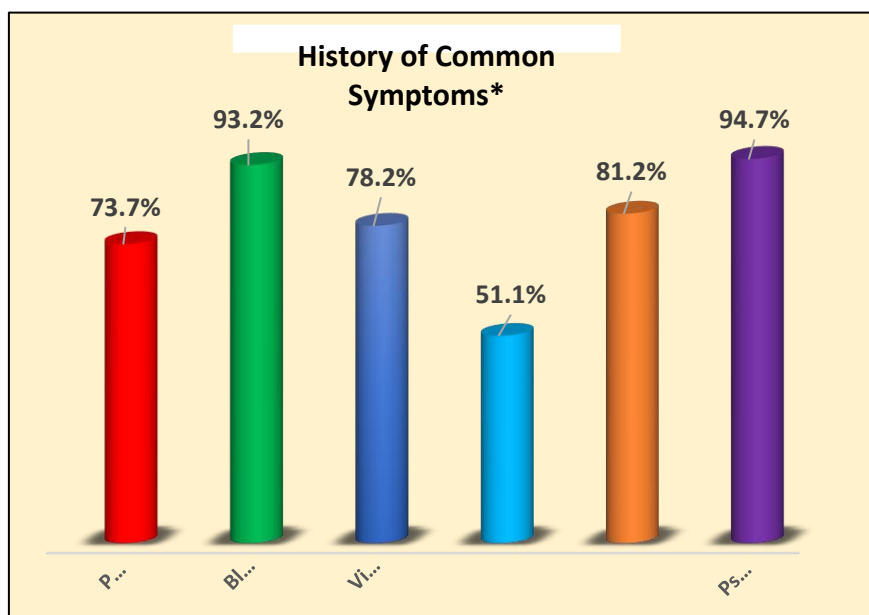
Table (1): Distribution of patients according to their socio-demographic characteristics (n=133).

Items	No.	%
Age (Year)		
25 ≥ 35	53	39.9
36 ≥ 45	54	40.6
46 ≥ 55	26	19.5
Mean ± S.D	35.69±5.97	
Gender		
Male	53	39.8
Female	80	60.2
Marital status		
Single	14	10.5
Married	97	72.9
Divorced	13	9.8
Widow	9	6.8
Educational level		
Illiterate	16	12.0
Read & write	26	19.5
Secondary education	59	44.4
University / Postgraduate education	32	24.1
Occupation		
Working	63	47.4
Not working	70	52.6
Residence		
Rural	40	30.1
Urban	93	69.9
Monthly income		
Sufficient for medical expenses	65	48.9
Insufficient for medical expenses	68	51.1

Table (2): Distribution of the patients according to their medical history (n=133).

Clinical Data	No.	%
A-Past medical history		
chronic diseases history		
Yes	49	36.8
No	84	63.2
Previous hospitalization		
Yes	26	19.5
No	107	80.5
Surgical history		
Yes	46	34.6
No	87	65.4
B- Family history		
Family history of multiple sclerosis disease		
Yes	26	19.5
No	107	80.5
The degree of kinship (n=26)		
First-degree (Father, Mother, Grandfather, Brother)	6	23.1
Second-degree (Uncle, Aunt)	20	76.9
C- History of smoking		
Smoking		
Yes	44	33.1
No	89	66.9
Does anyone smoke in the house?		
Yes	77	57.9
No	56	42.1
D. Current patient condition		
Type of multiple sclerosis		
Relapsing-remitting MS	100	75.2
Secondary progressive MS	21	15.8
Primary progressive MS	8	6.0
Progressive relapsing MS	4	3.0
Previous relapses		
Yes	80	60.2
No	53	39.8
If the answer is yes, the number of relapses (n=80)		
1-3	58	72.5
4-6	16	20.0
7 or more	6	7.5

Figure (1): Distribution of the patients according to their history of common symptoms (n=133).



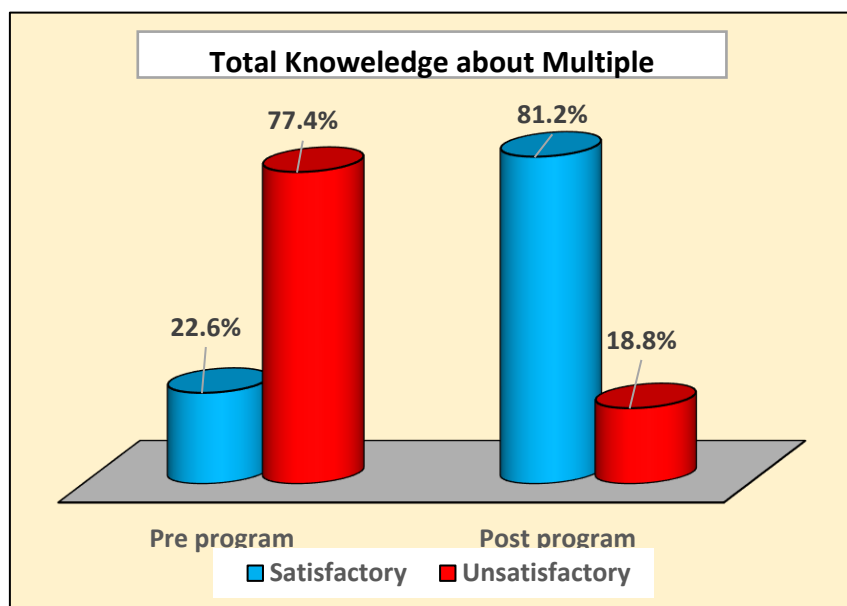
*No mutual response

Figure (1): shows that 94.7% of patients had a history of psychological problems and 93.2% of them had a history of bladder and bowel problems.

Table (3): Distribution of the patients according to their knowledge score level about multiple sclerosis disease pre and post-implementation (n=133).

Knowledge subscales	Pre-intervention				Post-intervention				X ²	P-value
	Satisfactory		Unsatisfactory		Satisfactory		Unsatisfactory			
	No.	%	No.	%	No.	%	No.	%		
Nature of multiple sclerosis	26	19.5	107	80.5	104	78.2	29	21.8	91.53	0.000**
Types of multiple sclerosis	13	9.8	120	90.2	90	67.7	43	32.3	93.93	0.000**
Causes and risk factors for multiple sclerosis	39	29.3	94	70.7	106	79.7	27	20.3	68.05	0.000**
Clinical manifestations of multiple sclerosis	78	58.6	55	41.4	121	91.0	12	9.0	36.88	0.000**
Complications of multiple sclerosis	16	12.0	117	88.0	98	73.7	35	26.3	103.21	0.000**
Diagnosis of multiple sclerosis	46	34.6	87	65.4	106	79.7	27	20.3	55.26	0.000**
Treatment of multiple sclerosis	26	19.5	107	80.5	90	67.7	43	32.3	62.61	0.000**
Fatigue from multiple sclerosis	52	39.1	81	60.9	115	86.5	18	13.5	63.85	0.000**
Pain from multiple sclerosis	36	27.1	97	72.9	105	78.9	28	21.1	71.85	0.000**
Bladder and bowel problems from multiple sclerosis	20	15.0	113	85.0	100	75.2	33	24.8	97.16	0.000**
Vision problems from multiple sclerosis	25	18.8	108	81.2	109	82.0	24	18.0	106.1	0.000**
Sexual problems from multiple sclerosis	16	12.0	117	88.0	97	72.9	36	27.1	100.9	0.000**
Psychological problems from multiple sclerosis	30	22.6	103	77.4	103	77.4	30	22.6	80.13	0.000**

Figure (2): Distribution of the patients according to their total knowledge score level about multiple sclerosis disease pre and post-implementation (n=133).



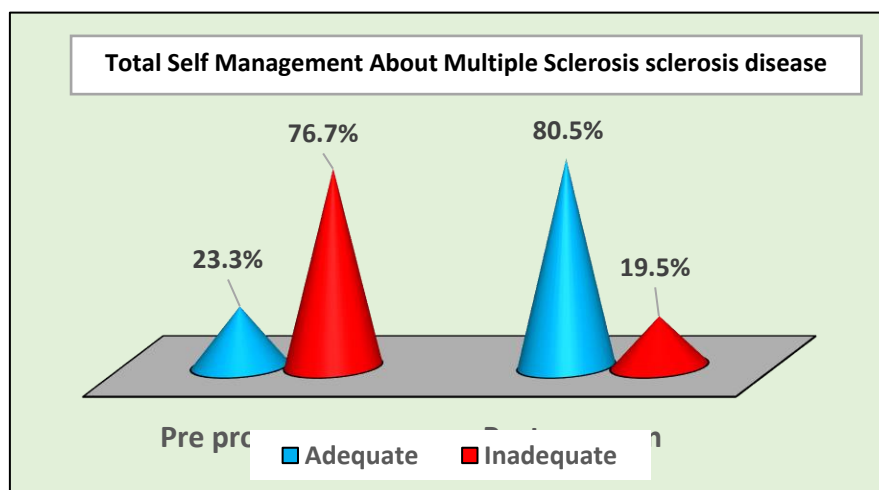
$X^2=88.30$ p value < 0.001 HS

Figure (2): reveals that 22.6% of patients had a satisfactory level of total knowledge pre-implementation. On the other hand, 81.2% had a satisfactory level of total knowledge post-implementation with highly statistically significant improvement ($p<0.001$).

Table (4): Distribution of the studied sample according to their stated self-management of multiple sclerosis pre and post-implementation (n=133).

Self-management subscales	Pre-intervention				Post-intervention				X ²	P-value
	Adequate		Inadequate		Adequate		Inadequate			
	No.	%	No.	%	No.	%	No.	%		
Nutrition	35	26.3	98	73.7	114	85.7	19	14.3	95.22	0.000**
Physical activity	16	12.0	117	88.0	86	64.7	47	35.3	77.91	0.000**
Stress coping techniques	33	24.8	100	75.2	100	75.2	33	24.8	67.50	0.000**
Health and symptom awareness	24	18.0	109	82.0	106	79.7	27	20.3	101.1	0.000**
Health maintenance behaviour	13	9.8	120	90.2	105	78.9	28	21.1	128.9	0.000**
Treatment adherence	52	39.1	81	60.9	119	89.5	14	10.5	73.50	0.000**
Communication about symptoms/changes	48	36.1	85	63.9	102	76.7	31	23.3	44.57	0.000**
Emotional health and social support	26	19.5	107	80.5	108	81.2	25	18.8	101.1	0.000**
Working effectively with healthcare professionals	62	46.6	71	53.4	113	85.0	20	15.0	43.44	0.000**

Figure (3): Distribution of the patients according to their total self-management of multiple sclerosis pre and post-implementation (n=133).



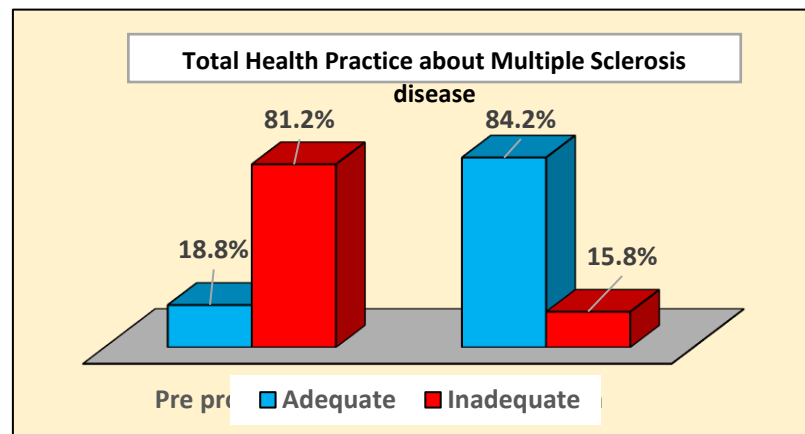
$\chi^2 = 86.98$ p-value < 0.001 HS

Figure (3): indicates that 23.3% of patients had adequate level of total practice in pre-implementation. On the other hand, 80.5% of them had an adequate level of total practice post-implementation with highly statistically significant (p=<0.001).

Table (5): distribution of studied patients according to their reported health practices pre and post-implementation (n=133).

Health practices subscales	Pre-intervention				Post-intervention				χ^2	P-value
	Adequate		Inadequate		Adequate		Inadequate			
	No.	%	No.	%	No.	%	No.	%		
Fatigue	26	19.5	107	80.5	104	78.2	29	21.8	91.53	0.000**
Pain	14	10.5	119	89.5	105	78.9	28	21.1	125.9	0.000**
Bladder problems	10	7.5	123	92.5	94	70.7	39	29.3	111.4	0.000**
Diarrhea	39	29.3	94	70.7	100	75.2	33	24.8	56.06	0.000**
Constipation	42	31.6	91	68.4	109	82.0	24	18.0	68.76	0.000**
Sexual problems	22	16.5	111	83.5	98	73.7	35	26.3	87.69	0.000**
Vision problems	34	25.6	99	74.4	107	80.5	26	19.5	80.42	0.000**
Psychological problems	26	19.5	107	80.5	97	72.9	36	27.1	76.23	0.000**

Figure (4): Distribution of the patients according to their total health practices pre and post-implementation (n=133).



$$\chi^2 = 113.92 \text{ } p\text{-value} < 0.001 \text{ HS}$$

Figure (4): reveals that 18.8% of patients had an adequate level of total health practices in pre-implementation. On the other hand, 84.2% had an adequate level of total practice post-implementation with highly statistically significant ($p < 0.001$).

Table (6): Correlation between patients' total knowledge score, total self-management score and total health practices score pre and post-implementation (n=133).

Variables		Total knowledge score		Total self-management score	
		Pre-intervention	Post-intervention	Pre-intervention	Post-intervention
Total knowledge score	r			0.969	0.944
	p			0.000**	0.000**
Total health practices score	r	0.914	0.943	0.945	0.953
	p	0.000**	0.000**	0.000**	0.000**

r= Pearson correlation coefficient test. ** Correlation is significant at < 0.01 .

Discussion

The unpredictable nature of MS symptoms makes it hard to manage, leading to a decline in quality of life for patients. Recent studies emphasize the importance of self-management programs and preventative actions in improving quality of life and managing symptoms of this chronic condition. (*Jelinek et al., 2022*).

Regarding the socio-demographic characteristics of the patients under investigation, the current study's findings showed that the average age of the patients under investigation was 35.69 ± 5.97 , indicating that MS is most commonly diagnosed between the ages of 20 and 40. This result is in the line with the research carried out in **Egypt about the Effect of Educational Guidelines on Self-Management and Clinical Outcomes for Patients with Multiple Sclerosis by Abozeid et al. (2023)**, who found that the mean age of the studied patients was 36.75 ± 5.63 .

While more than half of the studied patients were female, married, and from urban areas, this might be due to the increased incidence of MS disease among females and may point to the role of female hormones. This finding is consistent with the study **Understanding**

Lifestyle Self-Management Regimens that Improve the Life Quality of People Living with Multiple Sclerosis: A Systematic Review and Meta-Analysis by *Wills & Probst, (2022)*, which showed that the majority (95%) of the studies included both female and male participants, with approximately 75% of the participants being female. Also, the study **Self-Management Guidelines: Effect on Knowledge, Fatigue, Self-Efficacy, and Medications Adherence among Patients with Multiple Sclerosis** by *Abd Elsalam & Ali, (2022)* found that nearly three-quarters of the patients were city residents.

As regards educational level, near to one-half of the studied patients had secondary education, and this result is in agreement with the research conducted about **self-management guidelines: Effect on Knowledge, Fatigue, Self-Efficacy, and medication adherence among Patients with Multiple Sclerosis** by *Abd Elsalam & Ali, (2022)*, who stated two-fifths of MS patients had an intermediate level and only one fifth had a bachelor level.

Related to occupation and monthly income, more than one-half of the studied patients didn't work, and their monthly income was reported to be sufficient for medical expenses. These findings are not consistent with the study about **fatigue and self-management among multiple sclerosis patients** by *Shawli et al. (2019)*. More than one-third of the studied patients were not working. As well, *Abozeid et al. (2023)* stated that more than three-quarters of the studied patients reported that their monthly income was insufficient to cover medical expenses.

Regarding current patient condition, the current study revealed that three-quarters of the studied patients had a relapsing-remitting MS (RRMS) type. This is because 85% of patients with MS worldwide are diagnosed with RRMS. While more than one-half of them had previous relapses of the disease, these findings are in line with the article **Types of Multiple Sclerosis: Overview, Progression, Facts, and Outlook** by *Dellwo, (2022)*. As shown, relapsing-remitting MS is the most common type, and about 80%–85% of MS cases are initially diagnosed as RRMS. Also in the study about predictors of **severity and outcome of multiple sclerosis relapses** by *Hosny et al. (2023)*, it was revealed that out of the 300 attacks included in the study, 169 (56.3%) were first-ever attacks and 131 (43.7%) were attacks that occurred during the course of the disease.

Moreover, the results of the study about patients' histories of common symptoms of MS revealed that the majority of them had physical (bladder and bowel) and psychological problems, while more than a fourth of them had sexual and vision problems, and more than one-half of them had pain and communication problems. These may be a result of the patient's immune system attacking their brain and spinal cord. These results are consistent with *Gustavsen et al. (2021)*, where it was found that the most frequently reported symptoms were bowel and bladder dysfunction (74%), and pain (666%), in the study about **the association of selected multiple sclerosis symptoms with disability and quality of life: a large Danish self-report survey**. Conversely, in the study **Onset Symptom Clusters in Multiple Sclerosis: Characteristics, Comorbidities, and Risk Factors** by *Ajdacic-Gross et al. (2021)*, it was reported that 40.8 per cent of the studied patients had vision problems, 12.2% of them had depression symptoms, and 6.7% of them had sexual and speech problems.

Regarding patients' level of total knowledge regarding disease and self-management of MS pre-implementation of self-management guidelines, the current study revealed that less than one-fourth of the studied patients had satisfactory knowledge about MS disease and its self-management. While more than three-fourths of them had a satisfactory level of

knowledge post-implementation of self-management guidelines, with a highly statistically significant difference at $p < 0.01$. This showed that the studied patients had needs about the disease and its self-management information and were keen to acquire this information, which might be attributed to the effect of self-management guidelines on increasing patients' awareness and satisfaction. These results were consistent with a study conducted by *Saad and Elsayed, (2021)* in Egypt. The **Self-Management Program to Adapt to Multiple Sclerosis Problems and Enhance Quality of Life** reported that there was a highly statistically significant improvement in all items of knowledge regarding disease and self-management at post-self-management program implementation.

Concerning the total self-management of the studied patients with MS, the current study showed that more than one-fifth of the studied patients had adequate self-management of MS. While more than three-fourths of them had adequate self-management of MS, post-implementation of self-management guidelines resulted in a highly statistically significant difference ($p < 0.01$). This emphasizes that Self-management guidelines are key to helping patients adopt positive self-management practices.

This result is in the line with the study about **self-management of falls in people with multiple sclerosis: A scoping review** by *Johnson et al. (2023)*, who assessed how the concept of self-management was defined and used to decrease fall risk among people with multiple sclerosis.

Also, *MScN et al. (2022)* concluded that self-management interventions may promote patient satisfaction with MS and improve adherence to rehabilitation interventions in the study **Nursing Interventions Focusing on Self-Efficacy for Patients with Multiple Sclerosis in Rehabilitation: A Systematic Review**.

In relation to the health practices of the studied patients with MS, the current study revealed that less than one-fifth of the studied patients had an adequate level of health practices regarding MS disease pre-implementation self-management guidelines, which improved to about the majority of them had an adequate level of health practices regarding MS disease with a highly significant difference post-implementation self-management guidelines ($p < 0.01$). This finding confirms that studying patients' health practices regarding MS was found to be one of the main items in self-management guidelines for adapting to MS.

In this finding, *Heidari-Soureshjani et al. (2023)* found that educational self-management interventions (SMI) have an important role in improving symptom management, preventing relapse of multiple sclerosis (MS), and promoting the quality of life of the studied patients.

Also, the finding of the study was supported by *Soheila et al. (2022)*, who clarified that evidence-based self-management interventions may be used to improve care processes and resolve caregiver concerns through research about **The Effect of a Self-Management Program on Care Burden and Self-Efficacy in Family Caregivers of People with Multiple Sclerosis**.

Also, the current study showed that there was a significant positive correlation between the total level of knowledge, total self-management, and total level of health practice scores pre- and post-intervention among the studied patients. So that this positive and significant correlation between them proved that they are indispensable in achieving the guidelines positively for patients with MS disease.

This finding is consistent with the study about **Self-Care Practices and Related Factors in Patients with Multiple Sclerosis (MS) Based on the Health Belief Model** by *Habibi et al. (2021)*, as their findings of the study showed that the more knowledge, perceived benefits, and cues of action in practices increase and perceived barriers decrease, the better self-care is ultimately conducted by the patients.

Conclusion

The implementation of self-management guidelines for patients with MS has a statistically positive effect on their health practices which supports the stated hypothesis.

Recommendations

In light of the findings of the current study, the following recommendations are suggested:

Self-management guidelines should be included in the routine nursing care and rehabilitation process for patients with MS.

A simplified, comprehensive, and illustrated Arabic-language guided image booklet about self-management guidelines and health practices should be distributed for each newly admitted patient diagnosed with multiple sclerosis.

Further research is needed to investigate contributing factors affecting health practices for patients with MS.

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الملخص العربي

تأثير إرشادات الإدارة الذاتية على الممارسات الصحية لمرضى التصلب المتعدد

المقدمة: التصلب المتعدد هو مرض عصبي مزمن يمكن أن يسبب العجز ويؤثر على الدماغ والحبل الشوكي مما يسبب مشاكل جسدية ونفسية واجتماعية مزعجة. ويمكن تعريف إدارة الذات بأنها "قدرة المريض على إدارة تلك المشكلات للتعيش مع هذه الحالة المزمنة".

الهدف: تهدف الدراسة إلى تقييم تأثير إرشادات الإدارة الذاتية على الممارسات الصحية لمرضى التصلب المتعدد.

التصميم: تم استخدام التصميم شبه التجريبي

النتائج: متوسط عمر المرضى الذين شملتهم الدراسة 5.97 ± 35.69 حيث شكلت الإناث 60.2% من المرضى الذين شملتهم الدراسة. كما أن 81.2%، 80.5%، و84.2% منهم حصلوا على مستويات مرضية من المعرفة والإدارة الذاتية والممارسات الصحية بعد تنفيذ إرشادات الإدارة الذاتية. علاوة على ذلك، كان هناك تحسن كبير في المثانة لدى المرضى، والتحكم في الأمعاء، والنشاط الجنسي، والرضا بعد تنفيذ إرشادات الإدارة الذاتية.

الخلاصة والتوصيات: تطبيق إرشادات الإدارة الذاتية لمرضى التصلب المتعدد له تأثير إيجابي إحصائياً على ممارساتهم الصحية ولذلك يجب تحديث إرشادات الإدارة الذاتية لتعزيز معرفة المرضى وممارساتهم الصحية ويجب تضمينها في الرعاية التمريضية الروتينية وعملية إعادة التأهيل للمرضى الذين يعانون من مرض التصلب العصبي المتعدد.