Effect of Self-Care Education on Social Adaptability in Patients with Multiple Sclerosis

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Abstract

Background: Multiple sclerosis (MS) is a chronic disease of the central nervous system (CNS), which affects the adaptability and interaction skills of the patient with family, relatives, and the society. Maintaining proper social relationships is very important for patients with MS.

Objectives: This study aimed to evaluate the effect of self-care education on the social adaptability of patients with MS.

Methods: This randomized clinical trial was conducted on 50 patients with MS, referred to the MS society of Markazi province, Iran. They were selected based on inclusion criteria and were randomly divided into 2 groups, intervention and control. The patients were educated face-to-face, through a 5-session program on self-care behaviors. Social adaptability scores of the groups prior to the intervention and 1 and 4 weeks after the intervention were compared. Demographic data and the personal resource questionnaire (PRQ) were used for data collection. PRO was translated into Persian and assessed psychometrically by the researchers.

Results: In the intervention group, the mean social adaptability score 1 and 4 weeks after the intervention showed a significant increase as compared with the mean score prior to the intervention (57.36 ± 6.6 and 87.8 ± 9.7 , respectively, vs. 29.04 ± 5.6 ; $P = 0.0001$). Such a significant increase was also observed between the social adaptability scores at Week 1 and 4 ($P = 0.0001$). No increase was observed in the scores of the control group. The mean social adaptability score 1 and 4 weeks after the intervention was significantly higher in the intervention group (57.36 ± 6.6 and 87.8 ± 9.7 , respectively) than it was in the control group (30 ± 6.6 and 30 ± 6.6 , respectively) ($P = 0.0001$).

Conclusions: Results of the current study indicate that face-to-face education about self-care behaviors improved social interactions in patients with MS. Hence, this intervention can be utilized to enhance social skills in this patient population.

Keywords: Self-care, Adaptation, Social Support, Multiple Sclerosis

1. Background

Multiple sclerosis (MS) is a progressive chronic disease caused by the demyelination of the central nervous system (CNS) in young adults, which causes disability and reduces personal and social performance (1, 2). MS commonly affects females approximately 2 or 3 times more than it does males (3, 4), and the disease onset usually occurs between the ages of 20 to 40 years (4, 5). The number of patients with MS has been increasing, and based on reports of researchers in the 9th International congress on multiple sclerosis that was conducted in 2012, the prevalence of MS was 73 and 60 per 100 000 individuals in the world and in Iran, respectively (4).

MS is a highly debilitating chronic disease associated with social and economic consequences. The prognosis of MS is unknown, and therefore, patients experience differ-

ent mental and social complications that affect their daily performance, social and familial lives, functional independence, and future planning (6-8). MS affects different aspects of patients' lives; these patients spend the best time of their lives on the disease and its complications instead of participating in social activities and interactions with relatives (9).

MS may dissuade patients from participating in activities they used to enjoy, which can dramatically affect the dynamics of their family. Some studies report that these patients may even lose old friends (7). MS also changes the communication pattern of the family. For instance, some studies report higher levels of anxiety and disruption of social relationships. Patients with MS need to learn how to adjust to the disease, especially handling social interactions. However, it is not easy for patients to learn this on

their own, and it can usually be fostered through effective interventions (10).

Disease, especially when it is progressive and disabling, such as MS, disrupts the communication pattern of patients and causes further unpleasant effects on their lives. These effects in turn can cause maladaptive responses, such as tendency to be alone and isolated, dissatisfaction with others, and inability to communicate, anxiety, nervousness, and depression (11). A study on patients with MS showed that the patients experienced social and familial outcomes of the disease in 4 realms, familial relationships, social relationships, occupational disruption, and failure to meet living expenses (7).

The daily progress of MS and the drug therapy complications suggest that current drug therapy and periodic follow-ups alone are insufficient. Instead, patients should also be assisted using non-pharmaceutical methods that enhance their ability to perform daily activities and reduce barriers. Hence, promoting patients' learning skills increases their decision-making and performing abilities as well as their use of adaptability mechanisms (9,12). Psychological adaptability, resulting from self-care education, can reduce complications of the disease in these patients (13).

Afrasiabifar et al. (2016) believe that self-care empowerment is one of the methods patients can use to cope with the signs and symptoms of MS. This was also stressed upon in the 2014 slogan of the WHO, "healthy life with self-care," which indicates that self-care has the highest priority in medical services. The importance of self-care is confirmed by its success in managing different diseases, such as cardiac failure, asthma, renal diseases, cystic fibrosis, and diabetes (14).

Fraser et al. (2013) reported that self-management assists patients based on the idea that MS symptoms can be controlled better with self-management, consequently improving quality of life (15). Kistner et al. (2013) mentioned, if patients can appropriately manage the complications caused by MS, their interaction with others can improve accordingly. This in turn reduces their maladaptive behaviors and enhances adaptive behaviors (11).

2. Objectives

Considering the problems experienced by patients with MS and the need to improve their adaptability with their current condition, self-care education can be used to increase the adaptability of patients with different aspects of life, especially social relationships. Since the present researchers could not find studies in this area, the present study aimed to evaluate the effect of self-care education on the social adaptability of patients with MS.

3. Methods

3.1. Study Design

A randomized clinical trial was conducted on patients with MS who had been referred to the multiple sclerosis society of Markazi province, Iran, in 2016. The society is a non-governmental organization located in Arak city. It helps patients with medication cost, rehabilitation equipment, free education, and laboratory services.

3.2. Sampling

In total, 50 patients with MS who were referred to the MS Society and met the inclusion criteria were selected, and each of them were assigned a code. Then, using simple randomization (the drawing method), patients were assigned to one of 2 groups, intervention or control. The sample size was calculated based on the following formula used in a previous study (16). Finally, 25 subjects were assigned to each group.

$$S1 = 18.2, S2 = 17.7, \mu_1 - \mu_2 = 14.5, \alpha = 0.05, \beta = 0.2$$

$$n = \frac{\left(Z_{1-\frac{\alpha}{2}} + Z_{1-\beta}\right)^2 (S_1^2 + S_2^2)}{(\mu_1 - \mu_2)^2} \quad (1)$$

Patients who met the following inclusion criteria were eligible for participation in the study: 20 to 65 years of age, educational level of primary school or higher, Arak city residence, ability and willingness to cooperate with the study, signing the informed consent form, member of the Multiple Sclerosis society of Markazi province, experiencing MS symptoms, wheelchair independence, not experiencing the chronic phase of the disease, zero attacks within the last 3 to 6 months, balanced clinical status, expanded disability status scale (EDSS) score > 6, and diagnosed with relapsing and remitting MS.

Additionally, the following exclusion criteria were considered: lack of cooperation, lack of interest in continuing with the program, and death.

Thus, 10 patients were excluded because they did not meet the inclusion criteria, and no patients dropped out during the study (Figure 1).

3.3. Data Collection

To collect data, a questionnaire consisting of 2 parts was used. The first part asked questions about a patient's demographics, such as age, gender, marital status, educational level, occupation, smoking status, disease symptoms, duration of MS, history of using rehabilitative services (physiotherapy, occupational therapy, and speech therapy), and medication. The second part was the personal resource questionnaire (PRQ), which relies on the

Figure 1. Study Procedure

personal beliefs of the patient regarding their social adaptability. The PRQ was first developed by Brant and Weinert in the 1970s, and it has undergone changes over time. The PRQ-2000 is the latest version, and it includes 15 items scored on a 7-point Likert scale. Its total score ranges from 15 to 105, with higher scores indicating a higher level of social adaptability. The PRQ, a self-administered question-

naire, is easy for patients to understand and answer within approximately 15 minutes. Studies have confirmed the validity and reliability of the PRQ and have confirmed an internal consistency between 0.87 and 0.93 (17, 18). Additionally, its divergent validity was compared with that of the center for epidemiological studies depression (CES-D) Scale and its correlation was -0.44 (17, 18).

In this study, the PRQ was translated into Farsi and its psychometric characteristics were assessed.

After the translation process, to assess the content validity, the content validity ratio (CVR) and content validity index (CVI) were calculated.

- The CVR was determined through 10 experts' judgment, and based on Lawshe's table, items with a score of 0.62 or higher were considered acceptable. The calculated score for all items was > 0.8 .

- The CVI was determined by 10 experts using the four-point scale described by Waltz and Bausell. The calculated score was 94.0.

Then, to assess the reliability, internal consistency and test retest methods were considered.

- The internal consistency of the PRQ was assessed using the Cronbach's alpha on data collected from 15 patients. The Cronbach's alpha was 0.78 in the present study.

- For the test retest method, 10 patients completed the PRQ twice, at an interval of one week. The correlation between the two measurements was 0.8.

3.4. Intervention

First, participants in the intervention group were asked to report their availability, and then, their face-to-face education sessions were scheduled accordingly. Sessions were conducted by the researcher in a room at the MS Society. The compiled self-care education program was conducted individually for each participant, based on the educational goals. The program consisted of 5 weekly face-to-face education sessions, and each session was about 45 minutes long (total duration: 5 weeks) (Box 1). The educational content was composed of text reviews and was confirmed by the experts. Educational pamphlets were also used along with the verbal education. Participants of both groups completed the PRQ thrice, prior to the intervention, and 1 and 4 weeks after the intervention (or after the first assessment for the control group).

3.5. Statistical Analysis

Data were analyzed using descriptive statistics and measures of central tendency, and the Chi-square, independent t, Fisher's exact test, and repeated measures analysis of variance (ANOVA). All analyses were conducted using SPSS version 21, and a P value of < 0.05 was considered significant.

The normality of distribution was checked for all quantitative variables, and parametric tests were performed for normally distributed variables, while non-parametric tests were used for non-normal variables. In the present study only the duration of disease was non-normal, which was analyzed using the Mann Whitney test.

Box 1. The Content of the Educational Program

Sessions	Content
1	Introduction, familiarization with the study
	Learning about self-care
2	Familiarization with the disease and its symptoms
	Talking about the patient's problems (need assessment)
3	Answering the patient's questions
	Self-care education regarding fatigue and imbalance problems (improvement methods and related exercises)
4	Answering the patient's questions
	Self-care education about muscular spasm and weakness (improvement methods and related exercises)
5	Answering the patient's questions
	Self-care education regarding elimination problems (improvement methods and related exercises)

The repeated measures assumption was checked, and normality and randomness was established. The Mauchly's test showed that sphericity could not be assumed. Therefore, the Greenhouse-Geisser correction was used to perform the test for the three different assessment points.

3.6. Ethical Considerations

All participants were informed about the aim of the study, were assured about the confidentiality of study data, and signed the written informed consent prior to enrollment. The protocol of this clinical trial was approved by the ethics committee of Arak University of Medical Sciences (Ir.arakmu.rec.1394.81). The study was registered in the Iranian registry for clinical trials (registration code: IRCT2015100224290N1).

4. Results

In this study, a total of 50 participants were evaluated within one of 2 groups, the intervention or control group. Most participants were female and married, with a mean age of 30 years, and most were non-smokers. Most participants also held an associate's degree or bachelor's degree and reported their work status as not employed, students, or clerks. In general, no significant difference was

Table 1. Demographic Data of the Intervention and Control Groups

Variable	Intervention Group	Control Group	P Value
Gender			
Female	15	18	0.3
Male	10	7	
Age (year) (mean ± SD)	3.36 ± 6.075	31.72 ± 7.43	0.48
Marital status			
Married	11 (47.8)	12 (52.2)	0.777
Single	14 (51.9)	13 (48.1)	
Educational level			
Under high school diploma	2 (8)	1 (4)	0.07
High school diploma	6 (24)	1 (4)	
Associate's and bachelor's degree	11 (44)	19 (76)	
Higher education	6 (24)	4 (16)	
Occupational status			
Clerk	6 (22)	19 (76)	0.5
Self-employed	4 (16)	1 (4)	
Student	7 (28)	7 (28)	
Not employed	8 (32)	8 (32)	
Smoker			
Yes	2 (8)	1 (4)	0.999
No	23 (92)	24 (96)	

Abbreviation: SD, standard deviation.

observed between the study groups in terms of any of the studied variables (Table 1).

Among all participants, the average duration of the disease was 31 months. The most common symptom reported was fatigue, followed by muscular spasms and dizziness. Most participants had not used rehabilitation facilities (physiotherapy, occupational therapy, and speech therapy). Cinnovex, ReciGen, and Rebif were the commonly used medications. There was no significant difference between the study groups regarding their knowledge of MS (Table 2).

The results of the independent t test on the mean social adaptability score revealed no significant differences between the intervention (29.04 ± 5.6) and control (30.16

Table 2. Characteristics of Multiple Sclerosis in the Study Groups

Characteristics	Intervention Group, N (%)	Control Group, N (%)	P Value
Signs and symptoms			
0.5			
Numbness	1 (4)	5 (20)	
Urinary incontinence	0 (0)	1 (4)	
Muscular spasms	4 (20)	4 (16)	
Fatigue	10 (40)	8 (32)	
Dizziness	4 (16)	2 (8)	
Feeling of imbalance	5 (20)	5 (20)	
Duration of disease (month) (mean $\pm$ SD)	23.36 $\pm$ 18.5	25.28 $\pm$ 19.7	0.747
Use of rehabilitation facilities			
0.75			
Yes	7 (28)	8 (32)	
No	18 (72)	17 (68)	

Abbreviation: SD, standard deviation.

± 6.6) groups before intervention ($P = 0.5$). However, the intervention group's social adaptability score was significantly higher at week1 (57.36 ± 6.6) and week 4 (87.8 ± 9.7) after the intervention as compared to that prior to the intervention (29.04 ± 5.6) ($P = 0.0001$). There was no significant change in the control group's scores across the three assessment points (Table 3). The mean social adaptability scores in the intervention group, both at 1 and 4 weeks after the intervention (57.36 ± 6.6 and 87.8 ± 9.7 , respectively), were significantly higher than those in the control group were (30 ± 6.6 and 30 ± 6.6 , respectively) ($P = 0.0001$) (Table 4 and Figure 1).

5. Discussion

This study aimed to evaluate the effect of self-care education on the social adaptability of patients with MS. A total of 50 participants were assigned to the intervention and control groups (25 in each). Most of them were female, with a mean age of 30 years. Previous studies indicate that MS is more common in females within the age range of 20 to 40 years (4, 13). The most common symptoms among the present study participants were fatigue, muscular spasm, and dizziness. Fatigue was reported as the most common and disabling complication associated with MS, and its prevalence among participants was dramatically high (19).

Table 3. Adaptability Score of the Study Groups Prior to the Intervention, and 1 and 4 Weeks After the Intervention

Adaptability	Group				Independent t Test		
	Intervention		Control		Statistic	Degree of Freedom	P Value
	Mean	SD	Mean	SD			
Prior to intervention	29.04	5.6	30.16	6.6	-0.642	48	0.5
1 week after intervention	57.36	6.6	30	6.6	14.5	48	0.0001
4 weeks after intervention	87.8	9.7	6.4	30	24.8	48	0.0001

Abbreviation: SD, standard deviation.

Table 4. Paired Comparison of Adaptability Scores Prior to Intervention, and 1 and 4 Weeks After the Intervention in the Study Groups

Adaptability score	Assessment Period		Intervention Group			Control Group		
	Assessment Period	Assessment Period	Mean Difference	SD	P Value	Mean Difference	SD	P Value
	Prior to intervention	Week 1	-28.3	1.5	0.0001	0.16	0.27	0.566
		Week 4	-56.7	2.5	0.0001	0.16	0.25	0.538
	Week 1	Week 4	-30.4	1.9	0.0001	0	0.15	0.999

Abbreviation: SD, standard deviation.

Figure 2. Comparison of the Mean Adaptability Scores Prior to Intervention, and 1 and 4 Weeks After the Intervention in the Two Study Groups

The social adaptability score was assessed in both study groups, and results showed no significant difference between the groups prior to the intervention. However, post intervention, the mean score of the intervention group was significantly higher at week 1 and 4 as compared to that prior to the intervention. Some studies indicate that self-care education can affect other outcomes in patients with MS. In a quasi-experimental pretest-posttest study, the mean score of quality of life in physical health, pain, fa-

tigue, concept of health, health status changes, sexual activities, and the total score on quality of life significantly improved after the intervention (20). According to other studies, self-care education could positively affect the outcomes of other diseases. For example, in patients with migraine, self-care education could significantly improve quality of life aspects, such as physical functioning, physical role limitation, bodily pain, general health, social performance, emotional role limitations, and mental health (21). In patients with MS, various types of non-conventional interventions have been found to improve quality of life. For example, one study evaluated the effects of a creative art program (which included watercolor, collage, and embroidery) on the self-confidence, hope, perceived social support, and self-efficiency of females with MS. The results showed participants score improved on all the variables assessed (22).

Based on the results of this study, social adaptability scores were significantly different between the two groups at 1 and 4 weeks after the intervention. In other words, the social adaptability score in the intervention group showed a significant increase at weeks 1 and 4 after the intervention as compared with that in the control group. Another study indicated that educational interventions can significantly increase the knowledge and self-efficiency of patients with MS regarding pain control (23). Additionally, a study that evaluated the effect of an education program on the self-management abilities of patients with MS indicated that this program increased patients' self-management abili-

ties and quality of life, and decreased their anxiety (24). Another study showed that self-care education can improve MS patients' sleep quality significantly (25). In another study, life skills training was found to have a significant effect on enhancement of patients' adaptation with MS (26). Litchfield and Thomas (2010) believed that self-care is increasingly recognized as an important component of the management of all long-term conditions, including MS. People with MS need access to timely and appropriate information (27).

Other types of interventions were also performed on the patients with MS; for example, a study on the impact of aqua sports intervention in females with MS found that, following the intervention, fatigue reduced significantly in the intervention group as compared to that in the control group (28).

In some studies, other outcomes were considered. For example, a care program based on the Roy adaptation model decreased the mean fatigue scores in MS patients (29).

5.1. Conclusion

The disabling nature of MS affects all daily activities of patients, especially their relationship patterns with families and friends. The design and implementation of education programs focusing on self-care skills can enhance patients' sense of independence and competence, increase their ability to cope with problems related to the disease, and, accordingly, improve their adaptability skills, especially when interacting with others. The positive results of self-care education suggest that healthcare professionals should integrate such programs in the care plan for patients with MS, and these programs should be implemented in care centers and patient societies formally and regularly.

There were some limitations in the present study. Subjects were selected only among patients referred to the MS society of Markazi province and other patients were not included. Further, the number of subjects was limited. It is recommended that the same study be carried out on a larger sample, for a longer duration. All patients in this study had relapsing-remitting MS, and a study on other types of MS is recommended.

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Footnotes

Conflict of Interest: Authors declare no conflicts of interest.

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