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Original Article

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Effect of Family-centered Empowerment Model on Self-care Behaviors of Patients with Multiple sclerosis

Farshid Mohammad Mousaei[1], Hamid Reza Zendehtalb[2*], Masood Zare[2], Hamid Reza Behnam Vashani[3]

Abstract

Background: Self-care behaviors contribute greatly to the management of multiple sclerosis (MS) and the prevention of its complications. The family has a critical role to play in the adoption of these behaviors in these patients. The present study aimed to assess the effect of the family-centered empowerment model on the self-care behaviors of MS patients.

Method: This experimental study was performed on 60 patients referred to the MS Clinic of Ghaem Hospital in Mashhad in 2020-2021. The subjects who met the inclusion criteria were non-randomly assigned to two groups of control and experimental. Data collection tools included the demographic information form and the Performance Assessment of Self-care Skills (PASS) which were completed before and one month after the intervention in both groups. The educational content was presented to the experimental group in eight 45-60 min sessions in accordance with the family-centered empowerment model, while the control group received the routine training. Data were analyzed in SPSS software (version 16) using independent t-test, analysis of variance, and Mann-Whitney test.

Results: The majority of participants in the experimental and control groups were female, single, and hold a diploma. The mean total scores of self-care behaviors after the intervention were obtained at 38.86±6.24 and 42.20±6.17 in the control and experimental groups, respectively. After the intervention, the mean total score of self-care behaviors and their dimensions in the experimental group was significantly higher than that in the control group (P<0.05).

Implications for Practice: Hugo point massage with ice is suggested to be used as an available, efficient, and cost-effective method before arterial blood sampling.

Keywords: Family-centered empowerment model, Multiple sclerosis, Self-care

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Introduction

Multiple sclerosis (MS) is the most prevalent non-traumatic cause of neurological disability in young people (1). This disease causes fatigue, sensory and motor disorders, sphincter changes, optic neuritis, diplopia, cerebellar syndrome, gait Abnormalities, spasticity, and cognitive impairment (2). Various factors, such as genetic, defective immune system, environmental factors, such as viral infections, and stress have been proposed to promote this disease (3). The age of onset for MS ranges within 20-40 years (4) (mean age of 30 years), and women have a two to three times higher risk of developing this disease (5).

 According to the Multiple Sclerosis International Federation (MSIF), more than 2.3 million people worldwide are inflicted with this disease (4) and 8,000 new patients are diagnosed each year (5). Conservative estimates suggest that there are currently 400,000 MS patients in the United States (6). The Iranian MS Society reported about 70,000 MS patients in Iran (7).A number of 4,800 MS patients have been identified in Khorasan Razavi province. Several studies pointed to high levels of stress, low self-esteem, depression, and mental distress in these patients (8). About 60%-50% and 25%-40% of patients suffer from depression and anxiety, respectively (9).

Moreover, 68% and 44% of MS patients' families experienced anxiety and depression, respectively. It has also been found that families experience high levels of fatigue and anger (10). The side effects of MS treatment suggest the inadequacy of current medication and periodic follow-ups. Therefore, patients should be helped to use non-pharmacological methods to increase their ability to perform daily activities and overcome obstacles. Therefore, the enhancement of patients' learning skills increases decision-making, performance, and adaptation mechanisms (5, 11).

Evidence suggests that self-care behaviors can help prevent and control numerous psychological and physical consequences of chronic diseases and reduce their economic burden. Therefore, assiduous attention should be devoted to counseling and the empowerment of patients (both physical and mental) (4). The World Health Organization defines self-care as the activities performed to promote health, prevent disease, and restore health. These activities are derived from knowledge and skills gained from professional and intervention experiences. They are performed by non-specialists on their own or in partnership with specialists (6).

The results of some studies on MS patients have pointed out that self-care programs not only reduce the adverse effects of MS, including depression, anxiety, and stress but also elevate self-esteem (7, 12). In the same context, in their study, Farazian et al. (2019) concluded that people's self-efficacy can affect the effort they made to achieve a specified goal and their overall performance. Therefore, these concepts are typically a part of programs designed to improve self-care in patients with chronic diseases (13).

Empowerment is a suitable scientific solution to create and strengthen these abilities in people. Self-efficacy as one of the most important components in empowerment refers to the ability of a person to attain the desired consequence. It is also defined as one's perception or judgment about his/her ability to successfully perform a particular action by controlling the surrounding factors (8). The social, physical, psychological, and physiological dimensions of this disease require the use of a comprehensive model.

In this regard, one of the models of health education is the family-centered empowerment model developed by Alhani to prevent iron deficiency anemia in adolescent girls (14). So far it has been performed in chronic diseases, such as thalassemia (15), hemophilia (16), diabetes (17), asthma (18), and MS (19). The family-centered empowerment model has been designed with an emphasis on the role of the family in the dimensions of motivation, psychology (self-confidence, self-control, and self-efficacy), and the characteristics of the problem itself (knowledge, attitude, and perceived threat) (14). This model puts an emphasis on the involvement of family members to offer support to patients, especially in chronic diseases that require home care (20). Family can cooperate with health system personnel in care program, such as medication, nutrition, physical activity, examination of symptoms, control, and even making changes in the program based on the patient's new condition (21, 22). The quality of care and self-care behaviors can be improved and many health problems can be prevented by implementing the family-centered empowerment program (23 The educational interventions in family-centered care aim to promote self-care capabilities to overcome the existing barriers to health and wellness. In light of the aforementioned issues, the present study aimed to assess the effect of the

family-centered empowerment model on the self-care behaviors of patients with multiple sclerosis.

Methods

This experimental study was conducted based on a pre-posttest design from 2020-2021. Based on the findings of the study by Kerman Saravi study (24), the formula of comparison of means, 95% confidence interval, and 90% statistical test power, the sample size was calculated at 28 cases for each of the experimental and control groups. Finally, considering sample attrition, 60 patients with MS were determined as the sample size. Before the commencement of the study, it was approved by the Ethics Committee of the School of Nursing and Midwifery, Mashhad University of Medical Sciences. The letter of introduction was obtained from relevant authorities and presented to the head of the MS clinic in Ghaem Hospital.

This center was selected due to its easier access to research participants. In order to maintain confidentiality, the list of active patients was initially received from the head of MS Clinic. The subjects were non-randomly assigned to the experimental and control groups. To this end, the patients who were referred to the clinic on even days were assigned to the experimental group, and those who were referred on odd days were allocated to the control group. The participants were provided with the objectives of the research and signed the written consent. The data collection tools included demographic information form and the Performance Assessment of Self-care Skills (PASS).

The PASS consisted of 25 items in three domains of functional mobility(n=2), basic activities of daily life (n=7), and instrumental activities of daily life(16). The items are rated on a three-point Likert scale ranging from 0-2, and the scores range from 0-50, with higher scores indicating greater independence, safety, or adequacy. This questionnaire was translated and used by Azadi et al. (25) according to the cultural conditions of our country, and since some items were modified in the present study, their validity was determined using content validity.

Therefore, in order to evaluate the content validity of this tool, the content validity ratio(CVR) and content validity index(CVI) were also assessed. To calculate the CVR, three options were considered for each item, (1: necessary, 2: useful but unnecessary, and 3: unnecessary). It was provided to 10 relevant professors and specialists. The CVR coefficients were obtained at 0.65 and 0.79 for each item. Given that all these values are greater than the minimum standard value for 10 professors (0.62), the content validity of all items in this questionnaire was confirmed.

In addition, to calculate the CVI, four options were considered for each item (1: unrelated, 2: the need for serious review, 3: relevant but needs to be reviewed, 4: completely relevant) and the questioner was provided to 10 professors and specialists in this filed. The mean score of CVI coefficients of the items was reported as 0.86. Since the CVI of ≥0.80 is acceptable for this kind of instrument, the content validity of this questionnaire was confirmed. Furthermore, the internal consistency method was used to determine the reliability of this scale. In this regard, the self-care behaviors of 20 subjects were initially measured; thereafter, Cronbach's alpha coefficients were calculated for each dimension and overall score.

Cronbach's alpha coefficients were obtained at 0.79, 0.84, 0.83, and 0.88 for the dimensions of functional mobility, basic activities of daily life, instrumental activities of daily life, and the overall score of self-care behaviors, respectively. The inclusion criteria were as follows: written consent to participate in the study, non-participation in similar educational programs, no history of other diseases, such as mental and cognitive disorders, No history of drug addiction and other neurological disorders, affliction with MS for more than one year, homogenization of MS patients based on disease severity (progressive relapsing, relapsing-remitting, primary progressive, and secondary progressive).

On the other hand, the exclusion criteria entailed participation in a similar training program during study and absence in training sessions more than once. Data analysis led to the identification of limitations, needs, and weaknesses of the study population in various fields. Subsequently, changes were made in the family-centered empowerment program to fit the needs of participants. Training sessions were held once a week (Tuesday) in groups of 6 at the MS Clinic of Ghaem Hospital. The educational content encompassed complications and risks of the disease, nature of MS, relief of patients' fatigue and physical problems, concerns over the recurrence of the disease, explaining the required skills, the need for lifestyle changes, self-care, the effects of the disease on caregivers' lifestyle, the burden of care, and its effective management.

Since this study was performed in experimental and control groups, the training program was only conducted for the experimental group during eight 45-60 min sessions in the form of lectures, group

discussions, questions and answers, practical demonstrations, and brainstorming. Due to the mandatory presence of patients in the MS clinic of Ghaem Hospital and taking into account the conditions of the Covid-19 pandemic, training sessions were held in the MS clinic in adherence to social distancing protocols and hygienic behaviors (distance of 2 m, ventilated rooms, and personal protective equipment (face masks, gloves, and antiseptic gel). The family-centered empowerment model was performed based on the following steps:

Perceived threat
The images of patients who were hospitalized for neurological complications due to the lack of self-care were provided to participants in order to create a perceived threat. The participants visited inpatients to learn about the problems caused by disease mismanagement and non-compliance of self-care behaviors.

Enhancement of self-efficacy
To create self-efficacy, some self-care behaviors, such as getting out of bed, bathing, aerobic exercise, and kegel exercises were taught to patients in detail. The patient was then asked to perform the relevant technique in front of the researcher. While performing the technique, their self-efficacy was tried to be enhanced by encouragement.

Educational participation
In this stage, patients were asked to share what they had learned about their disease with a family member who is their primary caregiver. Upon the completion of these training sessions, during a face-to-face meeting, the active member of the family was asked about patient care. In this meeting, apart from process evaluation, the researcher also resolved the probable problems.

Assessment
During the intervention process, the subjects were asked about the content of previous sessions. One month after the last empowerment session for the experimental and control groups, a post-test was performed. Data were analyzed in SPSS software (version 16). Descriptive statistics included frequency distribution, mean, and standard deviation. In analytical statistics, the normality of quantitative variables was first assessed using Kolmogorov-Smirnov and Shapiro-Wilk tests. The independent t-test (and its non-parametric equivalent test (Mann-Whitney) in case of abnormal distribution) was used for intergroup comparison in each evaluation stage. Moreover, for intragroup comparisons, paired t-test or Wilcoxon test were used. A p-value of less than 0.05 was considered statistically significant.
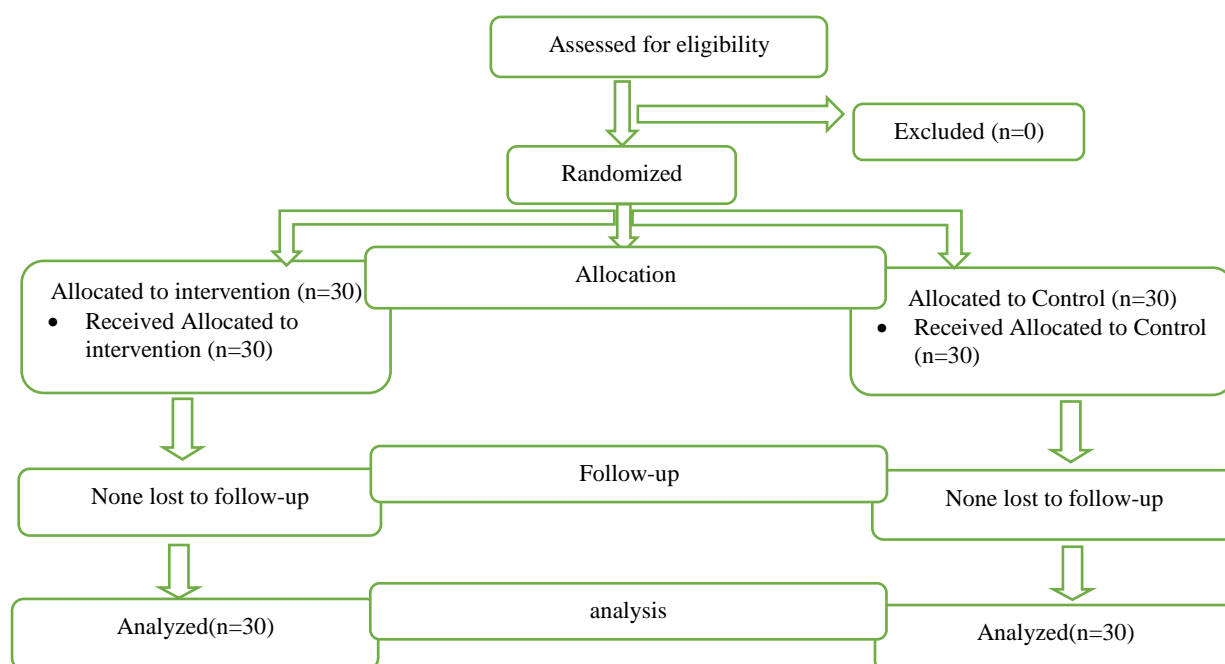
Figure 1. Study flow chart

Participation in the research was optional, and the subjects were explained about the objectives of the research and the confidentiality of information. The results were analyzed and published anonymously in accordance with ethical considerations. Furthermore, during a public session, all the educational issues were taught to caregivers and patients in the control group, and educational pamphlets were provided to them.

Results

The mean duration of MS and the age of patients in the experimental and control groups were reported as 27±4.44, 4.6, 6±06, 35.80±12.10, 38.86±12.81, respectively. According to the Mann-Whitney U test, the two groups were homogeneous in terms of variables (P<0.05). In terms of gender, the majority of patients in both groups were female. Demographic variables of the duration of MS, age, gender, marital status, level of education, type of MS, occupation, and income of the patient did not significantly differ between the experimental and control groups, and the two groups were homogeneous in this regard (Table 1) (P>0.05).

The mean total scores of self-care behaviors after the intervention were calculated at 42.20±6.17 and 38.86± 6.24 in the control and experimental groups, respectively. The results of the Mann-Whitney test showed a significant difference in this regard (P=0.02). Moreover, intragroup comparison using the Wilcoxon test in the experimental group displayed a significant difference in the total score of self-care behaviors after the intervention (P<0.001). In addition, the total score of self-care behaviors increased after the intervention, as compared to that before the intervention in the experimental (3.3±4.3) and control groups (-0.4±1.8). Mann-Whitney U test showed a significant difference (P<001) (Table 2).

After the intervention, the mean scores of daily activities, instrumental activities of daily life, and functional mobility of MS patients in the control group were obtained at 3.5±0.6, 25.4±3.3, 9.2±8.3, respectively. In the experimental group, these values were reported as 3.8±0.3, 27.3±3.9, 11.2±0.5,

Table 1. Demographic characteristics of qualitative variables in patients with multiple sclerosis

		Groups		
	Variable	Experimental (n=30)	Control (n=30)	Test results
Gender Number(percent)	men	13(43.3)	9(30.0)	P=0.28*
	women	17(56.7)	21(70.0)	
Marital status Number(percent)	Single	18(60)	20(66.7)	P=0.62 **
	Married	7(23.3)	6(20.0)	
	Divorced	3(10.0)	4(13.3)	
	Widow/widower	2(6.7)	0(0.0)	
MS surface type Number(percent)	Progressive relapsing	4(13.3)	5(16.7)	P=0.59**
	Primary progressive	8(26.7)	12(40.0)	
	Relapsing Remitting	14(46.7)	9(30.0)	
	Secondary progressive	4(13.3)	4(13.3)	
Educational level Number(percent)	elementary	3(10.0)	6(20.0)	P=0.17**
	high school	4(13.3)	0(0.0)	
	Diploma	12(40.0)	12(40.0)	
	university	11(36.7)	12(40.0)	
Job Number(percent)	housekeeper	11(36.7)	18(60.0)	P=0.05**
	Employee	8(26.7)	8(26.7)	
	Labor	0(0.0)	1(3.3)	
	Other (free)	11(36.7)	3(10.0)	
Income Number(percent)	Not at all	10(33.3)	12(40.0)	P=0.43**
	Low	4(13.3)	3(10.0)	
	Moderate	15(50.0)	11(36.7)	
	Enough	1(3.3)	4(13.3)	

∗Chi-squared test ∗∗ exact Chi-squared test

Table 2. Mean and standard deviation of the total score of self-care behaviors of patients with MS before and after theintervention in the experimental and control groups

Total score of self-care behaviors	Groups		Intergroup test result
	Control (n=30) Mean±SD	Experimental (n=30) Mean±SD	
Pre-intervention	39.30 ± 6.42	38.86±9.18	P=0.83 ∗
Post-intervention	38.86±6.24	42.20±6.17	P=0.02∗∗
Differences between pre- and post-interventions	.-0.44±1.84	3.33±4.30	P<0.001 ∗∗
Intragroup test results	P=0.07 ∗∗∗∗	P<0.001 ∗∗∗	

∗ T independent ∗∗ Mann-Whitney U test ∗∗∗ Wilcoxon test ∗∗∗∗ Paired t-test

respectively. The result of the intergroup test (Mann-Whitney U) demonstrated that this difference was statistically significant (P>0.05). Intragroup comparison (Wilcoxon test) in the experimental group showed that the dimensions of daily activities, instrumental activities of daily life, and functional mobility were significantly different after the intervention, as compared to beforer the intervention (P<0.05).

In addition, according to the Mann-Whitney U test, the total score of daily life activities dimension after the intervention did not show a significant difference, compared to that beforer the intervention (P=0.103). Nonetheless, after the intervention, the total score of instrumental activities of daily life and functional mobility in the experimental group illustrated a significant difference, compared to that beforer the intervention (P<0.05) (Table 3).

Table 3. Mean scores of different dimensions of performance of self-care behaviors of patients with multiple sclerosis before and after experimental in the experimental and control groups

Variables		Groups		
		Control (n=30) Mean±SD	Experimental (n=30) Mean±SD	Intergroup test results
activities of daily living	Pre-interventionimental	3.53 ± 0.77	3.56 ± 0.72	P= 0.93∗
	Post-intervention	3.50 ± 0.62	3.86 ± 0.34	P=0.009∗
	Differences between pre-and Post-intervention	-0.03± 0.61	0.30 ± 0.74	P=0.01∗
	Intragroup test results	P=0.73∗∗	P=0.03∗∗	
instrumental activities of daily living	Pre-intervention	25.66±4.52	25.48±8.98	P= 0.79∗
	Post-intervention	25.36±4.35	27.33±3.95	P= 0.04∗
	Differences between pre-and Post-intervention	-0.30±1.64	1.86±2.80	P=0.001∗
	Intragroup test results	P=0.27∗∗	P=0.001∗∗	
Functional mobility	Pre-intervention	10.10±2.04	9.83±3.15	P= 0.88∗
	Post-intervention	9.80 ± 2.38	11.00±2.59	P= 0.04∗
	Differences between pre-and post-intervention	-0.30±1.08	1.16±1.68	P<0.001∗
	Intragroup test results	P=0.14∗∗∗	P=0.002∗∗	

∗ Mann-Whitney U test ∗∗ Wilcoxon test ∗∗∗ Paired t-test

Discussion

As evidenced by the results of the present study, the intervention based on the family-centered empowerment model increased the self-care behaviors of MS patients. Along the same lines, the results of the study by Habibnia et al. (2017) pointed out that self-care education improves the performance of MS patients; therefore, it can be used as an effective intervention in this regard (26). The findings of the mentioned study were in agreement with the results of the current research; however, the use of the family-centered empowerment model increased the self-care behaviors of MS patients in the present study.

Consistent with the results of the present study, Habibi et al. (2019) conducted research on MS patients

based on the health belief model. The results showed that the quality of life of MS patients was strongly influenced by self-care behaviors. Since perceived benefits and signs of action are the main predictors of self-care measures, interventions based on these two constructs can be used to improve self-care programs and quality of life in MS patients (27). This study indicated that the use of health interventions improves self-care behaviors in MS patients. The study population was similar to the present study; nonetheless, in the stated study, the health belief model was used for MS patients, while in the current research, the family-centered empowerment model was implemented.

In their study, Ciol et al. (2017) concluded that MS patients with a score higher than 3.50 in Expanded Disability Status Scale had a statistically significant reduction in timed up and go test performance even with the addition of a simple cognitive task, and it may affect complex daily activities (28). Hina Garg et al. (2016) also concluded that fatigue is one of the predominant symptoms in study participants, and those with higher levels of fatigue showed more serious impairment in functional mobility, depression, as well as physical and mental health (29).

The results of these studies confirmed the findings of the present study which reported that the application of the family-centered empowerment model can improve functional mobility, which in turn, enhances self-care behaviors. According to the findings of this study, in the rehabilitation of MS patients, daily activities need to be tracked as a part of occupational therapy intervention. The usefulness of occupational therapy interventions, along with educational interventions, in improving the daily instrumental activities of patients with MS in various studies is indicative of more assiduous attention to this issue, which in turn, improves self-care behaviors (30, 31). The findings of the study by Salter and Walshaw are consistent with these results.

The results suggested that balance and independence in daily life activities can predict the quality of life in MS patients. Accordingly, in the interventions performed for the rehabilitation of MS patients, important factors, such as quality of life and daily living skills, should be taken into account. Rehabilitation and instructions for daily life activities can seemingly improve the physical dimension in the lives of MS patients. This finding is in line with the results of Dehghani and Noori (32, 33). Based on the findings of the present study, self-care behaviors of MS patients were not significantly correlated with age, gender, marital status, education level, occupation, income, type of MS, and duration of MS (4, 26, 34).

Implications for Practice
The results of the present study pointed out that the constructs of the family-centered empowerment model, especially the perceived threat and self-efficacy, are able to empower patients and their families in self-care management. The perceived threat was able to motivate patients to engage in self-care behaviors by highlighting the adverse effects and problems which arise from inappropriate self-care. Moreover, the self-efficacy construct led patients to realize that they were able to easily perform numerous self-care behaviors. Patients' quality of life can be enhanced by encouraging patient responsibility, their participation in empowering themselves, and involving their families in health education which improves knowledge, attitude, and performance. Based on this finding, this educational method can be effectively used to educate patients' families and elevate the level of care.

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Conflicts of Interest
The authors declare that they have no conflict of interest.

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