

The Effect of Implementing an Educational Program on Adherence to Treatment and Self-compassion of Patients with Multiple Sclerosis

Hanie Dahmardeh¹, Mahnaz Rakhshan^{2,3*}, Farshid Saeedinezhad³, Roya Dokoohaki²

¹Community Nursing Research Center, Department of Medical-Surgical Nursing, Faculty of Nursing, Zahedan University of Medical Sciences, Zahedan, Iran.

²Community Based Psychiatric Care Research Center, School of Nursing and Midwifery, Shiraz University of Medical Sciences, Shiraz, Iran.

³Student Research Committee, School of Nursing and Midwifery, Shiraz University of Medical Sciences, Shiraz, Iran.

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ABSTRACT

Background: Multiple sclerosis, as one of the most important causes of disability in the world, can cause a feeling of despair in a person to be compassionate and follow his treatment, so it is important to use self-compassion methods for these patients. Therefore, the present study was conducted with the aim of determining the effect of the educational program on treatment compliance and self-compassion of patients with multiple sclerosis.

Methods: In the current clinical trial study, 80 patients with multiple sclerosis, members of the MS Association of Zahedan city in 2023-2024, were selected by the available method and randomly divided into two groups of 40 people, intervention and control. 8 sessions of face-to-face educational program were designed and implemented for patients, and the rate of application of the programs by patients was followed up under the supervision of the researcher. Before, one month and 3 months after the implementation of the intervention, patients' adherence to treatment was measured using the "Treatment Adherence in Chronic Patients" questionnaire and self-compassion was measured using the "Multiple Sclerosis Patient Self-Compassion Assessment Questionnaire". The data were analyzed using statistical tests of repeated measures, Chi-Square under SPSS 21 statistical software at a significance level of less than 0.05.

Results: The average age of the intervention group was 40.05 ± 9.61 years and in the control group was 40.13 ± 8.78 years, and according to the findings, before the intervention, there was a statistically significant difference between the variables of gender, age, education level, marital status in Two intervention and control groups were not observed. The results of the independent t-test show a statistically significant difference between the average changes in the total score of adherence to treatment and the average total score of self-compassion after the intervention ($P=0.000$).

Conclusion: The results of the present study showed that the present educational program can increase self-compassion and adherence to treatment in patients with multiple sclerosis, so it is necessary to take advantage of it in rehabilitation programs to promote or improve the mental and psychological conditions of patients.

The authors declare no conflicts of interest.

*Corresponding author.

E-mail address: mzhakhshan@gmail.com

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Introduction

Chronic diseases are one of the most important health and treatment issues, because they are permanent, debilitating and accompanied by irreversible damage that is impossible to cure [1]. Meanwhile, multiple sclerosis is a chronic, progressive and common inflammatory disease of the nervous system, the cause of which is unknown [2], but in most cases, autoimmune mechanisms are considered to be effective in causing the disease [3].

Geographically, the spread of this disease is very high in northern Europe, southern Australia, northern parts of the United States and southern parts of Canada [4], so that currently 2.5 million people are suffering from this disease [5] and 1.5 annually. Up to 11 people per 100,000 people get this disease and this number is still increasing [4]. In Iran, the number of patients with multiple sclerosis has increased in recent years, according to the available statistics, it is estimated that there are 30 to 50 thousand people with this disease in Iran, and 7 thousand new patients are added to it every year. [4]. This disease can affect people at any age, but it is especially seen in young people aged 20-40 years [6-7]. The age at which a person has the most family and social responsibilities, as a result, harms the productive forces of society and can cause problems in playing the role and social relations of these patients [2]. These problems, following early and early symptoms and complications such as vision disorders, pain, urinary incontinence and weakness, also threaten a person's independence and ability to be an effective presence in the family and society, and as a result, affect all aspects of the patient's daily life [6]. Therefore, living with multiple sclerosis is challenging and multidimensional and affects all aspects of a person's life and gradually leads him to disability [7].

Due to the uncertainty of the exact cause of multiple sclerosis, there is no definitive treatment for this disease, so the goal of treatment is to prevent the progression of disability, chronic attacks or disease recurrence and control the disease. However, in addition to the symptomatic treatment that should be done for all patients, some patients should also receive immunosuppressive and modulating treatments [8-9]. Therefore, the successful treatment of this disease, considering its chronic nature, requires that for a long period of time, a person should follow the special medication regimen provided by the treatment team [10], which is only possible with the active participation of the patient in the treatment and the implementation of the recommendations of the treatment team members, which is referred to as adherence to the treatment [11].

Adherence to treatment includes the three concepts of acceptance, persistence and adaptation. Before patients can follow a long-term drug regimen, they must first

accept its necessity and continue the treatment after accepting the drug regimen. Acceptance includes following the usual prescribed instructions such as taking medicine at the right time, with the right dose and on the right day [12] and it is important to pay attention to the fact that the treatment of the disease does not rely only on the acceptance of the drug regimen and to pay attention to other aspects of the treatment. Diet, weight control, follow-up of visit time and lifestyle changes are essential in measuring compliance with treatment [13].

In patients with multiple sclerosis, treatments can control the symptoms and progress of the disease to some extent, but due to the long-term nature of the treatments, patients often have difficulty in complying with them, therefore they may not get the maximum clinical benefit [14]. According to statistics, the percentage of people who strictly follow the treatment recommendations varies from 49 to 93 percent [12]. The level of adherence to treatment in patients with multiple sclerosis has not been satisfactory [13,15], the reasons for which are long periods of treatment, frequent injections, fear of side effects, disappointment, lack of motivation-awareness, and unfulfilled expectations of treatment. [16]. Other reasons for non-compliance with treatment include lack of understanding of treatment effects, reaction to injection and other side effects of treatment [17]. Also, forgetfulness has been mentioned as one of the most important factors of non-compliance with treatment, which causes the patient to take the prescribed medicine less frequently than what the doctor prescribed [18].

It is important to note that poor compliance or non-compliance of patients with treatment is one of the main reasons for treatment failure, increasing disease complications, prolonging the duration of treatment and increasing health care costs. If the patient does not use the recommendations of the health system staff, even the best treatment regimens will become worthless [19-20]. Therefore, the goal of treatment based on acceptance and commitment is to create psychological flexibility, which means the ability to choose an action that is appropriate among the available solutions, not an action to avoid stressful emotions and thoughts [21]. Due to the use of techniques such as acceptance of conditions, mental awareness of everyday issues, living in the present, separation from thoughts and committed action, this treatment improves psychological characteristics by increasing flexibility in behaviors [23-25].

Compassion-based therapy consists of three components, including kindness to oneself in hardships and stressful experiences instead of self-judgment, human commonality and the inevitability of suffering and failure instead of isolation, and balanced awareness of one's feelings and thoughts instead of extreme assimilation. In other words, self-compassion is an adaptive way to communicate with oneself when being aware of one's inadequacies and facing difficult life

conditions such as critical periods of life, interpersonal problems, leaving behind traumatic events and natural disasters and diseases. It is chronic. Also, full self-acceptance, while we are in pain and suffering, also makes sense and is also related to mental health and is considered as a potentially important protective factor that promotes the development of emotional resilience and coping. This means that self-compassion is a moderate emotional reaction of people to negative events and helps people to evaluate themselves and their life experiences more accurately, and ultimately causes people's sad and anxious reactions to natural events, imaginary and real negative events to decrease [22].

Teaching self-compassion programs affects brain areas related to stress such as amygdala and cingulate. Despite this importance, the effect of teaching self-compassion programs on behavioral responses related to stress and neurobiology is less known. [17]. In compassion-based therapy, people learn not to avoid or suppress their painful feelings. Also, self-compassion can activate a kind of biological care system in a person that regulates stress and compassionate behaviors and creates beneficial biological and psychological effects for a person against social stress [23]. Self-compassion can improve self-regulation by reducing defensive responses, emotional states and self-blame, as well as increasing compliance with medical recommendations [23]. In addition, a compassionate mind with its associated adaptive coping skills helps maintain optimistic expectations about the future [24]. This, in turn, leads to improved treatment compliance. Self-compassion and compassion-focused therapy are effective in improving and increasing people's optimism about their abilities when facing challenging situations [25].

By teaching self-compassion systems, which increases emotional flexibility, it can neutralize the threat system and activate the care system [26]. The research literature indicates the effectiveness of these treatment methods on reducing symptoms of disorders and improving people's performance. Also, people with physical disorders have less self-compassion compared to healthy people [23].

Considering the high prevalence of multiple sclerosis and the role of this disease in reducing health and psychological well-being, the necessity of intervention to improve the well-being of those suffering from this disease is determined. Another important point is that many methods of improving psychological well-being were evaluated, but the effectiveness of treatment based on compassionate interaction has received less attention. Considering the point that if we strengthen self-compassion in multiple sclerosis patients, we can change their mental attitude towards their conditions by increasing the abilities of these patients and obtain better results, this study aims to investigate the effect of implementing the self-compassion program was

implemented on the adherence to the treatment of patients with multiple sclerosis.

Methods

The present study was conducted in a semi-experimental manner. The research community consisted of all patients with multiple sclerosis who were members of the Zahedan MS Association in 2011-02. According to the study of Izanlou et al. (2019) ($S_1=4.22$, $S_2=4.33$, $S_2=43.33$ and 34.60) for each group, the sample size was estimated to be 40 [27]. A total of 80 people were included in the study using the available method and were placed in two intervention and control groups using a random number table, but 6 people from the intervention group and 10 people from the control group were excluded from the study due to non-return and cooperation. The final analysis of the data was done with 64 people.

The criteria for entering the study include: definite diagnosis of multiple sclerosis by a treating physician, age between 20-50 years, having literacy, not suffering from other acute or chronic physical, mental or mental disorders such as severe depression, speech or hearing disorders, and Non-participation in classes or educational workshops at the same time and criteria for withdrawal from the study include: the occurrence of serious complications of the disease (severe movement disorders, vision), hospitalization or death of the patient during the study, absence of more than one session in the training session, unwillingness to continue participation. In the study, it was for any reason. The data collection tools included: questionnaire of personal characteristics and questionnaire of adherence to treatment in chronic patients, self-compassion questionnaire of MS patients.

Questionnaire of personal characteristics: It included questions to measure age, sex, education level, marital status and duration of illness, which were completed by both intervention and control groups before the intervention. Questionnaire of adherence to treatment in chronic patients: This questionnaire was designed and validated in 2017 by Seyed Fatemi and colleagues [13]. The measurement scale in this questionnaire is a 6-part Likert, which is designed from completely with 5 points to not at all with 0 points. The scoring of a number of expressions is reversed, i.e. it is given a score of 5 for not at all and a score of 0 for completely. Statements No. 33, 34, 35, 37, 38, 39 and 40 were scored inversely. In this way, the maximum and minimum score for each class can be calculated. The direction of scoring the expressions is positive, that is, the more the degree of desirability of the attribute is added, the more points are assigned to it. In this way, the higher the total score or the score of each class, the higher the compliance of the respondent. The face and content validity of the questionnaire was done. Qualitative face validity was done with the participation

of 10 patients and 10 experts. 10 patients participated in determining the quantitative face validity (effect coefficient) of the questionnaire. Providing qualitative and quantitative content validity was done by 15 and 26 experts, respectively. In order to provide quantitative content validity, content validity ratio and content validity index were calculated. The average content validity index of the questionnaire was 0.914. The internal consistency of the questionnaire was ensured by calculating Cronbach's alpha ($\alpha=0.921$) and the reliability of the questionnaire was ensured by retesting with a two-week interval ($r=0.875$). Questionnaire of self-compassion in patients with multiple sclerosis: this questionnaire was designed and validated by Dehmardeh et al. (2021) [28]. It has 73 items. The measurement scale in the current 5-point Likert questionnaire includes always (score 5), most of the time (score 4), sometimes (score 3), rarely (score 2) and never (score 1). Based on the above scoring and the number of items in the questionnaire measuring self-compassion in patients with MS (73 items), the minimum total score of the questionnaire will be 73 and the maximum total score of the questionnaire will be 365. In order to check the validity, the internal consistency was calculated and it was favorable (Cronbach's alpha more than 0.7). The results of the test-retest (intra-cluster correlation of the whole instrument=0.778) confirmed the reliability of the questionnaire in the whole structure, and according to the indicators estimated in the psychometric section, this instrument has the necessary validity and reliability for multiple sclerosis patients.

After explaining the objectives of the study to the patients referring to the Zahedan MS Association, they

were asked to complete an informed consent form if they wish to participate in the study. For the intervention group, before the start of the educational program, a questionnaire on demographic characteristics, compliance with treatment and self-compassion was completed, then the educational program was presented in 8 sessions of 45 minutes during 4 weeks at the place of the MS Association. In these sessions, after additional explanations about the research and its goals, the content of the educational program based on the definition and discovery of self-compassion, mindfulness, kindness-loving, discovering the voice of self-compassion and compassion for oneself and the body, living deeply, facing emotions difficulties and reducing shame, discovering challenging relationships, and accepting life were presented (Table 1). This program was taught to the patients in the form of group discussion and lectures, brainstorming and role playing, and finally, a review of the taught items was made and the patients' questions were answered. For control group patients, routine interventions and usual trainings have been done.

After completing the intervention, the patients continued to implement the program taught at home for 2 months under telephone follow-up. After 2 months, the questionnaires were completed again by the people of the two groups. In order to comply with the ethical standards, after the completion of the study, the educational program compiled in the form of educational pamphlets was provided to the control group. Data analysis was done using independent t-test and chi-square tests (to compare the frequency distribution of some demographic variables between two groups) under SPSS 26 statistical software.

Table 1- The structure and content of self-compassion training intervention

Session	objective	The subject of education
First	Basic acquaintance, introducing self-compassion training, discovering self-compassion	Introduction and initial communication, review of group rules, explanation about the structure and goals of the meeting, explanation about the nature of self-compassion and its principles, presentation of the task: making a list of your sufferings.
Second	Mindfulness training	Reviewing and reviewing the assignment of the previous session, performing mindfulness exercises: (breathing exercise, focusing on something, checking and touching the body, eating and touching raisins), presentation of the assignment: including forty minutes of mindfulness exercises at home.
Third	Practicing kindness-loving	Examining the feedback and review of the previous session, the importance of cultivating a kind mind, feeling warmth and kindness towards oneself, practicing the role playing of the kind self, teaching the styles and methods of expressing compassion using expressions (I feel safe, I am with myself) I am kind, practice, imaging from a safe place, presentation of homework.
Fourth	Discovering the voice of self-compassion and self-compassion and body (finding the place of self-compassion)	Examining homework, strengthening self-compassion behaviors, practicing being kind to yourself using phrases (I love you and I don't want you to suffer, practicing taking kindness from others), cultivating a kind mind, presenting homework: repeating these phrases in Daily life as well as performing the task of being kind to yourself and others.
Fifth	live deeply	Evaluation and review of the previous assignment, review and discovery of important things that give meaning to one's life, carrying out the exercise of depicting a fruitful and valuable life, writing a letter about kind criticism of one's life, practicing the metaphor of a great day, presenting the assignment: related to Roshan Becoming important for group members.

Sixth	Facing difficult emotions and reducing shame, managing difficult feelings and emotions	Getting feedback and reviewing assignments, teaching the relationship between physical, mental, and mental components of difficult emotions and how these components affect each other, performing physical, mental, and intellectual relaxation exercises, introducing logical reasoning and kind reasoning, introducing kind sensory experience, presenting homework: Physical and mental relaxation with conscious mind exercises, as well as freeing your mind from negative thoughts.
Seventh	Exploring challenging relationships (changing relationships)	Evaluation and review of the past session, identification of all the painful relationships that have been cut off with oneself and others and laying the groundwork for one's relationship with oneself and oneself with others, practicing reconciliation with oneself, retelling the characteristics of a kind person, presenting the assignment: identifying one's anger with one's self; Anger with situations and others and the practice of reconciling and establishing relationships with these three types of relationships
Eighth	acceptance of life	Evaluation and feedback of the last session, examining the negative biases of life by relying on good things and good features in the person in order to reduce prejudices and irrational beliefs, gain more pleasure from life, providing solutions to maintain and apply these methods in life.

Results

The average age in the intervention group was 40.05 ± 9.61 years and in the control group was 40.13 ± 8.78 years. The information related to the demographic variables of the participants is shown in (Table 2). According to the findings, before the intervention, there was no statistically significant difference between the variables of gender, age, education level, and marital status in the intervention and control groups.

The independent t-test did not show any statistically significant difference for the mean total score of adherence to the treatment before the educational

intervention in the control and intervention groups ($P=0.11$), but based on the independent t-test, there was a statistically significant difference between the mean changes in the total score. Adherence to the treatment was present after the intervention ($P=0.000$) (Table 3).

The independent t-test did not show any statistically significant difference for the mean total score of self-compassion before the educational intervention in both control and intervention groups ($P=0.27$), but based on the independent t-test, there was a statistically significant difference between the average changes in the total score of self-compassion. It was present after the intervention ($P=0.000$) (Table 4).

Table 2- Individual characteristics of the participants

Variable	Group	Intervention number (percentage)	Control number (percentage)	Total	P value
Gender	Female	20(58.8)	18(60.0)	38(59.4)	0.92 DF=1
	Man	14(41.2)	12(40.0)	26(40.6)	
Level of Education	illiterate	4(11.8)	3(10.0)	7(10.9)	0.67 DF=4
	elementary	10(29.4)	6(20.0)	16(25.0)	
	diploma	9(26.5)	12(40.0)	21(32.8)	
	Bachelor's degree	8(23.5)	8(26.7)	16(25.0)	
Marital status	Master's degree	3(8.8)	1(3.3)	4(6.3)	0.88 DF=1
	Single	13(38.2)	12(40.0)	25(39.1)	
	married	21(61.8)	18(60.0)	39(60.9)	
Average age (years)		40.05 ± 9.61	40.13 ± 8.78		
Chi-square test					

Table 3- comparison of the average total score of adherence to treatment before and after the intervention in patients of two groups

Variable	Group	Before intervention Standard deviation \pm mean	After the intervention Standard deviation \pm mean	P value
Intervention group		75.85 ± 9.97	138.97 ± 8.84	0.000
control group		79.13 ± 5.43	76.00 ± 10.31	0.001
**P		0.000	0.114	

× T-paired test

×× Independent t-test

Table 4- Comparison of the mean total score of self-compassion before and after the intervention in patients of two groups

Group Variable	Before intervention Standard deviation ± mean	After the intervention Standard deviation ± mean	P value
Intervention group	131.17±8.26	303.47±7.72	0.000
control group	133.500±8.41	133.93±8.25	0.001
**P	0.270	0.000	

Discussion

The present study was conducted with the aim of investigating the effect of the educational program on treatment compliance and self-compassion of patients with multiple sclerosis. According to the findings, the average score of adherence to treatment in patients with multiple sclerosis in the intervention group has increased, indicating the effectiveness of the educational program. Ayubi et al. (2020) implemented a cognitive-behavioral training program for patients with diabetes and according to the results of their study, this program has led to an increase in patients' compliance with treatment, which shows the effectiveness of the training program [29]. Bahram Begi et al. (2023) have also increased and improved compliance with treatment in heart patients by using written emotional expression training [30]. The study of Moqtadaei et al. (2023) also showed that the treatment method of acceptance and commitment to follow the treatment was effective in patients with irritable bowel syndrome [31]. These results indicate the effect of cognitive-based educational programs on treatment compliance in chronic patients such as MS, therefore, they are in line with the results of the present study.

On the other hand, the results show the effect of the educational program on increasing self-compassion in patients with multiple sclerosis in the intervention group. In line with the results of the present study, the study of Hosni et al. (2021) showed that providing a structural model of psychological well-being, compassion and hope in women with multiple sclerosis is effective [32]. Also, the results of Ahmadi et al.'s study (2020) also show that training based on self-compassion has significantly reduced the symptoms of irritable bowel syndrome [23].

The results of Abdullahi et al.'s study (2018) also showed that self-compassion training had a significant effect on reducing the anxiety, stress and depression of mothers of children with autism [31]. According to these studies, patients suffering from multiple sclerosis experience the symptoms of the disease during their lifetime, such as frequent relapses, which are accompanied by the appearance of new clinical symptoms or the worsening of old symptoms. It affects all aspects of patients' lives and over time. Due to the disabling nature of this disease and the impact it has on the ability and daily activities of life, it can affect all

dimensions of the sufferers' lives and cause disturbances in various aspects of the quality of it can affect all dimensions of the sufferers' lives and cause disturbances in various aspects of the quality of life [26].

Finally, it should be stated that educational programs such as implementing a self-compassion program that focuses on the person and maintaining or promoting self-importance and self-spirituality can lead to an increase and promotion of treatment compliance and self-compassion in chronic patients such as MS sufferers. but there are limitations in the implementation of such programs that require follow-up and numerous referrals and practice by the patients due to the conditions of the patients who may sometimes become ill or suffer from complications caused by the disease such as weakness and disability or even despair, and holding and carrying out educational sessions were faced with problems and limitations, and in order to solve them, an attempt was made to interact personally and face-to-face with the patients who were unable to attend the sessions due to the conditions created due to their illness, despite their wishes, and an attempt was made to reduce the drop in volume. The sample and implementation were studied as best and as detailed as possible.

Conclusion

The findings of this study show that the existing program can increase self-compassion and adherence to treatment in patients with multiple sclerosis. For this reason, the successful treatment of this disease requires a person to follow a special drug regimen provided by the treatment team for a long time [12]. It should be noted that this is only possible with the active participation of the patient in the treatment and implementation of the recommendations of the treatment team members, which is referred to as compliance with the treatment [13]. Self-compassion can improve self-regulation through reducing defensive responses, emotional states and self-blame, as well as increasing compliance with medical recommendations [31]. Considering that chronic diseases are accompanied by anxiety and other psychological symptoms, these patients are somehow involved in psychological problems and worries about the future of the disease and have less adaptive coping skills; Therefore, this treatment helps them deal with the disease in an effective way when change is not possible by accepting chronic conditions, which in turn has an

effective role in increasing their treatment compliance [33]. Therefore, in the future planning, other educational methods should be used to improve them, and these programs can be implemented with the help of experienced nurses in multiple sclerosis treatment centers.

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