The effect of self-regulatory program based on Leventhal's model on the illness perception and resilience of people with multiple sclerosis

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Abstract:

BACKGROUNDS: The study at hand seeks to examine the influence of a self-regulation program rooted in Leventhal's model on the illness perception and resilience of patients with multiple sclerosis (MS). By exploring the impact of Leventhal's model-based interventions, healthcare professionals can enhance their ability to effectively address the challenges associated with this disease. In addition, this research endeavor can serve as a valuable resource for the development of nursing knowledge in the realm of MS patient care.

MATERIALS AND METHODS: This study was a semiexperimental two-group study. The statistical population of the study consisted of all patients with RRMS-type MS in Shahrekord city. Ninety patients were initially selected through convenience sampling and then randomly allocated into intervention and control groups (each with 45 participants) using the Random Allocation software. Before the intervention program was provided, the patients' perception of the disease and their resilience were assessed using the Illness Perception Questionnaire-Revised (IPQ-R) and Connor-Davidson Resilience Scale (CD-RISC), respectively.

RESULTS: The intervention group had a mean age of 34.78 ± 4.27 years, whereas the control group had a mean age of 34.51 ± 4.43 years. After the Leventhal self-regulatory model, a statistically significant difference was observed in the mean scores of illness perception and the mean score of resilience between the intervention and control groups, both immediately and two months later, implying that the intervention group had a higher score in illness perception and the mean score of resilience (P value < 0.001).

CONCLUSION: Our study indicated that the Leventhal self-regulatory model had a significant positive effect on improving both illness perception and resilience in individuals with MS. Therefore, enhancing these factors among MS patients can have a tremendously positive impact on their psychological health, quality of life, and treatment adherence.

Keywords:

Illness perception, Leventhal self-regulatory, multiple sclerosis, resilience

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Introduction

Multiple sclerosis is a chronic and progressive disease of the central nervous system that involves demyelination of nerve cells.[1] MS is one of the human diseases, which affects approximately three million people worldwide today.[2] The disease is common in young adults between the ages of 20 and 40 years, and its prevalence in women is twice that of men.[3,4] It is the third leading cause of disability in the United States. There is no accurate statistics available on MS patients in Iran,

but the Iranian Society of Neurology reports that there are 50,000 MS patients in the country, and the prevalence rate is estimated to be about 9 per 100,000 people.[5]

MS not only affects the functioning of sensory and motor systems, but it can also cause psychological symptoms and damage.[6,7] In this regard, researchers have recently focused on two important psychological factors related to the disease, including illness perception and resilience.[6,8] Proper perception of the disease can reduce the complications and consequences of the disease and improve the quality of life. Resilience is a general capacity to prevent, minimize, and overcome problems. Greater resilience implies a greater ability to recover from negative events rather than vulnerability to stress. Patients adhere to disease management and treatment protocols when they possess a comprehensive understanding of the ailment and bolster their resilience.[9] In this context, Leventhal presented a self-regulation and perception-based program that leads to adaptive behaviors and resilience to cope with the disease. This model recognizes healthy behaviors as a result of the complex and multidimensional perception of the disease. The basis of Lountal's self-regulation model is that patients strive to regain their natural state of health. In this model, the patient plays a dynamic and active role in perceiving their disease.[10] In the study by Rakhshan *et al.*,[11] it was found that the self-regulation program created a more positive outlook on the disease and may affect the treatment of the disease and even reduce the complications. William Kilgore and colleagues' research showed that self-regulation and problem-solving are related to better quality of life and performance in resilience, expression, independence, empathy, and optimism. Illness perception pertains to the emotional response and reaction of individuals toward their illness, which can significantly impact their adaptive and coping behaviors.[12]

Illness perception and resilience of MS patients and the impact of Leventhal's model-based interventions can assist healthcare professionals in better planning for managing the challenges of the disease and provide a good guide for developing nursing knowledge in the field of MS patient care. Therefore, the present study aimed to investigate the effect of a self-regulation program based on Leventhal's model on illness perception and resilience of MS patients.

Materials and Methods

Study design and setting
This study was a semiexperimental two-group study. The statistical population of the study consisted of all patients with RRMS-type MS (relapsing-remitting MS) in Shahrekord city.

Study participants and sampling
Ninety patients were initially selected through convenience sampling and then randomly allocated into intervention and control groups (each with 45 participants) using the Random Allocation software. Before the intervention program was provided, the patients' perception of the disease and their resilience were assessed using the Illness Perception Questionnaire-Revised (IPQ-R) and Connor-Davidson Resilience Scale (CD-RISC), respectively. The inclusion criteria were as follows: age between 20 and 40 years, confirmed diagnosis of MS by the treating physician and medical records, no history of any other psychological or medical conditions according to the medical records, not participating in a similar self-regulation program, ability to read and write in Persian, no communication problems, no cortisone use in the past six months, and no relapse of the disease in the past six months. The exclusion criteria were worsening of patients' condition, absence from two or more sessions in the Leventhal self-regulatory model, and lack of willingness to continue the study. Relevant explanations regarding the study were provided to the participants after obtaining their consent.

The control group only received standard education and care, whereas the intervention group received standard education and care as well as a self-regulation program based on the Lorig model (consisting of five weekly educational sessions, each lasting about 60 minutes) based on cognitive domains (identity, cause, timeline, consequences, control, and treatment), and in accordance with the stages of the Lorig model, including understanding the nature of the disease, understanding the cause of the disease, understanding the consequences of the disease, understanding the course of the disease, and understanding how to control and treat the disease. The intervention content was the same for both groups. Individual counseling sessions were also held if needed. The interventions were performed for about five weeks.

Data collection tool and technique
Data were collected using the IPQ-R and Connor-Davidson Resilience Scale immediately after the intervention and two months later. The intervention was formulated with the objective of enhancing patients' comprehension of the ailment and augmenting their resilience. The IPQ-R measures nine items, including consequences, duration, personal control, treatment control, identity, concern, understanding, emotional response, and cause of the disease. The scores for the first eight questions range from 0 to 10, and the ninth question is an open-ended question that asks about the three major causes of the disease. The score is obtained from the patients' responses to the IPQ-R questionnaire during three measurements (before, immediately after, and two

months after the intervention). The lowest score on this scale is zero, and the highest score is 90. Scores of 60 and above indicate a high level of illness perception.[13] The Connor-Davidson Resilience Scale consists of 25 statements that are scored on a Likert scale ranging from zero (false) to four (true nearly all the time). The final score is between zero and 100.[14] Scores between zero and 33 indicate low resilience, scores between 34 and 67 indicate moderate resilience, and scores above 68 indicate high resilience.[15]

Data analysis was performed in SPSS version 22. The *P* value of 0.05 was considered statistically significant. A mean and standard deviation were used to express the quantitative data, whereas numbers and percentages were used to express qualitative data. The assumption of normality was checked using the Kolmogorov-Simonov test, and the association between disease and qualitative data was checked using the independent *t*-test, analysis of covariance, and repeated measures.

Ethical considerations
The study protocol and its ethical considerations were approved by the ethics committee of Shahrekord University of Medical Sciences (IR.SKUMS.REC.1400.245).

Results

Table 1 displays a comparison of demographic characteristics between the intervention and control groups. The intervention group had a mean age of 34.78 ± 4.27 years, whereas the control group had a mean age of 34.51 ± 4.43 years. The study found no significant difference in age between the two groups (*P* value = 0.77). In terms of gender, approximately 68.9% of participants in the intervention group were female and 31.1% were male, whereas 60% of participants in the control group were female and 40% were male. However, there was no statistically significant difference in gender between the intervention and control groups in this study (*P* value = 0.51).

Table 2 displays a contrast in the level of comprehension regarding the illness between the intervention and

control groups. The analysis showed that there was no noteworthy difference in illness perception within the control group before, immediately after, and two months after the intervention (*P* value = 0.52). Conversely, a substantial difference was observed in the mean score of illness perception before, immediately after, and two months after the intervention in the intervention group, indicating the favorable effect of the Leventhal self-regulatory model (*P* value < 0.001). Furthermore, before the intervention, there was no meaningful difference in the mean scores of illness perception between the intervention and control groups (*P* value = 0.82). However, after the Leventhal self-regulatory model, a statistically significant difference was observed in the mean scores of illness perception between the intervention and control groups, both immediately and two months later, implying that the intervention group had a higher score in illness perception (*P* value < 0.001). This indicates the considerable and affirmative impact of the intervention.

Table 3 shows the comparison of resilience in the intervention and control groups. Resilience levels did not show any significant changes in the control group before, immediately after, and two months after the intervention. Nevertheless, the intervention group showed a meaningful increase in the mean score of resilience before, immediately after, and two months after the intervention, indicating that the Leventhal self-regulatory model had a favorable impact (*P* value < 0.001). Moreover, there was no substantial difference in the mean score of resilience between the intervention and control groups before the intervention (*P* value = 0.83). However, immediately and two months after the Leventhal self-regulatory model, a statistically significant difference was observed in the mean score of resilience between the intervention and control groups (*P* value < 0.001), demonstrating the intervention's significant positive influence.

Table 4 displays the results of Pearson's correlation between the variables of illness perception and resilience. Based on the findings, a significant positive correlation was observed between illness perception and resilience (r = 0.497, *P* < 0.001).

Discussion

The aim of this study was to examine the impact of a Leventhal self-regulatory model on illness perception and resilience in MS patients. The results of the study indicated that this program had a significant positive effect on improving both illness perception and resilience in individuals with MS. Illness perception refers to how individuals emotionally respond and react to their illness, which can influence their adaptive and coping behaviors. Better illness perception can lead

Table 1: Comparison of demographic characteristics in the intervention and control groups

Variable	Subgroup	Intervention	Control	*P*
Age (mean±SD)	Years	34.78±4.27	34.51±4.43	0.77
Disease history (mean±SD)	Years	9.09±2.94	8.18±2.77	0.13
Gender, *n* (%)	Female	31 (68.9)	27 (60.0)	0.51
	Male	14 (31.1)	18 (40.0)	
Education, *n* (%)	Less than a diploma	14 (31.1)	7 (15.6)	0.01
	diploma	16 (35.6)	30 (66.7)	
	university	15 (33.3)	8 (17.8)	

Table 2: Comparison of disease perception scores before, immediately, and two months after the intervention in two groups

Variable	Groups	Before		Immediately after intervention		Two months after the intervention		Intragroup *P*
		Mean	SD	Mean	SD	Mean	SD	
Illness perception	Control	40.73	5.95	42.16	6.45	41.11	5.67	0.052
	Intervention	40.33	9.77	62.93	8.96	63.71	9.70	<0.001
Between-group *P*		0.82		<0.001		<0.001		-

Table 3: The comparison of resilience in the intervention and control groups

Variable	Groups	Before		Immediately after the intervention		Two months after the intervention		Intragroup *P*
		Mean	SD	Mean	SD	Mean	SD	
Resilience	Control	50.93	11.38	56.40	11.30	50.98	11.82	0.97
	Intervention	50.44	9.82	67.13	8.67	66.78	11.16	<0.001
Between-group *P*		0.83		<0.001		<0.001		---

Table 4: The results of Pearson's correlation between the variables of illness perception and resilience

variable	Statistical index	Resilience
Illness perception	Pearson	*0.497
	P	0/001

*Significance at a level less than 0.01

to decreased fear, anxiety, and concerns related to the disease, resulting in improved individual and social functioning, psychological well-being, and quality of life. Resilience, which is defined as an individual's ability to tolerate, adapt, and cope with challenges, is another factor that contributes to these outcomes. Therefore, enhancing these factors among MS patients can have a tremendously positive impact on their psychological health, quality of life, and treatment adherence.

Based on the results, the control group did not show a significant difference in illness perception scores immediately and two months after the Leventhal self-regulatory model intervention. This means that illness perception did not improve in the control group before and after the intervention. However, the intervention group showed a significant difference in illness perception scores before, immediately, and two months after the intervention, indicating a positive effect of the Leventhal self-regulatory model. The results of this study are consistent with the research conducted by Kachooei *et al.*, which demonstrated that augmenting health-related behaviors can enhance the perception of illness in individuals diagnosed with multiple sclerosis.[16] Nie *et al.* also reported an improvement in illness perception among MS patients by enhancing self-care behaviors.[17] Plow and Golding[18] identified factors that facilitate and hinder illness perception development among MS patients, confirming differences in illness perception among different communities. Khodaparast *et al.*[10] demonstrated an increase in illness perception in pregnant women with diabetes using the Leventhal self-regulatory model. Tabarian and colleagues also confirmed the effectiveness of the

Leventhal self-regulatory model in enhancing illness perception among individuals with diabetes.[7] Finally, Rakhshan and colleagues evaluated the effectiveness of the Leventhal self-regulatory model in enhancing illness perception in patients with spina bifida.[11]

Our study found a significant difference in the average resilience score of the intervention group before, immediately after, and two months after the Leventhal self-regulatory model was implemented, indicating that the program significantly improved individuals' level of resilience. Resilience is an important factor that enhances individuals' ability to tolerate, adapt, and cope with problems, and it also plays a vital role in maintaining the psychological well-being of patients.[19-21] Overall, our study observed an eight-point improvement in the average resilience score. Bishop *et al.*[22] found that resilience is lower among MS patients compared with healthy individuals, and Sadeghi *et al.* reported that MS patients have lower resilience compared with patients with other chronic diseases.[23] As a result of the inherent characteristics of the disease and its profound effects on the central nervous system, individuals diagnosed with multiple sclerosis (MS) consistently encounter elevated levels of stress and endure various mental and emotional challenges. Consequently, they exhibit a heightened susceptibility to diminished resilience.[22] Among patients with other diseases, Doustdar Tousi *et al.* reported in their study that those with higher resilience had a better chance of improvement among patients with cardiovascular disease.[24] Mirmoeini *et al.*[25] also reported in their study that compassion-based therapy significantly increased the resilience of MS patients and reduced their concerns.

Limitation and recommendation
This study is subject to several limitations that warrant consideration. First, psychological issues and individual variances in personality among the patients may have exerted an influence on the research outcomes. Secondly,

the ongoing coronavirus situation posed a challenge in terms of accessing the patients, thereby impeding their ability to travel conveniently. It is recommended that future studies be conducted to investigate the relationship between self-regulatory program based on Leventhal's model on the illness perception and resilience of people with MS. It is also recommended to conduct studies with a larger sample size and to investigate other individual factors, especially the psychosocial and psychological factors of the patients in this area.

Conclusion

The study demonstrated that the self-regulatory program, which followed Leventhal's model, had a notable effect on enhancing the perception of illness and resilience in persons with MS. As a result, improving these factors, namely illness perception and resilience, could have a substantial positive impact on the mental health, quality of life, and adherence to treatment of MS patients.

Ethics approval and consent to participate

The studies involving human participants were reviewed and approved by Shahrekord University of Medical Sciences (IR.SKUMS.REC.1400.245). The patients/participants provided their written informed consent to participate in this study.

Conflicts of interest

There are no conflicts of interest.

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