

The Effect of a Program Based on Roy's Adaptation Model on Coping Skills of Children of People with Multiple Sclerosis

Abstract

Background: The health of children is affected by Multiple Sclerosis (MS) in their parents and various complications of it. Given this, this study was conducted to investigate the effect of a program based on Roy's adaptation model on the coping skills of children of MS patients. **Materials and Methods:** This study was performed on 78 children of 78 MS patients from Shahrekord Support Association of MS patients including around 1800 patient members in 2018 using a quasi-experimental method. Samples were selected by the convenience sampling method, and a researcher-made checklist was completed based on Roy's adaptation model by them, and those who scored less than 80% on the checklist were included in the study and randomly allocated to control and intervention groups. The coping skills questionnaire was completed before, immediately, and 2 months after the intervention in two groups. In the intervention group, a supportive training program was developed and implemented based on Roy's adaptation model in six sessions and followed up for 2 months. Data were analyzed by SPSS version 23 using statistical tests. **Results:** There was a significant difference in changes in mean coping skills scores during the intervention between control and intervention groups ($p < 0.001$) so that the coping skills scores showed a significant increase in the intervention group. **Conclusions:** It is possible to increase the level of adaptation in children of MS patients and improve their coping skills by using educational and supportive programs based on Roy's adaptation model.

Keywords: Adaptation, coping skills, multiple sclerosis, nursing

Introduction

Multiple Sclerosis (MS) is one of the most common neurological disorders, and it is the main cause of nontraumatic neurological disability in young people across the world.^[1] MS has affected about 2.5 million people in the world and 50,000 individuals in Iran. The onset of MS usually occurs in people aged 20–40 years so that most affected people have children with special growth- and care-related needs,^[2] but the physical, psychological, and socioeconomic consequences of it prevent them from performing their duties in the family and produce stupendous pressure on all members of the family including children.^[3] In addition, the disease may influence parent–child interactions.^[4] Also, the children of these patients must take on a wide range of care responsibilities that obstruct their entertainment and education and cause behavioral disorders, decreased social activities, decreased self-esteem,

isolation, and academic problems as well as distress and weak adaptation to the existing conditions.^[5] McCabe *et al.*^[6] have reported that the healthy feeling of MS patients and their families depends on how they adapt to the conditions related to the disease. They have also argued that coping is an important mediator of chronic disease and the healthy feeling of patients and their families.

Therefore, family members need strategies for adjustment within the family and adoption of some key roles, responsibility, and functions.^[5] However, most of the studies have focused on the progression of the disease or the patient and have ignored the support-related needs of young caregivers and families.^[7] Lack of information about MS and the progression of the disease and its symptoms are the main stressors for children with MS parents; therefore, the patient and all family members must adapt to this disease and its

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consequences, which requires time, effort, and support.^[8] Since this support should be effective and based on their needs,^[9] they can improve themselves by learning coping skills to better adapt to the conditions.^[2] Lazarus and Folkman defined coping skills as constantly changing behavioral and cognitive efforts made to manage difficult internal or external needs.^[10] These skills can be learned and increase self-esteem and group interaction and reduce depression.^[11] In this regard, Roy's adaptation model is one of the well-established models of nursing in the field of adaptation which has been used in various clinical, educational, and nursing domains.^[12] According to this model, biological, psychological, and social dimensions belong to human beings who are constantly adapting in terms of health and disease in four physiological domains, namely, self-perception, role playing, independence, and interdependence with principal, contextual, and permanent stimuli that are constantly changing.^[13] Based on the model, the nurse conducts nursing measures and planning based on observation, interview, and measurement and having sufficient knowledge about diseases,^[14] the principal, contextual, and permanent stimuli so that the stimulus will be within the range of individual adaptation.^[15]

Young children whose parents suffer from MS face a number of stressful challenges that are risk factors for reduced health even in the future. These children must use coping skills to adapt to these conditions and maintain their health. We can make efforts to maintain and promote health and improve people's adaptation by using Roy's adaptation model, and considering that the focus of care and studies is on patients^[16-19] and not the needs and health of their children, we decided to investigate the effect of a program based on Roy's adaptation model on the coping skills of children of MS patients.

Materials and Methods

This quasi-experimental study was derived from a student thesis and was conducted on 80 (according to similar studies)^[20,21] 18- to 30-year children of patients with MS from the MS Association and Welfare Organization with around 1800 member patients in 2018. Participants were selected by the convenience sampling method. The inclusion criteria were having a parent with MS, providing informed consent to participate in the study, an age of 18 to 30 years,^[22] having literacy, being able to communicate and participate in care and training sessions, and earning a score of less than 80% on the Checklist Examination of Roy in the first stage, and the exclusion criteria were withdrawal from the study and having participated in other educational and care programs. Then, participants were randomly divided into two groups of intervention and control of 40 individuals each using random allocation software. The informed consent form to participate in the study was filled out by participants. A demographic characteristics checklist (age, gender, academic degree, and marital status

of the child and age, gender, and academic degree of the parent with MS), a researcher-made checklist, a self-report checklist, and the Blinges and Mouse coping skills questionnaire were used as tools of study. Using relevant literature, Roy's adaptation model checklist was designed and then the items were developed by the investigator in three domains, knowledge, insight, and function. Eighty-five items in four dimensions of physiology, interdependence, role-playing, and self-perception were developed. The content validity of the questionnaire was investigated by ten faculty members of the Nursing Faculty of Shahrekord University of Medical Sciences, and the Content Validity Ratio (CVR) for all items was above 0.7 and their Content Validity Index (CVI) was above 0.80. Its reliability was investigated by calculating Cronbach's alpha ($\alpha = 0.85$).

As per the training and supportive program based on the Roy's adaptation model, the self-report checklist was prepared by the investigator to assist the participants in complying with the training program precisely and also to more accurately monitor their adherence to the training program. As an easy and valid method for evaluating coping responses, the Blinger and Mose Coping Skills Questionnaire, consisting of 32 items, (1984) was administered. The items of the questionnaire are rated on a four-point Likert scale (from *Never*: 0 to *Always*: 3). The highest and lowest attainable scores on the scale are 96 and 0, respectively. Using the test-retest method, the reliability coefficient was calculated at 0.79 for the questionnaire, and Cronbach's alpha for its subscales was 0.7–0.9.^[23]

Before performing the interventions, the coping skills questionnaire was completed by both groups. In the second stage, maladaptive behaviors and their stimuli were determined by the investigator. Seven maladaptive behaviors were determined, including sleep disorders and constipation (in the physiological domain), stress and anxiety (self-perception domain), lack of self-confidence (self-perception domain, mental self-domain), embarrassment (self-perception, self-esteem), anger (self-esteem in relation to others), dependence on sick parents (independence and dependency domain), and dropout (role-playing domain). Some questions were as follows: Do you sleep enough and regularly (8 hours a day)? How much do you know about the four main food groups (bread and grains, meat, fruits and vegetables, and fats)? How much do you know about the dangers of smoking? How much do you see yourself as similar to others? How much do you use religious advice? How much do others expect from you? How often do you hang out with your family?

Then, nursing diagnoses were determined, targeted, and planned based on the data from the completed checklists and the specific behaviors and stimuli. Educational needs were determined based on the nursing diagnoses. Afterward, the educational goals and the methods of achieving them

were determined. Then, educational content was prepared based on a valid reference.^[24-27] Then, in order to check the validity of the educational content, it was given to four medical and nursing experts, and based on their opinions, modifications were made. Finally, the educational content was arranged in 57 pages and seven sections, including knowledge of care in MS, self-care, adaptation management, anger management, social self-management, psychological and emotional self-management, and communication skills. Besides this, the prepared educational content was provided to four participants to check its simplicity and comprehensibility. Educational content was presented in six educational sessions. Two sessions of six sessions (each session lasting for 45–60 minutes) of the intervention were allocated to training and presentation of general content, and the remaining four sessions to face-to-face training by the investigator (with the attendance and assistance of a psychologist).^[16] The sessions began with questions and answers, and then the content was presented by the researcher. Individual sessions were held during the week at the participants' request. The aim of the two sessions for presenting general content was to increase information and awareness about MS and its care and maintaining and increasing adaptation in terms of three physiological domains (self-concept, role-playing, and interdependence) under the supervision of a psychologist. The physiological domain included information about activity and rest, nutrition, regular sleep, regular exercise, and general self-care. Regarding conceptualization, participants were presented with information about increasing self-confidence and having a positive self-image. Methods for better management of new situations and roles, development of adaptation skills through familiarity with coping skills, and modeling the behavior and function as well as the importance of paying attention to the future were taught in order to increase adaptation in terms of the role performance domain. Subjects such as maintaining interpersonal relationships, preventing isolation, expressing feelings with relatives, and friends of sick parents were also presented to increase adaptation in the interaction domain. In the next four sessions (two sessions per week), which were held face-to-face, the investigator helped the participants in the intervention group separately by manipulating, adjusting, and eliminating the main and lasting stimuli related to each maladaptive behavior for each participant. At the completion of the sessions, a training booklet along with a self-report checklist was provided to the participants. The coping skills of the participants were re-evaluated immediately after the completion of the intervention and after the end of the follow-up period. For the control group, there was no care and intervention and only follow-up was done through phone contacts during the 2 months of intervention and the studied variables were examined simultaneously with the intervention group. After the completion of the study, during a meeting with the attendance of a psychologist, educational materials were provided to the control group

and their questions were answered. After completing the interventions and examining the variables at pretest and post-test in both groups, to comply with the principles of research ethics, all educational materials were also provided to the control group.

Mean \pm standard deviation was used as descriptive statistics. Normal distribution of changes was investigated by the Kolmogorov–Smirnov test. Differences in variables between the intervention and control groups were analyzed using the independent *t*-test, Mann–Whitney U test, Fisher's exact test, or Chi-square test where appropriate. The repeated measure analysis of variance was applied to determine whether any change existed among variables in question during the study. The multivariate F-tests of Greenhouse–Geisser were used within the subject analysis because of violation of sphericity assumptions. *P* value < 0.05 was considered a significance level, and data analysis was performed using SPSS.

Ethical considerations

The approval of the University Ethics Committee (IR.SKUMS.REC.2018.109) was obtained. All the necessary permissions were obtained from the Ethics Committee and the Vice-Chancellor of Research and Technology of the University. The objectives of the study were explained to the participants, and a signed written informed consent was obtained to participate in the study if they were willing to do so. The private information of the participants was not disclosed. In case of withdrawing from the study, no fees or fines were charged from the participants. Participants were allowed to withdraw from the study at any time. The results of this study were provided to the participants upon their request. Ethical and reliable principles were observed in publishing the data and results of the study.

Results

A total of 80 patients participated in this study. Due to withdrawal from the study, two individuals were excluded from the control group and the data of 38 people in this group were analyzed. The mean (SD) age of participants was 25.10 (4.06) years in the intervention group and 24/00 (3.67) in the control group ($p = 0.21$). The mean (SD) age of parents was 51.10 (7.31) years in the intervention group and 49.21 (5.24) in the control group ($P = 0.19$). 64.10% of the samples in the control group and 80% in the intervention group were female. There was no statistically significant difference between the two groups in terms of age, parent's age, gender, parent's gender, participant's education level, parent's education level, and participant's marital status [Table 1].

A significant increasing trend was seen in the coping skills scores of the intervention group but not in the control group. Also, change of coping skills scores during the study were significant so that an increase of 14.80 score was seen in the intervention group, but there was no significant

Table 1: Frequency distribution of demographic variables in the two groups of control and intervention

Variables	Control group	Intervention group	Significance (p-value)
	Number (%)	Number (%)	
Gender of participants			
Male	14 (35.90)	8 (20.00)	0.115
Female	25 (64.10)	32 (80.00)	
Sick parent's gender			
Male	2 (5.10)	1 (2.50)	0.49
Female	36 (94.90)	39 (97.50)	
Marital status			
Single	2 (66.70)	20 (50.00)	0.133
Married	13 (33.30)	20 (50.00)	
Participant's education level			
Senior secondary education diploma	0 (0)	2 (5.00)	0.76
High-school diploma	15 (38.50)	22 (55.00)	
Academic education	24 (61.50)	16 (40.00)	
Parent's education level			
Senior secondary education diploma	22 (56.40)	25 (62.50)	0.235
High-school diploma	10 (25.60)	13 (32.50)	
Academic education	7 (17.90)	2 (5.00)	

Table 2: Mean scores of coping skills in children of multiple sclerosis patients

Studied variables	Group Phase	Control	intervention	p-value
		Mean (Standard deviation)	Mean (Standard deviation)	
Coping skills	Before intervention	61.47 (9.04)	56.03 (11.63)	0.024
	Immediately after intervention	61.58 (8.86)	62.40 (10.50)	0.71
	Two months after intervention	61.61 (9.29)	70.80 (8.22)	<0.001
	p-value (within group)	0.891	0.001 <	<0/001
	Changes during study	0.13 (2.20)	14.8 (6.67)	<0.001

change in this score during the study in the control group [Table 2].

Discussion

In this study, the effect of a program based on Roy's adaptation model was investigated on the coping skills in children of MS patients. The results of the study showed that there was a statistically significant difference in the mean scores of coping skills between the control and intervention groups before the intervention ($p = 0.024$).

There was no statistically significant difference in the mean scores of coping skills scores between the intervention and control groups immediately after the intervention ($p = 0.71$). The mean scores of coping skills showed a statistically significant difference ($p < 0.001$) at 2 months after the intervention in the intervention group. An increase of 14.80 points was seen in the coping skills score in the intervention group.

Our results indicated that the change in the mean scores of coping skills at 2 months after the intervention (Roy's adaptation model-based training program) was due to the intervention factor in the two groups. This verifies

the importance of the follow-up course in acquiring coping skills. In this regard, studies have confirmed the positive effect of training based on Roy's adaptation model on coping skills and adaptation among different patients. Among them, the study of Lok *et al.*, which was conducted on the effects of motivational-cognitive therapy based on Roy's adaptation model on cognitive functions, coping skills, and quality of life in Alzheimer's disease patients, showed that the level of cognitive function of the experimental group (in the seventh week) was higher than that in the control group at the completion of the measurements, which also affected their adaptation skills. The importance of training duration on learning coping skills has already been demonstrated.^[28] In the present study, the results showed that it is necessary to spend time and follow the training in order to learn coping skills and adapt to new conditions caused by the chronic illness of parents.

The study of Sadeghnazhad Forotgeh *et al.*^[29] on the effect of a care program based on Roy's adaptation model for psychological adjustment in type 2 diabetic patients showed that the psychological adjustment of type 2 diabetic patients

could be increased by using a program based on the model and a follow-up that in turn improved the coping skills of adaptation, but there was no significant change in the role playing domain ($p = 1$). The results of that study are consistent with the present study with respect to increasing coping skills, but it seems that the results of that study are not consistent with the present study in terms of increasing coping skills because the educational needs have not been addressed in terms of role-playing. The two studies also differ in methodology and samples.

The study of Baksi *et al.*, which aimed to investigate the effect of a Roy's adaptation model-based training program on patients with primary brain tumor symptoms and their adaptation and coping with stress showed that the program was effective,^[30] which is consistent with the present study, but the participants in that study were patients with brain tumors and the study was performed in a clinical setting. In line with the results of Baksi *et al.* and the present study, it can be argued that the training program based on Roy's adaptation model can be effective in increasing coping skills in patients and healthy individuals. The results of the study of Farsi *et al.*,^[31] which was conducted to investigate the effect of a training program based on Roy's adaptation model on coping strategies in spinal cord injury patients, showed that there was a statistically significant difference between the two groups after the intervention in the scores on different domains of coping strategies, but there was no significant difference in social support.

The results of that study showed an improvement in coping strategies of most of the participants, which is consistent with the present study, but the results of that study showed no improvement in coping strategies of most of the cases in terms of social support because it was ignored in the educational needs of the participants. Similarly, the samples in that study were spinal cord injury patients and the coping skills questionnaire was different from the questionnaire used in the present study. Based on the results of that study and the present study, it can be concluded that an educational program based on Roy's adaptation model can assist in increasing the coping skills of patients and healthy individuals and performing needs assessment.

The results of the study of Akyil and Ergüney, which was done to investigate the effect of a Roy's adaptation model-based training program on the adaptation of patients with obstructive pulmonary disease, showed that the training program led to a significant change in the number of maladaptive behaviors in the physiological, self-perception, and role-playing domains in the patients. The results also showed that the application of the model was effective in improving adaptation and health in patients with obstructive pulmonary disease.^[32] The results of that study are consistent with the present study, but there are differences in the methodology and samples of the two studies. A difference that has been seen between the cited

studies and the present study is related to the lack of homogenization of the participants in terms of the need for training based on Roy's adaptation model since before the intervention.

The results of Mohammadi *et al.*'s^[33] study, which was conducted with the aim of investigating the impact of a program based on Roy's model on the general health of the children of people with MS, showed that the use of this program had a positive effect on the health of the children. From the results of that study and the present study, it can be concluded that the educational and support program based on Roy's model can have a positive effect on various aspects of the lives of these children.

In this study, the first revision was performed at baseline and the samples with a score of less than 80% of the researcher-made questionnaire were divided into the intervention and control groups. People who had educational needs were included in the study, and their educational needs were met by this method. It seems quite sensible that the study has progressed in an appropriate direction. Due to the specificity of MS and the unique cultural and geographical situation of Chaharmahal and Bakhtiari province as well as the possibility of stigmatization, it was very difficult to enroll eligible participants so that the process of enrolment took nearly 6 months. As well, during the implementation of educational programs, due to the dispersion of samples in the province, the problem of commuting and its cost was one of the problems of the researcher. This model can be used for both research and improving and promoting nursing services in children of patients with other chronic diseases and in different age ranges.

Conclusion

The findings show that the educational and support program based on Roy's adaptation model increases coping skills in children of MS patients. The wide range of educational fields of this model caused adaptation in different human dimensions. Our results indicated that the change in the mean scores of coping skills at 2 months after the intervention that verifies the importance of the follow-up course in acquiring coping skills

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Conflicts of interest

Nothing to declare.

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