ORIGINAL ARTICLE

The Effect of Collaborative Care Model-Based Intervention on Hope in Caregivers and Patients with Multiple Sclerosis: A Randomized Controlled Clinical Trial

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ABSTRACT

Background: Multiple Sclerosis can affect the patients' and their families' life. In this regard, the collaborative care model could be useful. This study aimed to investigate the effect of the collaborative care model on hope in patients with Multiple Sclerosis (MS) and their family caregivers.

Methods: This randomized controlled clinical trial was conducted in May to September 2015 on 60 patients with MS referring to the MS Society of Khuzestan province and 60 family caregivers. After block randomization, the intervention groups (patients and caregivers) received 8 intervention sessions based on collaborative care model over 12 weeks. The data were collected using Snyder's adult hope scale and a demographic questionnaire at baseline and 12 weeks after the beginning of the intervention. Data analysis was conducted through SPSS, version 19, using frequency, mean, Chi-square, independent, paired t-tests and Fisher's exact test ($P<0.05$).

Results: The results of independent t-test before the intervention showed no significant differences between the patients in the intervention (42.76 ± 8.75) and control groups (43.13 ± 7.20) ($P=0.86$) and caregivers in the intervention (50.26 ± 5.79) and control groups (49.23 ± 6.71) ($P=0.52$), regarding the score of hope. However, a significant difference was found in this regard 12 weeks after the beginning of the intervention, between the patients in the control (43.63 ± 6.97) and intervention groups (47.96 ± 8.72) ($P=0.03$), and caregivers in the control (50.66 ± 5.79) and intervention groups (53.80 ± 4.71) ($P=0.02$)

Conclusion: The collaborative care model promoted hope in patients with MS and their family caregivers. Hence, this model can be used by healthcare personnel for promoting hope among patients and caregivers.

Trial Registration Number: IRCT2015051121474N2

KEYWORDS: Caregivers, Hope, Model, Multiple sclerosis, Patient

INTRODUCTION

Multiple Sclerosis (MS) is a chronic and debilitating disease that causes a lot of disabilities.[1-3] The global prevalence of MS has been estimated to be 2,500,000.[4] Besides, it has been estimated that there are 60,000 patients with MS in Iran.[4] MS is often detected at 20-40 years of age with symptoms such as anxiety, weakness, and impaired vision.[5] MS patients also experience numerous problems such as fatigue, impaired balance, and muscle cramps.[5]

Today, treatment systems are inclined toward the early discharge of patients and care by family caregivers. Generally, caregivers experience quick burnout due to excessive pressure and demands.[6] Some researchers indicated that caregivers experienced emotional and psychological tensions, hopelessness, despair for the care recipient, anger, loneliness, guilt, and sleep disorders.[7] Thus, changing the caregivers' attitude can help them overcome their own challenges in dealing with patients.[8, 9] Although family is the most valuable and vulnerable source of support for patients with chronic diseases, most studies have focused on patients and diseases rather than family caregivers.[10] Research has also suggested that educational interventions improved the caregivers' well-being and significantly reduced their depression levels.[11, 12]

Hope is the ability to believe in the possibility of feeling better in the future with such persuasive power that encourages the individuals' activity and guides them toward new experiences.[13] A previous study demonstrated hope as a major source of power for patients with MS that enabled them to fight and challenge their disease and have a sense of purpose in life.[14] Moreover, it was revealed that hope therapy could improve different dimensions of quality of life in patients with MS.[15]

Overall, MS can affect the patients' and their families' economic, social, and emotional aspects of life. On the other hand, teaching the patients and their caregivers collaborative care

has been established as one of the ways for making patients self-sufficient in taking care of themselves. This goal can be accomplished by adopting the concept of "collaboration" in care, which can promote motivation, accountability and cooperation, and help involve the individuals in group processes.[16] In this regard, collaborative care model was designed and evaluated by Mohammadi et al in 2001. This model was designed based on Iranian factors and has been used for assessing numerous chronic diseases. However, this model is an educational method based on the patient's participation in the management of chronic disease, including phases of motivation, preparation, involvement, and evaluation.[17]

For instance, the collaborative care model improved the quality of life in patients with heart failure.[18] Collaborative care programs also reduced the risk of cardiovascular diseases and resulted in significant recovery. Thus, the nurses' use of the collaborative care model appeared to be beneficial to primary care services.[19]

Regarding the significance of hope in MS patients and their caregivers in addition to the importance of collaboration improvement, especially for these patients and their caregivers, it is necessary to examine the impact of collaborative care model -based interventions in these people.

Up to now, no attention has been paid to the effectiveness of interventions in promoting hope in MS patients in Iran. Indeed, most studies have focused on the patients and have failed to address their families and caregivers. Therefore, the present study aimed to assess the effect of the collaborative care model on hope in patients with MS and their caregivers.

MATERIALS AND METHODS

This randomized controlled clinical trial was conducted in May 2015 and within 4 months on all the patients with MS referring to the MS Society of Khuzestan province and their caregivers. MS Society is the unique center for providing services to these patients in

Khuzestan province. Given the lack of similar studies on MS patients in Iran, the researchers began their research with a pilot study on eligible MS patients and their caregivers (patients=20 and caregivers=20). Accordingly, the mean and standard deviation were measured. Then, based on α=0.05 and β=0.2 and using the sample size formula, a 96-subject sample size was determined (48 patients and 48 caregivers each group). Nonetheless, to increase the accuracy of the study and account for the probable loss during the study, the sample size was raised to 120 subjects (30 patients and 30 caregivers each group). Pilot samples were not included in the study sample (Figure 1)

$$N = \frac{\left(Z_{1-\alpha/2} + Z_{1-\beta}\right)^2 \left(S_1^2 + S_2^2\right)}{(\bar{X}_1 - \bar{X}_2)^2}$$

$$N = \frac{(1.96 + 0.84)^2 (6.86^2 + 4.62^2)}{(76.7 - 82.9)^2}$$

The inclusion criteria of the study were a neurologist's approval of the patient's diagnosis, lack of disease recurrence within six weeks prior to the study, no history of chronic physical and mental diseases, patients' and their families' consent to participate in the study, age of 20-55 years, being literate, and obtaining Expanded Disability Status Scale (EDSS) score of 2-3 that allows the patients to participate in the training sessions. Moreover, the patients' main caregivers had to be a family member responsible for all the care duties related to the patients. On the other hand, the exclusion criteria of the study were the patients' or caregivers' absence in the training sessions (absence in one motivation session, one preparation session, one evaluation session, or two engagement sessions) and disease recurrence or progression in a way that reduced the patients' EDSS scores by at least 1 point, as determined by a specialist.

This study was conducted on 60 MS patients and 60 of their eligible family caregivers selected through convenience sampling. After obtaining the participants' consent to participate in the study, a demographic information questionnaire (information about
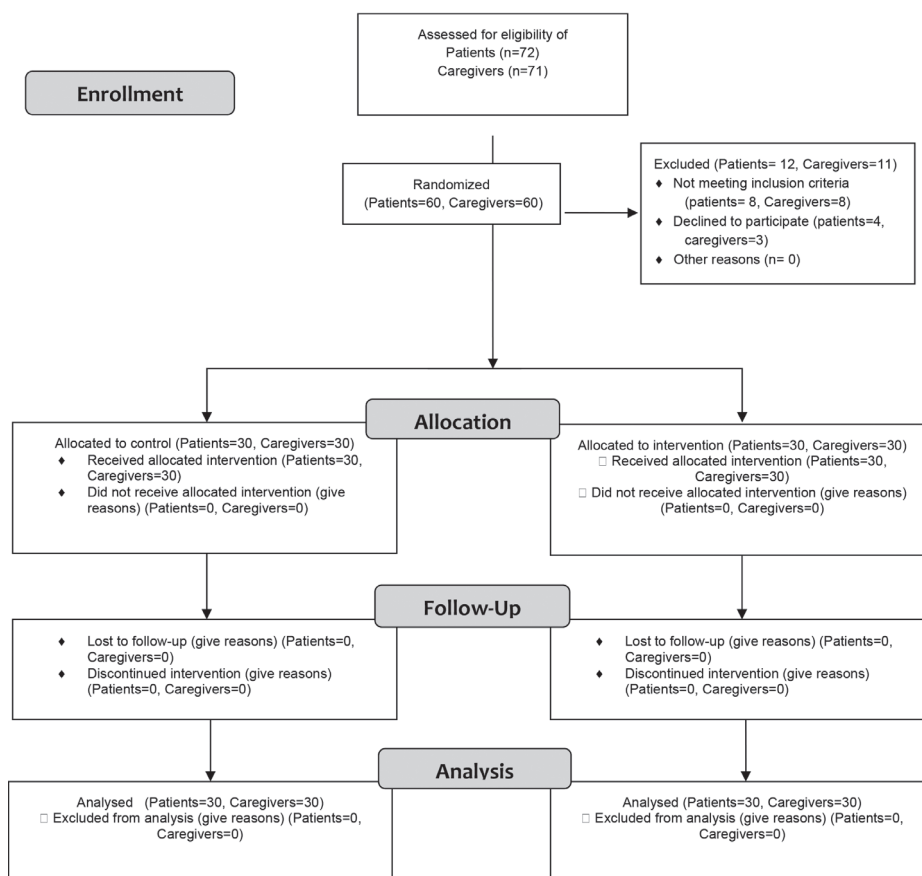

Figure 1: CONSORT Flow Diagram for patients-caregivers.

patients, caregivers, and disease complications) and Snyder's Adult Hope Scale (AHS) were distributed among the study subjects. Goals and instructions were also provided for completion of the questionnaires by researcher. Then, two demographic and adult hope scale questionnaires were completed by patients and their caregivers. The patients and their caregivers were then divided into an intervention and a control group through block randomization (15 blocks of 4 for the groups) by a co-author (for blinding). Goals and instructions were also provided for completion of the questionnaires. The intervention group received an intervention based on the collaborative care model (exclusively for each patient and his/her caregiver) through four stages and eight sessions over a period of 12 weeks. The model was implemented in four stages by the second author and included: 1-motivation, 2-preparation (The motivation and preparation steps were designed for preparing and planning of the training; also, these steps were performed for the intervention group during the first week. 3-engagement, and 4-evaluation (Table 1) [17].

The control group participants completed the routine treatment. They were also given an educational handbook at the end of the interventional program. At the end of week 12 after the intervention began, the AHS was completed by two groups of patients and caregivers (in two intervention and control groups).

The study data were collected using two questionnaires. The demographic information questionnaire contained the participants' demographic characteristics and disease information. The AHS designed based on Snyder's hope theory was also used to evaluate hope as a relatively stable personality trait.[20] This scale consisted of 12 items in two sub-scales, namely 'agency thinking' and 'pathways'. The items were responded through an 8-point Likert scale ranging from 'strongly agree' to 'strongly disagree'. The phrases 3, 5, 7 and 11 of this questionnaire are deviant and do not qualify for a score. In this questionnaire, the score is as follows: totally agree: 8, strongly agree: 7, agree: 6 agree slightly: 5, slightly opposed: 4, opposed: 3, strongly opposed: 2 and totally opposed: 1

Therefore, the range of grades in this test is between 8 and 64, with a score of 8 indicating the lowest level of hope and a score of 64 representing the highest level of hope. Psychometric properties of this questionnaire that was evaluated by Snyder et al. showed content validity more than 0.80. Also, the internal consistency of the scale was 0.84

Table 1: Educational content in the collaborative care model stages

1. Motivation	- Care problems were defined collaboratively - Increased the patients' awareness, attention, and motivation to pursue and continue the treatment program. This step was completed in a 2-3 hour session during 1st week.
2. Preparation	- Routine doctor examination - Presented the content about the nature, treatment, and control of the disease - Training about upgrading hope collaboratively - Hold two follow-up sessions with a one-week interval (review and assessment of the outcome). This step was completed in a 1-2 hour session during 1st week.
3. Engagement	- Implementation of the collaborative training and follow-up sessions - Four collaborative training visits and two collaborative follow-up visits. This was done from week 2 to week 8 for seven weeks. Each collaborative training visits completed in an 80-60 mi session.
4. Evaluation	- Assess the effect of the collaborative care model on hope in patients This stage, which is the final stage of the model, was implemented the end of week 12 after beginning of the intervention. Stage evaluations were carried out at the beginning and end of each visit, and at this stage, the final evaluation was done to measure the impact of model implementation on hope.

and its test-retest reliability was 0.80.[20, 21] Regarding the validity of this scale, it should be noted that in a study conducted in Iran in order to investigate the construct validity using factor analysis, it was found that the scale had a two-factor structure including factor thinking and strategies.[22] Consistency of the agency thinking and pathways subscales was also confirmed with Cronbach's alpha values of 0.74 and 0.62, respectively.[19] Given that AHS had never been used to examine the patients with MS and their caregivers, its reliability was evaluated using the test-retest method. In doing so, the reliability of the items was assessed using Pearson's correlation coefficient by the test-retest method with a 2-week interval (0.85 on both occasions).

The data were analyzed using SPSS statistical software, version 19, and were described using mean and variance. Moreover, frequency, mean, percent, Chi-square and independent, paired t-tests and Fisher's exact test were employed regarding the study variables before and after the intervention (P<0.05).

The research project was approved by the Ethics Committee of Shiraz University of Medical Sciences (CT-9379-7399). The subjects submitted their informed consent forms and were briefed on the confidentiality of their information, the voluntary nature of participation in the study, and the sessions being free of charge. At the end of the training program, all the educational pamphlets were also distributed among the controls and all the patients who had been excluded from the study due to not meeting the inclusion criteria.

RESULTS

This study was conducted on 30 patients and 30 caregivers in each of the intervention and control groups. The mean age of the patients was 31.36±8.32 years in the control group and 30.33±7.28 years in the intervention group. The mean age of the caregivers was also 33.03±6.60

Table 2: Comparison of the participants' demographic information of intervention and control groups

Study variables	Group		Control N (%)	Intervention N (%)	P value
Gender	Patients	Male	10 (33.33)	6 (20.00)	0.38*
		Female	20 (66.67)	24 (80.00)	
	Caregivers	Male	9 (30.00)	15 (50.00)	0.18**
		Female	21 (70.00)	15 (50.00)	
Marital status	Patients	Single	16 (53.33)	10 (33.33)	0.19**
		Married	14 (46.67)	17 (56.67)	
		Divorced	0 (0.00)	3 (10.00)	
	Caregivers	Single	9 (30.00)	6 (20.00)	0.44**
		Married	20 (66.67)	21 (70.00)	
		Divorced	1 (3.33)	3 (10.00)	
Level of education	Patients	Under diploma and Diploma	19 (63.33)	16 (53.33)	0.19**
		Associate's degree &higher	11 (36.67)	14 (46.67)	
	Caregivers	Under diploma and Diploma	16 (53.33)	13 (43.33)	0.43**
		Associate's degree &higher	14 (46.67)	17 (56.67)	
Employment status	Patients	Employed	14 (46.67)	10 (33.33)	0.68**
		Homemaker	10 (33.33)	13 (43.33)	
		Unemployed	6 (20.00)	7 (23.34)	
	Caregivers	Employed	15 (50.00)	14 (46.67)	0.95**
		Homemaker	9 (30.00)	10 (33.33)	
		Unemployed	6 (20.00)	6 (20.00)	

*Fisher's exact test; **Chi-squared test

years in the control group and 36.96±11.33 years in the intervention group. According to the results of independent t-test, both patients and caregivers of the intervention and control groups were homogeneous in terms of their mean age (P>0.05). Demographic information of the study participants is presented in Table 2.

The results of the independent t-test showed a significant difference between the patients in the control group (43.63±6.97) and those in the intervention group (47.96±8.72) as to the score of hope 12 weeks after the beginning of the intervention (P=0.03). Also, a significant difference was observed between the caregivers in the control group (50.66±5.79) and those in the intervention group (53.80±4.71) regarding the score of hope 12 weeks after the beginning of intervention (P=0.02) (Table 3).

DISCUSSION

The present study aimed to determine the effect of the collaborative care model on hope in patients with MS and their caregivers. The findings of the present study showed that the collaborative care model caused a significant difference between the patients in the intervention and control groups regarding the score of hope after the intervention. However, no significant difference was observed between the two groups concerning the mean score of hope prior to the intervention. This suggests that the increase in the score of hope in the patients

of the intervention group was due to their participation in the collaborative care sessions and their use of each other's experiences.

These results were in agreement with two other researches.[23, 24] Also, a research carried out on the effect of the collaborative care model on hope reported that this model reduced depression, thus increasing hope among the patients.[19]

In this study, females comprised most of the participants in both intervention and control groups. The female to male ratio was also about three to one, which is consistent with the generally higher incidence of MS in females than in males. Similar results were also obtained in other studies performed on patients with MS.[24, 25]

Moreover, several researchers have found that collaborative and group methods of training increased hope in patients with MS. For instance, a researcher assessed the effectiveness of mindfulness-based cognitive group therapy in promoting mental well-being and hopes in patients and found that this intervention increased hope significantly in these patients.[26] The other researcher indicated that teaching self-care based on Orem's self-care theory improved hope in patients with MS.[27] Although these studies used different approaches, they all found that their proposed methods were effective in increasing hope in patients with MS, which is consistent with the results of the present study.

Furthermore, the effect of patient training

Table 3: Comparison of the patients and caregivers in the intervention and control groups regarding the mean score of hope

Comparison of the patients			
Time of measurement / Group	Pre-intervention Mean±SD	Post-intervention Mean±SD	P value **
Control	43.13±7.20	43.63±6.97	0.83
Intervention	42.76±8.75	47.96±8.72	0.00
P value*	0.86	0.03	
Comparison of the caregivers			
Time of measurement / Group	Pre-intervention Mean±SD	Post-intervention Mean±SD	P value **
Control	49.23±6.71	50.66±5.79	.28
Intervention	50.26±5.79	53.80±4.71	0.01
P value*	0.52	0.02	

*Independent t-test; **Paired t-test

and tele-nursing on hope in renal dialysis patients was evaluated. However, their intervention did not significantly improve hope in one of the intervention groups, which is not in agreement with the present study findings.[28] This disparity might be due to the short duration of training (one hour), type of training, and failure to actively engage the patients' caregivers in training and follow-up. In the present study, however, the patients received care based on the collaborative care model and were actively engaged in the intervention. Moreover, continued training was ensured and future follow-ups were arranged, thereby leading to a significant improvement in hope among the patients.

In our study, the collaborative care model caused a significant difference between the caregivers in the intervention and control groups regarding the score of hope after the intervention. However, no significant difference was observed between the two groups in this regard before the intervention. This suggested that the increase in the score of hope in the intervention group caregivers could be due to their participation in the collaborative care sessions and their use of each other's experiences.

In the present study, examining the effect of the proposed intervention on hope was not limited to the patients and incorporated the caregivers, as well, which confirms the importance of the issue. A study results also showed that this family intervention reduced depression, anxiety, and stress; fostered hope in caregivers; and potentially improved the quality of life in both patients and their caregivers.[29] Moreover, the collaborative care model was more effective in improving hope in patients with MS than in their caregivers. Although not statistically significant, this difference might be due to the different and better understanding of the patients about the importance of hope and their greater motivation for learning and following up their training for the ultimate purpose of controlling and improving the symptoms of their disease. Yates argued that since the

life of individuals with chronic diseases is complicated by problems such as loss of functioning, disability, etc., these patients might perceive hope differently compared to healthy individuals.[28] Thus, disease could affect hope in individuals, including caregivers, who shoulder the great burden of patient care.[6]

Some researchers studied cancer patients and found that nurses could be involved in stimulating and changing hopefulness in patients through maintaining a good relationship with them. Therefore, nurses could play an effective role in improving hope in patients through performing interventions that meet the discussed objectives.[30, 31] Another study also examined the factors that increased hope in patients with chronic diseases and reported that patients perceived the support they received from their family members as the main factor contributing to their hopefulness. The patients also described the nurses' care measures as the factors contributing to their hopefulness.[32] The results obtained on the role of nurses in improving hope in patients are, therefore, consistent with the findings of the present study. In the same line, Miller believed that hopelessness and disease outcomes had a mutual interaction in patients with chronic diseases. Accordingly, hopelessness worsened the disease outcomes which in turn caused hopelessness in patients.[31]

Generally, hope, increased self-care, and patient support can be argued to be interrelated. Given that the collaborative care model was found to improve hope in patients and their caregivers, using this model may also help promote self-care abilities in patients with chronic diseases. Using this model is, therefore, recommended for promoting hope and self-care abilities in patients with other chronic diseases.

One of the limitations of the present study was the lack of follow-up due to time constraints. Thus, future studies are recommended to take advantage of a long-term follow-up so as to be able to assess the stability of the intervention's effectiveness. Additionally, given the lower

level of hope in patients with chronic diseases compared to the general population, further studies are recommended to assess the effect of this model on hope in patients with other chronic diseases.

CONCLUSION

The collaborative care model promoted hope in patients with MS and their family caregivers. Hence, this model can be used by healthcare personnel for promoting hope among patients and caregivers.

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