

The effect of group psycho-education program on the burden of family caregivers with multiple sclerosis patients in Isfahan in 2013-2014

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ABSTRACT

Background: Lack of adequate training and support of primary caregivers of multiple sclerosis (MS) patients is the major factor in causing stress, anxiety, and increase of burden. Therefore, the treatment team members such as psychiatric nurses can help these vulnerable people overcome psychiatric pressures effectively not only through their care and referral role but also through their supportive characteristic, which helps the patients improve their clinical status, together with their social, familial, and work adaptation. Therefore, the researcher tried to identify the effect of a group psycho-education program on the burden family caregivers with MS patients.

Materials and Methods: This is a two-group three-stage clinical trial. The researcher referred to the heads of neurology clinics to present the purpose of the study and to start the sampling. The neurology clinics of AL Zahra University Hospital, and also a Private Neurology Clinic were selected to collect the data of the study. The subjects were randomly selected, and then, assigned to two groups of study and control.

Results: Independent *t*-test showed a significant reduction in family caregivers' burden immediately after and 1-month after intervention in the study group, compared to control. Repeated measure ANOVA showed a significant reduction in caregivers' burden mean score in the study group ($P < 0.001$).

Conclusions: As group psycho-education reduced family caregivers' burden, it is recommended to develop and design other programs for the family caregivers of the patients with MS.

Key words: Burden, caregiver, family, group, Iran, multiple sclerosis, psycho-education

INTRODUCTION

Multiple Sclerosis (MS) is a chronic progressive and relatively common disorder of nervous system, which mostly occurs in youth (often in the third decade of life) and involves some of the people. The progressive trend of the disease is so that, if not diagnosed, it leads to a disabling condition and a notable decrease in patients' productivity in their age of work. This has a great impact on the patients, their family, and the society.

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Meanwhile, appropriate treatment and nursing care, and psychological education result in an increase in patients', and their families' physical and psychological abilities, and a diminished pace of the disease progress.^[1] Based on WHO statistics, by September 2012, there were 4,00,000 individuals involved in MS in the USA (about 2.5 million) in the world, and about 2,844 people died of MS by that time.^[2] There is no statistic about MS patients in Iran, but the head of Iranian Neurologists Association estimated the involved people to be 50,000.^[3] Number of these patients shows a notable increase during three past decades. In Isfahan province, research shows that the prevalence of this disease in this province has increased from 5 out of 1,00,000–60 out of 1,00,000.^[4] In fact,

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Isfahan with 4,250 patients has the highest population of MS patients in Iran.^[3,5] As in MS, relatively numerous and unpredictable changes occur, especially in early stages of life, the disease can leave severe psychological effects not only on the patients, but on their families and principle caregivers so that the families who give them care face several clinical challenges.^[6] It is to the extent that 70% of these patients need to receive help from their family members.^[7] Most of the care is administrated at home by family members and patients' friends, and family caregivers.^[8,9] The care given to these patients is counted as one of the most difficult and challenging cares for family caregivers.^[10] Despite that these caregivers are the first patients source of support,^[11] they are named nonofficial caregivers.^[12] Word "care burden" is used to describe the complications improved by the care that includes physical, emotional, economical, and social problems associated to care.^[8,13] If the main caregivers are not adequately trained, they face stress, anxiety, and psychological signs continue, even after their patients' disability is managed.^[11] Family caregivers need to be educated about the disease and it's care.^[14] In this direction, there are various supportive and educational programs for MS patients' families and numerous studies have evaluated these programs. In a study, on the MS patients' spouses as the caregivers, those who acted as the main caregiver were reported to be predisposed to lowered quality of life (QOL), depression, marital life dissatisfaction, chronic fatigue, and increased burden of care due to inadequate training and lack of supportive organizations. The caregivers who had higher stress were predisposed to more depression and chronic fatigue.^[12] In another study, on the effect of psychological educational program administration on burden of care and QOL of MS patients, it was revealed that treatment neglect, caregivers' fatigue, stress, and a reduction in caregiver's capability was associated with their level of knowledge about the disease so that lowered knowledge led to their burden of care.^[15] Forbes *et al.*, believed that to a lower burden of care in a family member, other family members should accept the responsibility of the patient so that the whole family acts as the unit of care. Nurses often consider the family as a baseline for MS patients' care.^[16] Hence, the treatment team members such as psychiatric nurses, in addition to their caring and referring role, can help this vulnerable population to reduce their psychological pressures and improve their clinical condition and social, and familial adoption and care.^[17] With regard to inadequate research in this field, and the difficult task of MS patients' care, the present study aimed to investigate the effect of group psycho-education program on familial caregiving burden of MS patients. The specific goal of this research was determination and

comparison of MS patients' family caregivers' burden level in study and control groups.

MATERIALS AND METHODS

This is a two-group three-stage intervention conducted on 70 MS patients' caregivers in Isfahan, Iran in 2013. Research environment included MS patients Clinic of Al-Zahra Hospital and MS Patients Association in Isfahan. Inclusion criteria were being the family member responsible for all patient's care and support, age > 18 years, giving care only to one MS patient in the family, ability of understanding and speaking Persian, no previous attendance in family education sessions, and no use of psychotropic medications or drug abuse, being the main caregiver of the MS patient with disabling level of 3–9.5 (disabling level is a quantitative method to determine the level of disability and monitoring the level of changes in MS patients' which is, vastly used in clinical trial interventions and MS patients' evaluation. Its point ranges 0–10 in which the points are added half by half. Points 1–4.5 refer to the patients who can walk and move with no need of help, points 5–9.5 refer to the patients who have defects in walking, movement, and conducting daily activities, and finally, point 10 refers to the MS patients with severe condition who die of MS).^[18] If the subjects were absent for more than two sessions in group psycho-education or was involved in one of the acute or chronic physical and mental diseases, which prevented patients' care, they would be excluded from the study. In the present study, the sample size was calculated 64 subjects after consultation with statisticians, which was finally considered 70 subjects for the possible subject drop. Sampling was conducted through referring to MS patients' special clinics of Al-Zahra Hospital and MS Patients Association in Isfahan as the only MS patients' referral centers from the patients' caregivers referring to above-mentioned centers by the researcher from April to August 2013. Then, the caregivers were assigned to study ($N = 35$) and control ($N = 35$) groups by random allocation (by draw). The subjects in the study group attended the psych-education program after signing the informed consent form. They were assured about the confidentiality of their information, and were offered to receive the results based on their request. The subjects' cooperation with the study was optional, and they could leave the study by their will. The subjects in the control group were promised to receive an educational booklet and the related compact disk (CD). The content of the program included an educational booklet, prepared and designed by the researcher after reviewing the articles, and literature review. The researcher handed the educational booklet to some psychiatrists, neurologists, and academic members in Isfahan Nursing and Midwifery School. Data collection tool were a questionnaire containing two sections. The first section included patients' personal familial

and treatment and main caregiver's characteristics concerning age, sex, marital status, employment status, patients' and caregiver's level of education, and the severity and length of giving care to the patient, which were collected by an interview from the caregivers. In the second section of the questionnaire, Zarit Burden Scale was used which included 22 questions on personal, social, emotional, and economic burden. The questions were pointed as never (0), seldom (1), sometimes (2), often (3), and always (4) ranging 0–88 points, obtained by the caregivers in relation with their level of psychological pressure and burden. The lowest point (0) was for no caregivers' burden and the highest (88) as the highest level of burden. Points 61–88 showed severe caregivers' burden; 31–60 moderated and lower than 30 showed minor burden. Its validity was confirmed by tests and references and consideration of above-mentioned questionnaire, as well as consultation with university professors and its reliability was calculated by test re-test ($r = 94\%$)^[19] and based on questionnaire application in evaluation of MS patients' family caregivers' burden in different countries like Spain.^[20] Subjects completed the questionnaire before the intervention, immediately after (after the end of seven sessions), and 1-month after the intervention. The control group underwent no intervention but received the educational booklet and CD,^[11] after the intervention was conducted in the study group. Psycho-education program [Table 1] was administrated in study group by a master of psychiatric nursing in seven weekly 90 min sessions^[21] during 6 weeks^[11] in forms of lecture, question and answers, role play, and skills such as brainstorming, group discussion, and small groups. At the end of sessions, a CD containing relaxation and anger and tension control techniques, and an educational booklet including a brief review of each session outline were given to the subjects. Collected data were analyzed by descriptive and inferential statistical tests.

Ethical consideration

All possible ethical issues addressed as explained above and the participants signed a written informed consent. The research project has been approved by vice-chancellor of research of Isfahan University of Medical Sciences.

RESULTS

The obtained results through Chi-square and independent *t*-test showed that study and control groups were almost homogenous concerning variables such as age, sex, marital status, family caregivers' and patients' level of education, the length and severity of patients' disease, the length of caregivers' care, and caregivers' relationship with the patients [Table 2]. The findings showed that family caregivers' burden gradually decreased in the study group. Caregivers' burden mean score in three

Table 1: Group psycho-education program content (the length of each session was 90 min)

Session 1	Familiarizing the families and main caregivers with the program and completing Zarit caregiver burden questionnaire and demographic characteristics questionnaire, question and answers
Session 2	Familiarizing the caregivers with MS (definition, etiology, risk factors, types and signs, complications, treatment and the emphasis on following it), questions and answers
Session 3	Familiarizing the caregivers with some methods to control disease sign and complications (fatigue, dizziness, headache, visual disorders, sleep disorders, sensory and motor disorders, loss of appetite, urinary disorders, sexual disorders, pain and immobility complications), questions and answers
Session 4	Familiarizing the caregivers with how to communicate with the patient, provide him/her with physical needs, efficient emotion expression methods, efficient communication ways and modification of communication process in the family, questions and answers
Session 5	Familiarizing the caregivers with how to cope with patient's negative feelings such as depression and hopelessness, stress and importance of its management, questions and answers
Session 6	Familiarizing the caregivers with one of the stress reduction methods such as relaxation and deep breathing, and problem solving method, questions and answers
Session 7	Familiarizing the caregivers with spiritual dimension empowerment and methods of life expectancy increase, questions and answers and group discussion, conclusion

MS: Multiple sclerosis

time points of before, immediately after and 1-month after administration of psycho education program were 62.31 (5.5), 27.3 (4.9), and 21.4 (3.3), respectively. Comparison of mean scores through repeated measure ANOVA showed a significant difference in these means in the study group ($P < 0.001$). Independent *t*-test showed a significant difference in caregivers' burden mean scores before and immediately after, and before and 1-month after intervention ($P < 0.001$). Least square difference *post-hoc* showed a significant difference in caregivers' burden mean scores before intervention and immediately after and before intervention and 1-month after in study group, but there was no significant difference in immediately after and 1-month after ($P > 0.05$) [Table 2]. The findings showed no notable difference in caregivers' burden mean scores in the control group. The caregivers' burden mean scores in three times points of before, immediately after, and 1-month after intervention were 61.82 (6.2), 60.05 (5.3), and 59.8 (4.8), respectively. Repeated measure ANOVA showed no significant difference in the mean scores in the control group [Table 2]. The independent *t*-test results, related

to comparison of family caregivers' burden in study and control groups in three time points, showed no significant difference before intervention in both groups (the groups were identical concerning family caregivers' burden), while the difference was significant in both groups immediately after and 1-month after intervention ($P < 0.001$) [Table 2].

DISCUSSION

As the obtained results showed, MS is somehow gender related. As observed in Tables 1 and 3, the highest frequency was for women; therefore, most of the caregivers were male. Results of Marry Why *et al.*, 2010 with a study on the effect of group psycho-education on MS patients' caregivers' (spouses') burden, Ashobeili's study (2008) investigating the effect of caregivers' burden on MS patient's caregivers' QOL and Nana *et al.*, (2009) were all consistent with the present study, and showed that most of the caregivers were men (11) meanwhile, Navidian *et al.*, (2010) in a study on the efficacy of family education on family caregivers' psychological burden among hospitalized mentally disordered patients showed that 70% of these caregivers were female in study group (19). Based on the study mentioned above, it can be concluded that in not gender-related diseases such as mental disease, most of the caregivers are women. The present study showed a significant decrease in family caregivers' burden immediately after administration of group psycho-education in the study group, which is consistent with many reviewed studies.^[11,12,15] In all these studies, family caregivers' burden was significantly decreased after a supportive and educational intervention. Results of Michael G's study were not consistent with the present study so that after administration of a supportive educational program, there was no significant difference in family caregivers' burden, compared to before intervention,^[22] possibly due to existing differences in the method, especially the components of the program including educational content. Researcher believes despite

the similarities between educational content and method in Michael G's study and the present study, the long time intervals in Michael G' study (immediately after and 2 years after intervention) can have increased the severity of the disease and family caregivers' burden, and lowered the effect of educational interventions. Another important point making difference in Michael G' study, and the present study is the difference in the studied disease, due to their different severity, trend of disease, and the effect on family caregivers' burden. Nana *et al.*, (2009), in a study on the effect of group psycho-education program on MS patients' family caregivers' burden, showed no significant difference in family caregivers' burden 1-month and 1-year after administration of the program in study group, possibly due to longer time interval of follow-up. Meanwhile, our obtained results showed that the effect of the educational program remained even 1-month after that. The researcher believes the difference in longevity of effect between Nanas' study and the present study is the shorter time intervals between follow-ups (immediately after and 1-month after intervention) in the present study, compared to Nanas' and preparation of an educational CD and telephone follow-ups, in addition to distribution of an educational booklet among caregivers in the study group. The obtained findings also showed a slight gradual reduction in family caregivers' burden during three time points of before, immediately after and 1-month after intervention in control group although the difference was significant in none of these time points. In another study, on the efficacy of a family caregivers program to support patients with dementia in India, it was revealed that family caregivers' burden had a slight reduction 3 months after intervention, compared to immediately after in control group,^[23] which is consistent with the present study. Meanwhile, in some other studies, family caregivers' burden got more through time.^[22,23] In this regard, it can be mentioned that an increase in severity of disease, followed by lowered caregivers' knowledge can have acted as a predisposing factor for the ascending trend of family caregivers' burden increase, but the difference in family caregivers' burden in various time points was not significant.^[24] The notable point of the present study is that the caregivers' continuing education background was made by an educational booklet and a CD. This study and its results also suggested evidences that group psycho-education can be an efficient family intervention among family caregivers of chronic patients in a sample of Iranian society. These results, consistent with other studies, reveal that prediction and provision of such psycho-educational programs in the mental health services system of patients and their caregivers are absolutely essential and effective.^[25] We believe that group psycho-education, designed and used in the present study, has caused appropriate changes in caregivers' knowledge

Table 2: Comparison of mean and SD of care burden before, immediately after and after intervention in study and control groups

Time	Group Mean (SD)		Statistical test	
	Study	Control	Independent t-test	P
Before	31.62 (5.5)	82.61 (2.6)	34.0	731.0
Immediately after	27.3 (4.9)	60.05 (3.5)	26.64	<001.0
1-month after	21.4 (3.3)	59.8 (4.8)	5.38	<001.0
Repeated measure ANOVA				
F	628.6	1.26		

SD: Standard deviation

Table 3: Patients' and caregivers' demographic characteristics in study and control groups

	Caregivers (n=35)		Patients (n=35)	
	Study	Control	Study	Control
Age (year)	43.5 (12.42)	14.5 (42.8)	31.9 (10.6)	33.4 (10.3)
Length of care (month)	51.8 (48.9)	48.2 (32.9)	-	-
Length of disease (month)	-	-	51.6 (49.03)	48.2 (32.9)
Disease severity	-	-	3.2 (1.3)	3.1 (1.4)
Hospitalizations number	-	-	2 (2.35)	1.97 (1.74)
Caregivers' gender (%)				
Female	42.9	48.6	82.9	73.4
Male	57.1	51.4	17.1	25.7
Employment status				
Working	48.6	45.7	20	14.3
Jobless	14.3	11.4	28.6	31.4
Homemaker	28.6	31.5	48.5	51.4
Retired	8.5	11.4	2.9	2.9
Marital status				
Single	5.7	17.1	34.3	45.7
Married	94.3	77.1	62.9	42.9
Divorced	0	2.9	2.9	5.7
Widowed	0	2.9	0	5.7
Education level				
Illiterate	0	0	0	2.9
Primary school	42.9	31.4	25.7	34.3
High school	22.9	40	37.1	34.3
University	34.3	28.6	37.1	31.4
Relationship with the patient				
Father	5.7	11.4	-	-
Mother	28.6	22.9	-	-
Spouse	48.6	28.6	-	-
Children	2.9	14.3	-	-
Immediate family	14.3	22.9	-	-

Standard deviation=<0/001

with regard to giving care to MS patients, and has lowered their care burden. Therefore, with regard to the efficacy of group psycho-education in reduction of family caregivers' psychological burden in study group (MS patients) and its content, this program seems to be capable of being applied to reduce family caregivers' burden of the patients with other medical diseases, after being modified for the related chronic disorder. In the end, it should be noted that further studies can be directed to detect specific components of the program that can reduce the burden better. Researchers' limitations in the present study were short follow-up intervals which was inevitable due to limited years of researcher's education and possibility of high number of the subjects drop. Therefore, it is suggested to evaluate and follow-up this program in longer time intervals.

CONCLUSIONS

With regard to the efficacy of group psycho-education in reduction of family caregivers' psychological burden in study group (MS patients) and its content, this program seems to be capable of being applied to reduce family caregivers' burden of the patients with other medical diseases, after being modified for the related chronic disorder. In the end, it should be noted that further studies can be directed to detect specific components of the program that can reduce the burden better. Researchers' limitations in the present study were short follow-up intervals, which were inevitable due to limited years of researcher's education and possibility of a high number of the subjects drop. Therefore, it is suggested to evaluate and follow-up this program in longer time intervals.

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