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The Effect of Participation in Support Groups on Depression, Anxiety and Stress in Family Caregivers of People with Alzheimer's: Randomized clinical trail

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ABSTRACT

This study sought to determine the effect of participation in support groups on the depression, anxiety and stress level of caregivers of patients with Alzheimer. This study was a single blind randomized clinical controlled trial (RCT) with 80 family caregivers of people with Alzheimer's (per group=40). The intervention group participated in eight sessions 1.5- 2 hours in support groups. The tool used in this study was the DASS-21 questionnaire for measuring depression, anxiety and stress level of the caregivers, analysis of parametric data, using SPSS version 21. Findings showed, participation in support groups showed no significant difference on depression, anxiety and stress in family caregivers of Alzheimer patients in the control group and the intervention group. Given that caring for these patients by their family members are very sensitive and costly issues for policy makers and health service providers, community and families of these patients.

Keyword: Support group, Care giver, Alzheimer

INTRODUCTION

Patients with Alzheimer because of cognitive difficulties are not able to meet their needs and with the disease progresses, they require formal or informal caregivers to meet their needs. Informal caregivers, who are often one of the family members, are the most important source of care and support for these patients and provide most of the care at home[1][2].In 80% of cases, family members are responsible for patient care [3]. Taking care of Alzheimer patients affects various aspects of caregivers' life including mental health, quality of life and life satisfaction [4].

Family caregivers in response to cognitive and behavioral symptoms, ongoing care of patients at home, in addition to physical problems such as; weight loss, general health deterioration and fatigue, show symptoms such as; anger, rage, despair, feelings of shame and guilt, stress and pressure communication which can lead to disruption of family relationships and social isolation[5]. In addition to problems such as; changing employment or hours of work or leaving job [6], caregivers are faced with psychological consequences such as; depression, anxiety, low self-esteem, feelings of loneliness and isolation [7]. Depression and anxiety are the most common problems that caregivers experience and often need medical interventions [8].

Depression can lead to decreased quality of life [9, 10] and the reduced quality of life as a vicious cycle, intensifies depression and loneliness [11].Beeson compared feelings of loneliness and depression in the spouses of patients with Alzheimer with spouses of patients without Alzheimer and showed that, spouses who care for Alzheimer patient had significantly more feeling of loneliness and depression than non-Alzheimer ones [12].Therefore, caregivers of Alzheimer patients require strategies to improve their mental health. In developed countries, the difficulty of caring for the elderly with Alzheimer disease which is on the shoulders of family caregivers, are reduced to some extent by providing them with effective support programs available [13].One of these programs and strategies is the formation of support groups as one of the self-care methods, and coping and stress-relieving strategies for caregivers that through participation in this group, they can share their feelings and experiences with other caregivers. The importance of these support groups have also been approved by the World Association of Alzheimer disease [14].

Participation in support groups is deliberate and systematic dialogue and interaction on a certain topic that is the common interest of participants [15].Support groups by creating a positive and constructive relationship among members, help them to reach a purposeful decision and lead to change attitudes and beliefs and deeper understanding of the subject, development of information, promote critical thinking and communication skills among the members [16].

Lack of research on the impact of Alzheimer patients' caregivers' participation in support groups on their depression, stress and anxiety level, was among the reasons to conduct this study. As the author had direct and indirect experience of caring for Alzheimer patient and has felt the difficulties of caring for people with Alzheimer up close, she always wondered if participation in support groups can affect the Alzheimer patients' caregivers' problems such as depression, anxiety and stress. Also in our country, given the particular circumstances of Alzheimer patients and their caregivers, a study which examines the impact of support groups on depression, stress and anxiety of caregivers of Alzheimer patients was not found.

Aim of research

The author decided to study the effect of participation in support groups on the depression, anxiety and stress level of caregivers of patients with Alzheimer.

MATERIALS AND METHODS

Design

This study was a single blind randomized clinical controlled trial (RCT) with Number IRCT201108037212N1 and endorsement of the ethics committee: /130/6289 which was conducted from March to June 2015 with a sample size of 80 participants (40 in each group). Researcher after obtaining the approval of the ethics committee and Vice-Dean for Research of Tehran School of Nursing and Midwifery to assess the impact of participation in support groups on depression, anxiety and stress of family caregivers of patients with Alzheimer disease, visited the Alzheimer's Association of Iran as the research environment and site and granted the approval of association's authorities.

Participants

Then 80 caregivers of patients with Alzheimer were invited to participate in the study. Inclusion criteria for all family caregivers of Alzheimer patients without age requirements were; to have at least one year of experience in the care of Alzheimer patients, to be able to, at least, read and write, having the desire to participate in support groups, lack of known psychological disease, and lack of experience of participating in support groups. Then a list of their names was prepared and each name (in the list of one to eighty) was given a number, and with the help of SPSS software, 40 numbers between one and eighty were randomly selected as intervention group and the other forty was considered as control group. Then both groups of caregivers were contacted and asked to participate in two separate sessions regarding research process. During these two sessions that were held one week prior to the study, the participants were given necessary explanations about the objectives and the research process and oral and written informed consent was obtained from them.

Data Collection Process

The tool used in this study was the DASS-21 questionnaire for measuring depression, anxiety and stress level of the caregivers. The questionnaire which was a shortened version of the DASS-42 questionnaire, was first presented by Loyband and Loyband in 1995, and in Iran in 2013 has been measured Psychometrically by NickAzin and Naeeniyan with Cronbach's alpha coefficient for depression, anxiety and stress, 0.79, 0.84 and 0.82 respectively[17]. At the beginning of the study, questionnaire was completed by the participants through self-report, and at the end of the eighth session (last session of the support group), was completed again for both groups. In order to prevent contamination of the data, caregivers in the intervention group was told in briefing sessions not to exchanging information with other care providers attending the Association. Meanwhile, support group meetings for the intervention group were held in another place instead of the Association's office building (which all caregivers visit to receive service as well as patients' visit). In addition, sessions for the intervention group were held on Sunday as doctors' visits were not done on Sundays from 8am to 1pm in order to furthermore prevent the exchange of information between the intervention and control groups. It should be noted that, in the Alzheimer Association in order to avoid unnecessary presence of caregivers, all caregivers' questions were answered by phone, which also helped to prevent the contamination of samples. It should be also noted that, in total, eight 1.5- 2 hours weekly sessions were held for the intervention group.

Caregivers in addition to active participation in the groups and receiving support from other caregivers, were provided with the support of experienced team of experts consisted of three geriatric nurses, a psychologist, a resident geriatrics, a general practitioner and a social worker.

While the expert team was present in discussion, dialogue and support of the caregivers, if any of the caregivers was asked for individual consultation, it was done by a psychologist or a nurse. Psychologist talked about how to deal and communicate with Alzheimer patients and methods of confrontation and control of the behavioral problems of these patients, and the groups' nurses gave participants information about the Alzheimer disease in general and how to care for Alzheimer patients and caregivers themselves, and discussed and evaluated different issues. Social worker informed the caregivers about the people who could help them in the prevention and resolution of problems and the services offered by the Alzheimer's Association for Alzheimer's patients (such as; the pressure relive mattress, wheelchairs, ...), and if any of caregivers needed these services, they were referred to the social worker department. Geriatrics resident and general practitioner answered caregivers' questions about treatment of the disease, medications, side effects of medications and strategies to reduce these effects. All expert team members had clear roles in the group, and participated in all sessions and group discussions of caregivers, and during the discussion, answered the questions related to their expertise.

In all these sessions, after reviewing the previous issues, the subject of the meeting was discussed with the participation of caregivers and necessary training was delivered. To help caregivers' commuting, transportation service was provided for them.

Data analysis

Analysis of parametric data, using SPSS version 21 and by comparing mean ratio and standard deviation of ratio in the form of raw frequency or relative were reported. For comparison of non-parametric statistical data the Mann-Whitney test was used. The significance level was set at 0.05.

The statistical test used for the study variables were; paired T-test for intergroup comparisons for each of the groups and independent T-test was used to compare differences in both groups before and after the study.

RESULTS

The findings showed, mean Standard Deviation (SD) of age of the caregivers in the intervention and control groups were 52/50 ± 8/57 and 57/67± 9/41 respectively and there was no significant difference between the two groups.

Table1: Baseline Characteristics of the Study family caregivers of people with Alzheimer's

Group		Intervention	Control	Result
Sex	Female	29(90.6)	27(90)	Fisher exact testP=1
	Male	3(9.4)	3(10)	
Marital statues	Marriage	27(84.4)	26(86.7)	Fisher exact testP=1
	Single	5(15.6)	4(13.3)	
children	Yes	27(84.4)	27(90.0)	Fisher exact testP=0.71
	No	5(15.6)	3(10.0)	
Education	Illiterate	1(3.1)	2(6.7)	Fisher exact testP=0.21
	Below high school degree	2(6.3)	6(20.0)	
	High school degree	18(56.3)	11(36.7)	
	University	11(34.3)	11(36.7)	
Employment status	Unemployed	2(6.3)	4(13.3)	Fisher exact testP=0.77
	Employee	6 (18.8)	6(20)	
	Retired	7(21.9)	7(23.3)	
	Housewife	17(53.1)	13(43.3)	
Caregiver	Spouse	8(25.0)	11(36.6)	Fisher exact testP=0.76
	Girl	20(62.5)	16(53.3)	
	Boy	2(6.3)	2(6.7)	
	Other relative	2(6.3)	1(3.3)	
Long-term care (year)	1-3	16(50)	14(46.7)	Mann–*Whitney U* *Z=-0.368* *P=0.90*
	3-5	6(18.8)	5(16.7)	
	>5	10(31.3)	11(36.7)	

Table 2. Compare depression in both intervention and control groups before and after intervention in family caregivers of people with Alzheimer's

Group	Before intervention Mean± SD	After intervention Mean± SD	Independent Sample test
Intervention	11.44±9.52	9.69±6.37	T=-0.675 Df=60 P=0.50
Control	13.07±9.48	13.27±9.24	T=-1. 765 Df=60 P=0.080

Table 3. Comparison of anxiety and stress in both intervention and control groups before and after intervention in family caregivers of people with Alzheimer's

Group	Intervention		Control		Result
	Before	After	Before	After	
Stress	17.01±10.11	16.49±9.88	17.00±10.59	17.47±10.57	
	Df=29 t=1.789 p=0.09		Df=29 t=2.041 p=0.06		
Comparison of the mean±sd	-1.75±10.56		0.47±1.25		Independent sample t-test Df=60 T=-0.795 P=0.25
Anxiety	8.01±8.54	8.88±8.59	8.00±8.60	8.20±8.50	
	Df=29 t=1.890 p=0.08		Df=29 t=1.759 p=0.11		
Comparison of the mean ±sd	-0.88±7.62		0.20±0.61		Independent sample t-test Df=60 T=-0.795 P=0.43

Other demographic characteristics are listed in (Table 1). Average depression in the intervention group was 11.44 ± 9.52 before the intervention and after the intervention was 9.69 ± 6.37, and paired t-test showed no significant differences. Also mean depression in control group pre-intervention was 13.07 ± 9.48 and after intervention was 13.27± 9.24, and paired t-test showed no significant difference. The independent t-test showed no significant difference in the depression between the two groups before and after the intervention (Table 2). Comparing the difference between the mean and standard deviation of depression (-1.75 ±9.78) before and after the intervention in the intervention group and the control group (0.20± 0.61) did not show statistically significant difference. Between the two groups in terms of mean and standard deviation of stress and anxiety statistically significant difference was not observed. Mean and SD of anxiety and stress are listed in (Table 3).

DISCUSSION

According to the findings of present Study, participation in support groups showed no significant difference on depression, anxiety and stress in family caregivers of Alzheimer patients in the control group and the intervention group. Thus, the results of the present study were not consistent with Donahue and Marziali study. In their study, they examined the role of internet interventions on family caregivers' stress, and after 12 sessions of video conference with caregivers and the expert team and discussing their problems, the authors concluded that, the stress of intervention group was reduced after the intervention compared to the control group [18].

Result of WANG study which was aimed to determine the impact of support group on distress of caregivers of patients with dementia, also was not consistent with the findings of the present study. WANG study showed that, the group receiving supportive education on distress and stress in family caregivers is significantly reduced. But supportive education did not affect their depression levels. However, in this study, participation in support group showed no significant difference in the stress, anxiety and depression of the groups.

Since several factors such as social support, family position, underlying medical condition, economic status, personal characteristics and other factors have an effect on people's stress, anxiety and depression, fear of the future and progression of the disease are among factors that may exacerbate stress and anxiety in people. Maybe in Wang's study, participants had received explanation about the prognosis of the disease and they have not had much ambiguity, but in the present study in the collaborative sessions on the progression and prognosis of the disease, caregivers were not provided with explanation, and this can be considered as a limitation of this study[19]. It is possible that the results of the present study vary from the results of Wang et al study. However, in line with the results of this study, in Wang's study the support group also did not have any effect on depression level. The author gives the possibility that, perhaps depression in caregivers has become chronic and requires medication along with participation in support groups. Also, since there is high prevalence of depression in older people, and often caregivers of Alzheimer patients are their spouses, it is possible that, the caregivers have already been depressed for various reasons or caring perhaps exacerbated that. So they require further treatments and measures.

In a study by Passoni et al (2014), cognitive and participatory interventions reduced the levels of stress and anxiety in caregivers of Alzheimer patients but had no effect on their depression level [20].

Thinnes and Padilla, in a study titled "The impact of training and support in the participation of family caregivers of patients with Alzheimer's disease," stated that, the participatory program with are held with the presence of clinical team, patients and their families, psychologist and social worker, reduced the level of anxiety and stress [21].

But the results of Ghaedi et al (2014) study were not consistent with the findings of present study. In their Study on the effectiveness of group education of family and its role in depression, anxiety and stress of family caregivers of individuals with Alzheimer's disease they concluded that, the mean score of depression, anxiety and stress after the intervention showed significant difference in intervention group and was decreased compared to the control group. So they recommend that, group psycho-educational interventions for family caregivers of elderly patients with dementia disorders have been conducted in a sample of Iranian society to reduce the stress, anxiety and depression of caregivers. They insisted that, predict and providing such services for family caregivers is essential in mental health care system [22].

In this regard, the study of Bastani et al, on "impact of focus groups discussion and telephone counseling on the stress of female caregivers of elderly patients suffering from Alzheimer" showed that, the focus groups discussion and telephone counseling are effective in reducing stress levels of female caregivers of elderly patients suffering from Alzheimer [23].Results of these studies are also inconsistent with the present study. However, the author givers the possibility that, perhaps the difficulties of caring for these patients as well as family problems might have caused caregivers' depression to become chronic and this intervention is not enough and other interventions such as medication therapy and participatory education are also required. On the other hand, cultural differences and personality traits, social support and emotional relationship of caregivers with the patient can also affect the level of depression. Perhaps in order to prevent depression in this population, adjustment programs should be initiated for the families at the early stage of the disease. Many of caregivers of patients with Alzheimer's disease are their spouses, and It is possible that due to aging, adverse conditions, inability to communicate with a person with Alzheimer's and being neglected by children, they already had depression, and care of the Alzheimer patients has increased the severity of their depression and they require medical intervention.

CONCLUSION

The findings of this study showed that, the participatory training program (in the study’s research community with a sample size) was not effective in reducing level of depression, stress and anxiety in caregivers of patients with Alzheimer's disease. Of course, this does not mean that, these programs are not effective in reducing the level of depression, stress and anxiety in caregivers of patients with Alzheimer. Perhaps because of limited time (8 weeks) of the study, or with larger sample size, the presence of psychologists, social workers and psychiatric nursing, the effect of these programs would be greater. Thus, given that caring for these patients by their family members is very sensitive and costly issues for policy makers and health service providers, community and families of these patients, and sometimes caregivers suffer irreversible mental and physical harms in the process of caring for Alzheimer patients, therefore it is suggested that, more studies with bigger sample size and longer duration to be conducted with the presence of experts and families of Alzheimer patients to examine the effect of participatory educational programs on the caregivers’ level of depression, anxiety and stress.

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