

# Evaluating the Effect of a Need-based Program for Caregivers on the Stress, Anxiety, Depression, and the Burden of Care in Families of Children with Attention Deficit-hyperactive Disorder

## Abstract

**Background:** Attention-deficit hyperactive disorder (ADHD) is the most common behavioral disorder of childhood, and due to its chronic nature, it would affect all the aspects of life of the child and the caregiver. Therefore, this study was conducted to determine the effect of a program based on the needs of caregivers on stress, anxiety, depression, and burden of care in families of children with ADHD. **Materials and Methods:** This randomized clinical trial was conducted on 70 family caregivers of children with ADHD from June to September of 2016. After convenience sampling, eligible samples were randomly allocated into two groups of control and intervention. The intervention group received the need-based educational program in eight sessions and the participants of the control group participated in two group sessions where they expressed their problems and experiences. Data were gathered through Zarit Burden Interview and Depression Anxiety and Stress Scale (DASS)-42 and then were analyzed using descriptive and inferential statistics. **Results:** The mean scores of stress, anxiety, depression, and burden of care had a significant difference between both groups right after and 1 month after the intervention ( $p < 0.001$ ), whereas in the control group, there was no gradual decrease in the mean scores of the dependent variables. **Conclusions:** The need-based educational program might reduce the level of stress, anxiety, depression, and burden of care in families of children with ADHD. It is recommended to develop similar programs and evaluate them through various studies. The use of nonpharmacological treatment of these children is evident in the results.

**Keywords:** Anxiety, attention deficit-hyperactive disorder, depression, Iran, stress

## Introduction

Attention-deficit hyperactive disorder (ADHD) is the most common neurological behavioral disorder during childhood and is defined as a constant pattern of inattention, hyperactivity, or both.<sup>[1]</sup> American Psychiatric Association has reported its prevalence to be 3–5% among the school age population. Its prevalence has been 33% among all the patients who have visited mental work-therapy centers in Iran.<sup>[2,3]</sup> These children have many problems including academic performance, interpersonal relationships, intrapersonal functions,<sup>[4]</sup> and communicational problems with their parents, teachers, and peers. Furthermore, parents of children with ADHD would experience more stress and less satisfaction compared with the parents of normal children.<sup>[5]</sup> In addition, most of these children, along with having

behavioral problems, are emotionally unstable. Therefore, children with ADHD are so sensitive and would be distressed easily. In most families, this matter would cause tension; as their child could have an emotional breakdown any minute, the family members are always alert. So, not only this disorder would affect the child, but it would also affect the comprehensive and wide system of the family.<sup>[6]</sup> Considering these evidence, need-based interventions, social support, and other supportive programs are necessary more than ever to improve the mental health of the parents of children with ADHD. Different interventions have been presented for these children and their caregivers, but according to Danforth, group education for parents, besides reducing inappropriate behaviors, would improve the parent-child relation and reduce their stress level. Actually, it

Sharifeh Mousavi<sup>1</sup>,  
Saeid  
Pahlavanzadeh<sup>2</sup>,  
Jahangir  
Maghsoudi<sup>2,3</sup>

<sup>1</sup>Department of Psychiatric Nursing, Isfahan, Iran, <sup>2</sup>Nursing and Midwifery Care Research Centre, Faculty of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran, <sup>3</sup>Department of Mental Health Nursing, Nursing and Midwifery Care Research Center, Faculty of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran

**Address for correspondence:**  
Mr. Saeid Pahlavanzadeh,  
Department of Mental Health  
Nursing, Nursing and Midwifery  
Care Research Center, Faculty  
of Nursing and Midwifery,  
Isfahan University of Medical  
Sciences, Isfahan, Iran.  
E-mail: pahlavanzadeh@  
nm.mui.ac.ir

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would help parents to find their strengths and weaknesses, deal with existing problems more effectively, and have a more positive feeling about their relation with their child.<sup>[7]</sup>

So educating is important as one of the aspects of treatment. Educating the patients and their families and caregivers about hyperactivity, its symptoms, course and prognosis, treatments, and services for resolving their needs is one of the necessities for coping with this disease. Undoubtedly, such educating would be of great importance in creating a commitment to long-term treatments for chronic diseases.<sup>[8]</sup> The importance of this matter would become clearer when we realize that the parents of children with ADHD would only accept medical therapy after they have been disappointed with behavioral and psychological interventions. Results of the study by Dosreis *et al.* showed that more than 50% of the parents, who have gained their information from public media, were reluctant about using medical therapy for their children.<sup>[9]</sup> In addition, results of a study that was conducted in America revealed that the most common concerns among parents of children with ADHD were wrong diagnosis, the effect of their parenting method or home environment on the symptoms of the disease, the effects of long-term consumption of drugs, and prescribing too much drug too early.<sup>[10]</sup> All of these results would indicate the necessity of improving parents' attitude and knowledge about ADHD. Different self-regulation programs are available<sup>[3,6]</sup> for educating parents. Their general purpose is to increase parents' knowledge and decrease children's behavioral problems. But the need-based program is based on the needs of caregivers at different levels and, regarding different

aspects of the caregiver's life that have been affected by the child's disease, could be a comprehensive approach for determining the educational content.<sup>[5]</sup> Therefore, due to lack of national studies in this field and the overwhelming nature of caring for children with ADHD,<sup>[5]</sup> the present study was conducted to determine the effect of need-based programs on stress, anxiety, depression, and the burden of care in families of children with ADHD.

## Materials and Methods

The present study was a two-group three-stage randomized clinical trial (IRCT201611232200N4). The researcher started convenience sampling at the centers for children with ADHD in Noor and Al-Zahra hospitals between June and September 2016 [Figure 1].

The inclusion criteria included being the main caregiver of a child with ADHD and being committed to all of their responsibilities, having sufficient physical and mental abilities for taking care of an ADHD child, willingness to participate in the study, being able to communicate in Persian, compliance with the rules of educational sessions, taking care of one patient with one chronic disease (which is ADHD) in the family, not having any drug addictions and not consuming any psychiatric drugs, not participating in any family educational sessions about children with ADHD before, and having an ADHD child of 7 to 12 years of age (school age) with a history of at least one hospitalization due to ADHD with no other disabling disease (physical disability, mental disability, autism) except for ADHD. The exclusion criteria were unwillingness to participate in the educational sessions, missing at most 2 of the educational

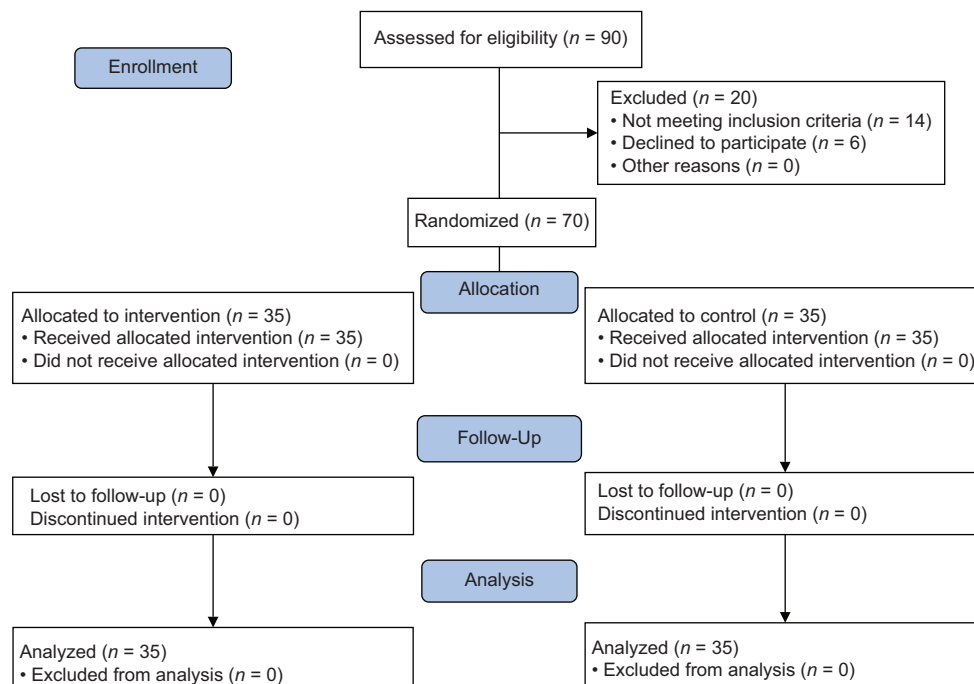


Figure 1: CONSORT flow diagram of the participants

sessions, and not being able to participate in the sessions for any reason. Considering similar previous studies,<sup>[5,10]</sup> the sample size for each group was at least 35 ( $Z_1 = 95\%$  confidence interval,  $Z_2 = 80\%$  statistical power, and  $d = 0.7$  SD).

The intervention group participated in the educational sessions after signing written informed consents. The participants of the control group were asked to only participate in the preintervention, postintervention, and follow-up stages and along with the routine treatment for their children; during the intervention, they were gathered in a separate place than the intervention group and asked to express their problems and experiences about their child's disease in two group sessions. The educational content of the intervention was gathered in a booklet about need-based programs, which included an introduction to the disease, its problems, reinforcing communicational skills, providing solutions for increasing attention and concentration and decreasing stress, anxiety and depression among caregivers, and assigning homework at the end of each session [Table 2]. This supportive educational intervention was conducted in eight sessions, 90-min each, for 3 weeks, using slide shows, images, pamphlets, and speech for the family members of the children with ADHD [Table 2].

The data of the caregivers were gathered using Zarit Burden Interview and Depression Anxiety and Stress Scale (DASS)-24. Zarit Burden Interview has 22 items and has been localized and validated based on the cultural condition of our country in 2004 by Navidian in Zahedan,<sup>[5]</sup> and DASS-42 has been designed by Brown *et al.* in 1997 and has been used repeatedly in different conditions.<sup>[11]</sup> The questionnaires were completed by both groups before, right after, and 1 month after the intervention. Collected data were analyzed using Statistical Package for the Social Sciences version 18 (SPSS18, IBM, USA), with inferential and descriptive statistics, Chi-square, Mann-Whitney, independent *t*-test, analysis of variance, and

least-squares difference. Testing the dependent variables, by Kolmogorov-Smirnov test, showed no significant deviation from normal distribution, and Mauchly's test for Sphericity approved the equality of covariance of the variables under investigation.

### Ethical considerations

Obtaining informed consent from the participants, assuring their anonymity and confidentiality, and giving them the right to leave the study at any desirable time were the most important ethical considerations in the present study. The present article is a part of a research that was approved by the Isfahan University of Medical Sciences. The ethical approval code was IR.MUI.REC.1394.1.194.

### Results

Results of the present study showed that both groups were similar regarding their demographic characteristics such as the age, sex, marital status, educational level, kinship, and duration of taking care of the caregivers and also the duration of the disease and children's age and sex. In the intervention group, the mean scores of the dependent variables (stress, anxiety, depression, and burden of care) gradually decreased at three time steps of before, right after, and 1 month after the intervention, whereas in the control group, there was no gradual decrease in the mean scores of the dependent variables [Table 1]. Paired *t*-test showed a significant difference between the mean scores of stress, anxiety, depression, and burden of care before and right after the intervention, before and 1 month after the intervention, and right after and 1 month after the intervention ( $p < 0.01$ ). Independent *t*-test showed that the changes in the mean scores right after the intervention compared with before the intervention were significantly more in the intervention group than the control group ( $p < 0.01$ ). This test also showed that the changes in the mean scores 1 month after the

**Table 1: The mean scores of stress, anxiety, depression, and burden of care before, right after, and 1 month after the intervention in the groups of intervention and control**

Variables	Groups	Before the intervention Mean (SD)	Immediately after the intervention Mean (SD)	1 month after the intervention Mean (SD)	Within subject comparison (df=2)
Stress	Intervention	33.31 (2.75)	17.02 (2.39)	12.14 (2.59)	$F=289.06$
Stress	Control	32.34 (3.02)	31.71 (3.54)	30.57 (3.32)	$p<0.001$
Between-subject comparison		df=1	$F=446.28$	$p<0.001$	
Anxiety	Intervention	30.20 (2.94)	15.80 (2.23)	11.23 (2.60)	$F=321.95$
Anxiety	Control	29.09 (2.99)	31.11 (3.80)	31.29 (2.93)	$p<0.001$
Between-subject comparison		df=1	$F=536.11$	$p<0.001$	
Depression	Intervention	32.01 (2.55)	14.31 (2.46)	11.01 (2.38)	$F=374.45$
Depression	Control	30.80 (2.87)	31.71 (3.67)	31.69 (3.29)	$p<0.001$
Between-subject comparison		df=1	$F=699.33$	$p<0.001$	
Caregivers' burden	Intervention	62.31 (5.52)	27.31 (4.94)	21.49 (3.34)	$F=397.89$
Caregivers' burden	Control	61.83 (6.23)	60.06 (5.33)	59.89 (4.85)	$p<0.001$
Between-subject comparison		df=1	$F=932.99$	$p<0.001$	

**Table 2: Content of the meetings**

sessions	subject
First session	Introducing the program, aims of the study and the researcher to caregivers, and completing the demographic characteristics questionnaire, Zarit Burden Interview and DASS-42
Second session	Introducing attention deficit-hyperactive disorder to caregivers: definition, etiology, signs and symptoms, and therapeutic interventions (medicinal and nonmedicinal), its complications, how to control it, group discussion, and questions and answer
Third session	Reviewing topics from the last session, correcting caregivers' misconceptions about this disorder, introducing the skills of communicating with the child and problem-solving to caregivers, question and answer and group discussion, and assigning homework
Fourth session	Reviewing topics from the last session, introducing methods for strengthening and restricting child's behaviors (punishment and encouragement), managing child's behaviors (controlling agitation, excitement, and anger), question and answer and group discussion, and assigning homework
Fifth session	Reviewing topics from the last session, reviewing homework, introducing effective methods for increasing attention and concentration (such as games, etc.), question and answer and group discussion, and assigning homework
Sixth session	Reviewing topics from the last session, introducing methods for reducing and resolving the physiologic problems of the child and the caregiver; introducing strategies for gaining familial and social support and maintaining personal and social abilities for reducing the economic load and improving caregiver's physical, mental, and social exhaustion; question and answer and group discussion; and assigning homework
Seventh session	Reviewing topics from the last session; reviewing homework; introducing strategies for controlling and managing emotions to reduce stress, anxiety, and depression and performing them (such as relaxation techniques, deep breath, etc.); question and answer and group discussion; and assigning homework
Eighth session	Reviewing topics from the last session, performing relaxation technique, reviewing homework, reviewing all of the discussed topics, receiving participants feedback about the topics, question and answer and group discussion and conclusion, and completing Zarit Burden Interview and DASS-42 again

intervention compared with right after the intervention were significantly more in the intervention group than the control group ( $p < 0.01$ ).

## Discussion

Results of the present study showed no significant difference between the mean scores of stress, anxiety, depression, and burden of care of the intervention and the control group. But right after and 1 month after the intervention, the mean scores were significantly lower in the intervention group compared with the control group and the scores had a significant gradual decrease. A study titled "the effect of behavioral education for parents on the general health of mothers of children with attention deficit-hyperactive disorder and the decrease in children's out flowing problems" revealed that educating parents had decreased children's behavioral problems in the intervention group and it had also prevented psychological and health problems in the parents.<sup>[12]</sup> Based on the results of the present study, it could be stated that need-based program might have significantly decreased the mean score of the burden of care for families of children with ADHD right after and 1 month after the intervention. Results of a meta-analysis by Mogan and Landy (2005), which has evaluated 72 studies from 1996 to 2001, showed that educating parents with a behavioral approach had been effective in reducing destructive behaviors in children and had consequently improved the physical and mental health of the caregiver.<sup>[13]</sup> The advantage of educating parents over other methods is that it would affect different aspects of parenting and family performance. Parents'

educating programs are based on this fact that behavioral disorders in children are caused and continued by parent-child inappropriate interactions. In this regard, results of other studies also showed that educating might improve the mental health of mothers of autistic children. These results are in line with the results of a study by which evaluated the effectiveness of cognitive-behavioral and supportive methods on the general health of mothers of autistic children.<sup>[14]</sup> also evaluated the effect of on-time need-based family-oriented psychological and educational interventions on the mental health of mothers of children with Down syndrome. Results of their study showed that this intervention had improved the performance of mothers of children with Down syndrome compared with the control group.<sup>[15]</sup>

In this regard, a study was conducted in Japan in 2012 where the parents of 22 children with attention-deficit hyperactive disorder were educated about the methods of coping with these children and reducing the parents' stress. The mean score of stress among parents was significantly decreased after educating which indicated that educated parents would choose more effective parenting methods and would be able to manage their stress better.<sup>[16]</sup> The study of Motoyoma *et al.* (2012) in China, which was aimed to evaluate the effect of an educational program based on the needs of the families of patients who were hospitalized in intensive care units on the level anxiety and satisfaction of the caregivers, revealed that the level of anxiety in the control group was significantly increased after the intervention compared with before the intervention.<sup>[17]</sup>



All of the previously conducted studies and the present study have indicated the effectiveness of educating parents on improving the performance of the parent and the child with ADHD. However, unlike the results of the present study, the study of Ghashang,<sup>[18]</sup> which was conducted to evaluate the effect of educational programs for families on the level of stress and improvement of parent-child relation, showed that their program had not been successful. One of the probable reasons for ineffectiveness in their study might be failure to completely and properly executing the program. The duration of the intervention might also be another reason. Ghashang conducted four sessions about parenting methods for mothers of 3–5-year-old children with behavioral disorders and resulted that educating mother had no effect on reducing the distress of the mother-child relation,<sup>[18]</sup> whereas in the present study, intervention was conducted in eight sessions and increasing the number of sessions could assess the process of implementation of the program by mothers and resolve their questions and problems during the intervention. In addition, the occurred changes in mothers and their children would become more obvious, because in short-term interventions, observing and assessing all of the changes might not be possible. Moreover, in the present study, the researcher assigned some homework for participants at the end of each session so that the parents would create a more effective relation with their child, do their homework, and report their feedback to the researcher. Therefore, the program based on the needs of caregivers was conducted in the field and the problems and barriers of the program were discussed with the researcher at the next session for resolving them; this would increase the effectiveness and durability of the interventional program. Although the methods of conducting the program have been different, eventually, the results would indicate the necessity of conducting interventions, especially need-based educational programs, for the caregivers. One of the limitations of the present study was the personal differences between the participants, which could affect their response to the intervention and its impact effect on them. It is recommended that, in future studies, besides minimizing the mentioned limitations, by using larger sample sizes and longer follow-ups, the insufficiencies of this study would be resolved.

## Conclusion

Need-based education for parents as the main caregivers of children might decrease the intensity of symptoms and problems for the children and their parents. Therefore, based on the results of the present study, a need-based program for caregivers could decrease the level of stress, anxiety, depression, and burden of care by increasing knowledge and attitude and improving the performance of families of children with ADHD. Moreover, these results, like the results of previous studies, would indicate that predicting and providing such need-based psychological

services in the mental health provision system is necessary and effective for patients with chronic diseases such as ADHD.

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## Conflicts of interest

Nothing to declare.

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