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Original Article

Evaluating the Relation between Family Functioning and Experienced Caring Load for the Parents of ADHD Children

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Abstract

Background: Attention deficit hyperactive disorder is one of the most common psychiatric disorders. The present study aimed to determine the relationship between family functioning and caring load in parents of ADHD children.

Methods: The present descriptive cross-sectional study's population included all the families of ADHD children who were referred to children's psychiatric clinics. Thirty families were selected using a convenient sampling method and enrolled in the study. Data gathering tools included the Family Assessment Device (FAD) and the Zarit Burden Interview.

Results: Of the studied children, 21 (70%) were boys and 9 (30%) were girls. 93.3% (28 children) had experienced severe hyperactivity. 80.1% (24) families had unhealthy functioning, and 47.2% (14) families experienced severe care burden. A significant relation was observed between family functioning and their experienced care burden ($p = 0.0001$).

Conclusions: Considering the relation between family functioning and the care burden on parents of ADHD children, it is necessary to help families decrease behavioral symptoms and experienced care burden by the families by determining the effective factors on family functioning and helping families improve their functioning in controlling hyperactivity disorder.

Keywords: Attention deficit hyperactivity disorder, family functioning, care burden

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Introduction

Attention deficit hyperactivity disorder is one of the most common psychiatric disorders that has affected many children, teenagers, and adults around the world. Its characteristics are a decreased stable pattern of attention and increased impulsiveness and hyperactivity. Most of these children would encounter problems in the field of attention. Also, another characteristic of these children is the inability to restrain impulsive behaviors (1). Reports about the prevalence of ADHD in the US among elementary school students vary from 2 to 20 percent and its prevalence has been cautiously reported between 3 and 5 percent among preschool children (2). In various studies that have been conducted in Iran, the total prevalence of this disorder has a wide range of 1.2% to 22.4%; 5.42% to 18.1% in boys, and 1.8% to 14.3% in girls (3). The main characteristic of this disorder is the inability to restrain attention deficit behavior, learning disability, aggression, educational problems, restlessness, and excitation which are unbearable for the parents, peers, and teachers (4). This disorder would cause a great deal of problems for many students and would affect their cognitive, social, emotional, and family functioning and also, their occupational and marital functioning in their adulthood (5). If not treated, it could cause behavioral problems at school. Also, these individuals are more prone to expressing criminal behaviors and drug abuse (6). Behavioral problems and ADHD symptoms would become more common during the transition from elementary school to higher grades (7). Parents have also acknowledged significant behavioral problems in their ADHD children (8). These cases and problems would indicate the necessary attention to effective causes and factors on incidence and continuous behavioral problems.

Much evidence has shown the significant role of genetic factors in the occurrence of ADHD among family studies and results have shown that genetics play an important role in the occurrence of ADHD. This disorder is more common in male individuals, those from families of lower social and economic rank, urban children, and children whose mothers have low or high academic degrees (9). It could be said that family factors have an important role in the expression of this disorder's symptoms and on the other hand, one of the outcomes of this disorder is its effect on the families. In a study, Johnston investigated the interaction between parents and ADHD children and observed that these parents had a more negative reaction toward their children and applied fewer positive methods (10). Barkley and Guningham in their study showed that mothers of ADHD children have a more controlling and criticizing method take on less social interactions and are less responsive toward their children (11).

Factors such as poor parents-child relationship, a father with unstable mood, busy parents, parents' psychopathology, and problems in parents' relationship have been effective on ADHD symptoms (12). Children's behavioral problems during the early ages are associated with the mother's negative relation and behavior and her stress (13) and therefore, problematic behaviors of the child would decrease the mother's self-confidence (14). In fact, children's behavioral problems would deeply affect on family's relations and actions (15). It could be said that both these patients and their families would be affected by each other.

Due to their problems, these children would put a great deal of pressure and stress on their parents (16). The effect of children's disorders on their parents' mental health is completely obvious. In the family of ADHD children, parents' tension, separation, anger, depression, and isolation are more observed (17). On the other hand, parents of ADHD children would experience severe mental pressure and depression, a sense of limitation, high failure, low self-confidence and ability, and also marital disputes are more observed among these families (5). In a study that was titled The Patterns Between Parental Relations of ADHD Children, it was revealed that parents of ADHD children would tolerate more care burden than parents of normal children (18). Mental discomforts and negative reactions are more common among parents of ADHD children than among normal children and it shows that ADHD children have less compatibility with their parents' requests, avoid their chores, and their negative behaviors would cause tension in their parents (19). The study by Sedighi and Rahimpour (2017) also showed that parents' tension, separation, anger, depression, and isolation were higher among parents of ADHD children (17). Also, the study of Danforth (2006) showed that parents of ADHD children would experience severe mental pressure and depression, a sense of limitation, high failure, low ability and self-confidence, and marital disputes are more observed among them (5). The study by Roniz et al (2015) in the US showed that parents who take care of hyperactive children would face high care burdens in financial and occupational fields too (20). Parenting stress might decrease parents' mental health and welfare. Parental and behavioral damage and parental stress are important risk factors in the outcomes of growing an ADHD child. On the other hand, living with a child that has a disorder or disability, is usually perceived as a stressor for the families and would affect all the aspects of family's life (21). A family's coping ability with existing stressors is of great importance and necessity. Families could achieve this goal through healthy functioning.

Paying attention to the function of families with ADHD children is of great importance for mental health specialists. The study by Dortaj and Mohammadi showed that the difference between the function of families with ADHD children and families with normal children has been unhealthy in all aspects (problem-solving, relations, roles, emotional companionship, behavioral control, emotional intercourse, and total functioning) (22). So, it could be concluded that the situation, function, and accommodation of these families and paying attention to family functioning is necessary. The study of Abbasi et al (2014) showed that ADHD students in comparison to normal students had more unstable family relationships (23). The study by Larsen et al (2016) indicated that the function of families with ADHD children was unhealthier than families with normal children (24). However, the study by Mojgan Taghaza et al (2012) showed no significant difference in the emotional environment between families of ADHD children and families of normal children (25). Results of various studies have shown that in families that have better coherence or solidarity, better relationships between family members and parents, and more satisfaction with their family condition, family members have more endurance and have more ability to encounter family tensions (26). Two-way interaction between ADHD child and their family could be a threat to their health by causing mutual pressure and also, could become an opportunity for health improvement of the child and the family through mutual helping and cooperation; this is of great importance for psychiatric nurses for whom, paying attention to families and children with disorders is one of their specialized duties.

Studies have shown that families of these children will experience more problems compared to families of healthy children. Their main problems were more stress, conflicted family environment, disciplinary actions along with violence and inappropriate interactions, marital conflicts, parents' distress, more economic burdens, parents' depression, and parents' aggressive and inappropriate behaviors toward other children caused by the burdens imposed on them by their child with ADHD. Also lacking appropriate coping skills and decreased social and familial support, ambiguity in dealing with the child, negative feelings and fear from ADHD-related labels, and consequently, hiding the disease and not pursuing its treatment are some of the other problems of these ADHD families. (21)

So, research and study in this field could provide necessary information for planning in the field of health and preventive stages in the field of mental health. According to the above-mentioned contents and the significant importance of paying attention to the care burden and

stress of parents of ADHD children and also the importance of healthy functioning in the family, the present study was conducted to determine the relation between family functioning and care burden in families of ADHD children.

Methods

The present study was a descriptive cross-sectional. The study environment was the Children's Psychiatry Clinic of Khorshid Hospital affiliated with the Medical University of Isfahan. The study population included all the families who had ADHD children and their children who had been referred to the study environment during the time of the study. The final sample size was calculated after performing a pilot study on 15 families who had the inclusion criteria. Based on the results of the pilot study, the correlation coefficient between care burden and family functioning was 0.60. based on this correlation coefficient and $\alpha = 0.05$ and $\beta = 0.05$ and using the formula of $n = [(Z1-\alpha/2+Z1-\beta)+C]2+3$ and $c = 1/2Ln(1+r/1-r)$, the final sample size was calculated to be 30 for each group who were selected using convenient sampling and were enrolled in the study. The inclusion criteria were not having any other diagnosed major mental disorder other than ADHD for the child such as bipolar disorder or schizophrenia, not having any major physical problem for the child such as epilepsy and physical abnormality, not being mentally retarded for the child, being 6 to 17 years old for the child, and having content for participating in the study. The exclusion criterion was not completing the questionnaires. For the present study, data was gathered in the field using demographic characteristics list and 2 questionnaires. The used questionnaires were Family Assessment Device (FAD) by McMaster, Epstein, Baldwin, and Bishop and Zarit Burden Interview. The Family Assessment Device was developed in 1983 by Epstein, Baldwin, and Bishop based on the McMaster model to evaluate family functioning. This device evaluates each family member's perception of family function through self-report and family members older than 12 are allowed to complete this questionnaire. This questionnaire has 60 items in 7 dimensions including general function 12 questions, problem solving 6 questions, relationship 9 questions, roles 11 questions, emotional fusion 7 questions, behavioral control 9 questions, and emotional responsiveness 6 questions. This questionnaire is scored based on a 4-point Likert scale as totally agreed (1), agreed (2), disagreed (3) and totally disagreed (4). The mean score of parents in each family was considered as the family's function score and in families where only one parent had completed the questionnaire, their

function score was considered as the score of the family. The threshold of this questionnaire for the functioning score is set at 2, therefore gaining higher scores indicates unhealthy functioning. Regarding its validity and reliability, in previous studies it was revealed that all 7 dimensions had significantly high internal consistency (Cronbach's α from 0.72 to 0.92), and its validity and retest within a week was satisfactory (0.66 to 0.76). in the study by Malek Khosravi (2003), Cronbach's α between its subscales was 0.51 to 0.94 and the correlation between all the subscales and family functioning was 0.47 to 0.97 (27). The Zarit Burden Interview was developed in 1998 by Zarit et al to evaluate the care burden. This questionnaire includes 22 questions about personal, social, emotional, and financial pressures that would be completed by the researcher through interviewing the family caregivers. The response of caregivers to each phrase was measured through a 5-point Likert scale (from never to always) which was scored from 0 to 4, respectively. To answer each question, participants chose one of the following items: never (0 points), rarely (1 point), sometimes (2 points), mostly (3 points) and always (4 points). Accordingly, the total score would range between 0 and 88. Lower scores indicate less care burden. The total achieved score by the caregiver would indicate their care burden (28). The lowest care burden score, 0, indicates no care burden, and the highest score, 88, indicates the highest care burden. Scores of 61-88 indicate severe care burden, 31-60 indicate moderate care burden, and lower than 30 indicate mild care burden (29). The validity and reliability of this questionnaire were approved in 2004 by Navidian et al, based on the cultural condition of Iran; its validity was approved using content validity and its reliability was approved with a reliability coefficient of 0.94 using the retest method (30). After getting approval for the subject from the research deputy of the nursing and midwifery faculty of Ahwaz University and getting approval from the ethics committee, the researchers referred to the children's psychiatry clinic of Golestan Hospital with an official recommendation letter from the faculty. After introducing themselves to the related authorities and gaining their permission, sampling was started. Researchers then introduced themselves to the participants and explained the study, its goals, and its methods to them. Since parents were supposed to complete the questionnaires, written informed consent was obtained from them and then, the questionnaires were distributed among them. After completion of the questionnaires, data was extracted and data analysis was started. To describe the data, mean and standard deviation (or median and interquartile range) were used for quantitative variables, and frequency and percent were used for qualitative variables. For data analysis, to determine the relationship between variables, the

Spearman correlation coefficient was used. The level of significance was set at 0.05 and SPSS software version 22 was used for data analysis. Researchers have tried to respect all the ethical considerations throughout the entire study.

Results

Results of the present study showed that, regarding education, 86.7% of mothers (26 mothers) had elementary school degrees and 86.7% of fathers (26 fathers) had diploma and under diploma degrees. Regarding their occupation, 53.3% of fathers (16 fathers) had freelance jobs, and 93.3% of mothers (28 mothers) were housewives. Regarding the source of income, 60% of families (18 families) had a freelance job as the source of income. Regarding the gender of the ADHD child, 70% of the studied children (21 children) were boys.

Regarding family functioning, 80.1% of families (24 families) reported unhealthy functioning. The highest level of healthy family functioning was 36.6% which belonged to the dimensions of problem-solving and family relations (11 families). Also, the highest level of unhealthy family functioning was 90.1% which belonged to the behavioral control dimension (27 families). Other information regarding the family functioning is shown in Table 1.

Regarding the experienced care burden by the families, results showed that 47.2% of families under study of ADHD children had experienced severe care burden (14 families). Other information regarding the experienced care burden by the families is shown in Table 2.

Regarding the relation between family functioning and experienced care burden by the families of ADHD children, the results of the Spearman correlation coefficient showed a positive significant correlation between the studied variables ($r = +0.631$, $p < 0.001$).

Table 1. Frequency distribution and percent of the type of family functioning of the participants based on their total functioning and its dimensions

Type of functioning	Healthy functioning		Unhealthy functioning	
Dimensions of family functioning	Frequency	Percent	Frequency	Percent
Problem solving	11	36.6	19	63.4
Relations	11	36.6	19	63.4
Roles	9	12	21	88
Effective responsiveness	9	12	21	88
Effective engagement	6	19.9	24	80.1
Behavioral control	3	9.9	27	90.1
Total functioning	6	19.9	24	80.1

Table 2. Frequency distribution and percent of studied families based on their experienced care burden

Care burden	Frequency	Percent
Severe	14	47.2
Moderate	12	39.6
Mild	4	13.2
Total	30	100

Discussion

Regarding the demographic findings of the present study, it must be noted that differences in the study population, type of study, study environment, and other variables could explain the observed differences in the results, but statistically, comparing the achieved results could be useful, even though the differences would not be emphasized. In the present study, the number of boys with ADHD was higher than girls. Other studies have also achieved a similar result. A study in Hong Kong showed that the prevalence of this disorder among boys was higher than among girls (31). Sandberg et al have also mentioned in their study that the prevalence of this disorder is higher among boys than girls (32). Tavakkoli Zadeh and Yousefi have indicated that gender is the most important risk factor for this disorder and mentioned that behavioral symptoms in boys were more serious than in girls. It could be guessed that hormonal effects and providing more freedom for boys than girls in families could be effective in higher prevalence of this disorder among boys than girls (33).

Parents have declared that besides having behavioral problems, these children are too sensitive and would become upset so easily. In many families, this matter would cause some tension because the family members are always alert since the child might have an emotional breakdown at any time. Therefore, not only would this disorder affect the child but it would also affect the integrated and wider system of the family. Considering all of this evidence, interventional measures, social support, and other supportive programs for improving the mental health of parents of children with ADHD are more necessary than ever, because trained caregivers would be able to make better communication with the child and control themselves and their child. In fact, insufficient information would lead to more damage to the child and the parents(37).

Results of the present study showed that most of the families under study had unhealthy functioning. This unhealthy functioning could have been observed in all the dimensions of functioning. The highest malfunctioning was observed in the dimension of behavioral control.

The study by Dortaj and Mohammadi (2010) in Tabriz showed a significant difference between the function of families with ADHD children and families with normal children in all dimensions (problem-solving, relations, roles, emotional companionship, behavioral control, emotional intercourse, and total function). This difference indicated the unhealthier functioning of families with ADHD children (17). Also, the study by Kimiaei and Beigi in Mashhad showed that the family functioning of mothers with ADHD children was significantly weaker than mothers with normal children (34). Also, the study by Abbasi et al (2014) showed that ADHD students had more unstable family relations than normal students (23). The study by Larsen et al (2016) revealed that families with ADHD children had unhealthier functioning in comparison to families with normal children (24). According to the achieved results in the mentioned studies, it could be concluded that their results were in line with the results of the present study. However, the study by Mojgan Taghaza et al (2012) demonstrated no significant difference between the emotional environment in families with ADHD children and families with normal children (25). Since one of the indices of family functioning is emotional responsiveness, it could be said that their results were not in line with the results of the present study. To explain this difference, it could be said that, that study had mostly evaluated the effect on the parents but not its outcome which would be the family functioning. Parents' functioning is effective upon children's behaviors and emotions. Studies have shown that family interactions in families with ADHD children are associated with high levels of incompatibility and inconsistency (23). Condition, function, and accommodation are of great importance in these families, and paying attention to family functioning is necessary. In fact, it could be said that these families and their ADHD children have a mutual effect on each other. Two-way interaction between ADHD children and their families could become a health threat by causing pressure. Also, it could be an opportunity for health improvement of the family and their ADHD child through help and cooperation, which must be highly noticed. By educating and helping families with ADHD children, a positive step could be taken toward controlling this disorder. In general, the results of the present study indicated a high care burden in families who take care of children with ADHD. Results of various studies have indicated the presence of this pressure on all the psychological aspects of families. Results of the study by Farrokhzadi et al (2015) showed that a high prevalence of disorders among parents of children with ADHD indicates lower mental health of these parents in comparison to parents of normal children (35). This matter indicates the high mental pressure

that has been experienced by these parents. The study by Sedighy and Rahimpour (2017) showed that parental tension, separation, anger, depression, and isolation were higher among parents of children with ADHD (17). Also, the study of Danforth (2006) showed that parents of ADHD children would experience severe levels of mental pressure and depression, a sense of limitation, high failure, low self-confidence and ability and marital disputes are more observed among them (5). The study of Roniz et al (2015) in the US also indicated that parents who take care of ADHD children would experience the care of burden in occupational and financial fields, too (20). According to the achieved results in the mentioned studies, it could be concluded that their results were in line with the results of the present study. Having a hyperactive child in the house would impose more requests on the parents and would increase their mental pressure and psychological problems. The effect of children's hyperactivity on the mental health of their families is completely obvious. Parenting stress might lead to decreased mental health and welfare of parents and cause them to experience various types of psychological problems including depression and anxiety, which have been mentioned in different studies. Behavioral problems and disobedience of these children, as one of the most serious problems of these children, have a significant effect on the family's system and functioning. On the other hand, the effect of parents' functioning on children's behaviors is undeniable. Parents who suffer from high levels of stress cannot perform their duties toward their children correctly. Unfortunately, as the behavioral problems of these children increase, the stress level of their parents also increases, which, unfortunately, intensifies their child's behavioral problems. Supportive system's attention toward these parents' mental pressure is necessary and inevitable; because these parents require professional help for coping with their child's condition.

Results of the present study showed a significant correlation between two variables of family functioning and experienced care burden. This correlation indicated that lower and unhealthier family functioning is associated with a higher experienced care burden. Scientifically, this level of correlation is of great validity and significance. The study by Roshanbin et al (2007) indicated that teaching positive parenting to mothers of ADHD children would be effective in decreasing their parenting stress for taking care of their children (36). Also, the study of Alizadeh (2012) showed that teaching the method of confronting and controlling these children to their parents, which was effective on their family functioning, also had a positive effect on decreasing their parental stress (37). The study by

Larsen et al (2016) showed that the experienced stress by parents of ADHD children is associated with their family functioning (24). Based upon the results mentioned above, we can see the present results are in line with them. The correct and effective function of a family would decrease the effects of stress and lead to the control of their experienced stress. One of the experienced stressors in families is one of the family members suffering from mental disorders. Effects and complications caused by children suffering from mental disorders would cause a great deal of stress for families, especially the parents, and would cause them to have unhealthy functioning. Healthy family functioning in different dimensions could decrease the level of experienced stress. Results of the present study showed that families with unhealthy functioning experience a higher care burden. In fact, having a hyperactive child would increase the level of stress in parents. It has been shown that, when the parents of these children are educated and their children are medically treated, their stress is decreased. This indicates the significant role of family functioning in controlling pressures and experienced stress in the family.

The limitations of the study were individual differences of the caregivers in their religious, moral, social, and cultural beliefs and mental conditions that may have affected their needs. These differences might be minimized through random allocation of the participants.

Conclusions

Results of the present study showed that most of the families under study had unhealthy family functioning and experienced high levels of care burden. Also, results have indicated a negative significant relation between two variables of family functioning and care burden in families. Therefore, the research hypothesis, which was the existence of a relationship between family functioning and experienced care burden by families, has been approved. If families of ADHD children would be helped to increase their family efficacy and functioning, their care burden could be decreased.

Since many parents would not refer to psychiatrists for treatment of their children, specialized clinics still do not have high rates of visitation and so, to achieve better generalization of the results, greater research populations are required. All of these results have revealed the necessity of paying attention to the knowledge and attitudes of children with ADHD more than ever. Appropriate and correct use of any of the resulting concepts and approaches in the present study might help organize systemic and need-oriented educational

programs through desirable and therapeutic relations with the caregivers of children with advanced ADHD. Therefore, we would be able to reach the ultimate goal of providing comprehensive high-quality, need-oriented, and reality-based care.

Conflicts of interest

Nothing to declare.

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