

## Exploring the Needs of Family Caregivers of Children with Attention Deficit Hyperactivity Disorder: A Qualitative Study

### Abstract

**Background:** Attention deficit hyperactivity disorder (ADHD) is one of the most common chronic childhood disorders that lead to dysfunction and disability in childhood and subsequently be careful. This study aimed to understand the needs of the children's caregivers in Iran. **Materials and Methods:** This qualitative research was conducted in 2016. Using purposive sampling, 27 participants from 20 families of children with ADHD were interviewed. Unstructured interviews were conducted within 6 months in Isfahan. Data gathering continued until no new data were accessed. Data were analyzed using qualitative content analysis. **Results:** The results of this research are shown in three main categories: (1) The caregiver's need for having sufficient information about the disorder, its cause and treatments (pharmacological and nonpharmacological); (2) the need to have enough knowledge about communication problems while caring for a sick child; and (3) the need to improve the performance of care. They were classified under the relevant concept. **Conclusions:** Caregivers of children with ADHD have different needs and problems and assessing them would decrease the child's problems and consequently, the family's problems. It would also increase the sense of control and authority over the child's condition in the caregivers. Since this disorder is chronic and permanent, ignoring the needs of caregivers not only would cut the process of the child's treatment but would also intensify the family's and child's problems. So it is recommended to conduct further studies about each of the resulted concepts in this study and the obstacles for reaching them.

**Keywords:** Attention deficit hyperactivity disorder, caregivers, need

### Introduction

Attention deficit hyperactive disorder (ADHD) is the most common behavioral disorder of childhood, which, despite all the conducted studies during the past decades, is still increasing. According to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, for diagnosing this disorder, having six specific functional and behavioral symptoms of lack of attention, hyperactivity, and impulsivity for 6 months before the age of 12 is necessary.<sup>[1]</sup>

According to the statistics, the prevalence of ADHD in the USA and Iran is 2–20%. Also, the prevalence rate of this disorder in DSM-5 has been reported to be 2.5% of adults and 5% of children; about 33% of the patients who refer to the mental occupational therapy centers of Iran have ADHD.<sup>[2]</sup>

Studies have shown that families of these children will experience more problems

compared to the 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. The mental pressure caused by raising such difficult children may cause losses in couples' relations. Not only children would be facing these problems, but they may also affect the families and the society.<sup>[3,4]</sup>

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Family is a social system where one member's disorder could disturb its entire system, and the disturbed system could intensify the disorders of the members and create new problems. So it could be easily imagined that various behaviors of a permanent disorder such as ADHD could lead to the destruction of the family's foundations. Also, due to the focus of health systems on symptomatic treatment of children and lack of appropriate communications with their families, they are usually not receiving sufficient attention and are left unsupported. So, if the needs and problems of the caregivers would not be attended sufficiently and necessary interventions would not be designed and executed on that basis to settle their care challenges, besides risking their physical and mental health, children would also be deprived of receiving appropriate care from their caregivers. As nurses are involved in all the stages of caregiving, they also have an important role in helping family caregivers to become a qualified and empowered caregiver; they could significantly change the concept of care for caregivers beyond the boundaries of just caring for the patients as a profession.<sup>[4,5]</sup>

In their literature review, the researchers did not find any qualitative, quantitative, or a combined study which has specifically evaluated the needs of ADHD children's caregivers or conducted an intervention based on the needs of these care providers; most of the conducted studies are qualitative and based on the existing observations and experiences.

Family care and various expected tasks from the caregivers for these patients in managing their disease is of great importance. Also the researchers had some personal experiences in dealing with the needs of family caregivers of children with ADHD. The families always have questions about their child's disease, the course and symptoms of the disease, drugs and the general method of caring for these patients. So far no studies have assessed the needs of caregivers for these patients in Iran or other countries and evaluating the needs of caregivers and developing any interventional program for them requires concerning cultural issues and underlying contexts. So the question is: "Do we need to develop and conduct interventions, by systematic evaluation of the needs, in our society and health system for children with ADHD and their families to prepare them for the process of care and meet their direct and indirect care-related needs?"

Therefore, the researcher decided to conduct this study so that using the tools of a qualitative study would explore the needs of family caregivers of children with ADHD and reach an in-depth recognition of their needs.

## Materials and Methods

The present study was a part of a wide qualitative content analysis research. Participants were the families of children with ADHD who referred to teaching hospital

affiliated with the Isfahan University of Medical Sciences and were selected purposefully. Sampling was conducted from February 2016 to July 2016 for 6 months at the mentioned centers. The main method of data gathering was unstructured interviews using open questions and field notes. Interviews were conducted individually at a quiet place and appropriate time for the participants. At the beginning of the interview, a neutral conversation was conducted; the aim of the interview was explained and written and verbal consent was obtained from all the participants.

Data were saturated after interviewing 27 participants: The inclusion criteria were being the main caregiver for the child and having all of his/her responsibilities, having the necessary physical and mental ability for taking care of the child, willingness to participate in the study, being able to communicate in Farsi and regarding the rules of educational courses, taking care of only one patient with a chronic disease such as ADHD in the family, and not having any addictions and not using any psychological drugs. Also the child must have been 7 to 12 years old (school age) and hospitalized due to ADHD at least once with no other disabling diseases (physical or mental disability, autism). The exclusion criterion was the caregiver's unwillingness to continue the study. The mean duration of the interviews was 47 min so that it would not disturb their daily activities. All of the interviews were conducted by one person.

After taking permission from the participants, the researcher got their phone number at the end of the interview to contact them if confirmation or further interviews were necessary. Based on the research questions, the interview started with general open questions such as "How long your child has been sick?", "Could you describe a typical day of your life?" or "How would your child's disease-related behaviors affect you and other members of the family?" After receiving the answers to the above questions, exploratory and in-depth questions such as "Could you explain this matter more?" were asked by the researcher. The interviews were recorded by permission from the participants and right after or at the first possible chance were written down.

Data were analyzed using conventional content analysis.<sup>[6]</sup> The interviews were listened many times and were written down word-by-word. The scripts of the interviews were also reviewed many times so that the general concept would be understood. Then the scripts were reviewed word-by-word to extract the codes. Interviewing the participants and coding the scripts were continued and partial codes were categorized into more general topics. Then, based on their similarities, codes were put into categorized classes and their relations were determined.<sup>[7]</sup> In this study data gathering and data analysis were conducted simultaneously. Some methods were applied to assure the reliability and accuracy

of the data of the present study. Credibility, dependability, fittingness, and conformability, which are the standards of scientific rigor in qualitative studies, were regarded. Also checking the results with the participants (member check) and experts' reviewing (external checks) were performed. To determine the fittingness, the results were shared with some of the caregivers who did not participate in the study and they approved the fittingness of the data. The technique of sampling with the maximum diversity that would help the fittingness or transferability of the data to others was also considered for this study. Also, to provide the conformability and accuracy of the study, the researcher accurately recorded and reported the entire process of the research so that it could be followed by others too.

### Ethical considerations

All the ethical issues including taking written informed consent, the anonymity of the participants, confidentiality of the information, the right of withdrawal during the study, and other ethical issues were regarded in the present study. This study is a part of a research that was approved by the Isfahan University of Medical Sciences and its Ethics Committee (IR.MUI.REC.1394.1.194).

### Results

The age range of the participants was 24 to 51 years old and their mean of age was 33.3 years. The onset of child's disease was between the age of 4 and 10 years. From 27 participants, 17 were females and 10 were males, and their educational level varied from elementary school to bachelor's degree; most of the participants had a high school diploma. The mean duration of having the disease was 6.5 years and the mean duration of taking care of the sick child was 3 years.

At the first step more than 175 first level codes were extracted and after categorizing merging, 3 classes and 17 subclasses were gained, which are summarized in Table 1.

#### General information about the disorder

According to the experts, although ADHD is not a newly discovered disorder, public's general information about its causes and especially its pharmacological and nonpharmacological treatments are insufficient. This would make the caregiver feel helpless and lead them to accept whatever anybody would tell them, even if they are not experts in this field. In fact, the caregiver would lose their ability to understand right and wrong and this would consequently worsen the child's and the caregiver's situation. In this regard, caregiver no. 2 stated that: *"The physician prescribed Ritalin but my spouse was against it because it was said on the internet that it is addictive. But if my child would not take the drug he/she would be out of control. I have no idea how this child became like this, I'm so tired."*

**Table 1: Summarized needs of the caregivers and their subclasses**

Category	Subcategory
The need for sufficient information about the disorder, its causes, and treatments (medicinal and nonmedicinal)	Insufficient information about the disorder
	Insufficient information about the causes of the disorder
	Insufficient information about medicinal and nonmedicinal treatments
	Insufficient information about the medicinal treatments' side effects and how to control them
The need for sufficient information about communicational problems between the caregiver and the child	Insufficient information about communicational skills
	Insufficient information about how to control restlessness and excitement
	Insufficient information about how to cope with attention deficit and lack of concentration
	How to use rewarding and punishment methods
The need for improving caregivers' performance	Decreasing or resolving the physiologic problems
	Improving physical, mental, and social exhaustion
	Gaining familial and social support
	Maintaining a job
	Gaining the skills of problem-solving and compatibility
	Gaining the skill of anger management
	Decreasing or resolving psychological problems (stress, anxiety, and depression)
	Decreasing the economic burden
	Decreasing the burden of care

#### Communicational problems

Communicational problem is the main problem caused by ADHD and all the participants have encountered it; they were all feeling miserable and were not able to control their child's fidgetiness and lack of attention. Also, using inappropriate methods of rewarding and punishment had made it harder for the caregivers to control the situation and have intensified the condition of the child. However, the participants believed that by knowing the right methods of communicating with their child, controlling their fidgetiness through games and entertainments, and rewarding and punishing them, they could have felt more relieved and their child's condition could be improved. caregiver no. 14 said: *"When my child was punished before it had some effect but now it seems that no method could be effective for him/her. It seems that the older he/she gets, the harder it is for us to control him/her. I have no clue how to handle my child. No one is content with his/her performance, not at home nor at school."*

### Caregiver's performance

Caregivers of children with ADHD in comparison to the parents of normal children have decreased performance in their parental and nonparental roles. Definitely, taking care of a patient with a chronic disease which has started at early ages of the child could diminish caregivers' powers. As the child ages, physical, mental, social, and psychological exhaustion would grow more on the caregiver and would have adverse consequences on the condition of other children and their marriage. To confirm the above-mentioned result, caregiver no. 9 stated that: *"My child always loses her toys or misplace them; she has also given some of them to her friends. She is creative and talented and her creativity would mostly cause trouble for us. Sometimes we should pay the penalty because of the damages she causes by her creativity. For example she damaged one of the toys at the bouncy park last month, broke her brother's bike 2 weeks ago and sheared my dress yesterday. Sometimes I feel that this uncontrollable child has made me reach the end of the world and there isn't anything I can do about it."*

### Discussion

In line with the results of the present study, the study of Lara *et al.*<sup>[8]</sup> showed that about 50% of children with ADHD would also exhibit the full criteria of the disorder in their adulthood too. Therefore, their parents' concerns about their future and adulthood seem rational and they have the right to gain sufficient and correct information about the disorder, its causes, treatments, medicinal side effects, and communicational skills so that they would be able to make appropriate communication and use effective techniques to reduce the symptoms in their children like attention deficit and hyperactivity and help them improve their condition. Therefore, educating is important as one of the great aspects of treatment. Educating the family and other caregivers for the child about hyperactivity, its symptoms, its course and prognosis, treatments and existing services is one of the necessities for coping with this disorder. Undoubtedly, such educations would be of great importance in creating a commitment to long-term treatment for a chronic disorder. The importance of this matter would become clearer when we realize that the parents of children with ADHD would only accept medicinal treatment when they are disappointed with behavioral and psychological interventions. Results of the study by Doris *et al.*<sup>[9]</sup> revealed that more than 50% of parents who have gained their information only through the public media were reluctant about using medicinal treatment for their children. Results of this study also showed fear of taking drugs and consequently delayed treatment and its adverse effects on cutting the child's treatment.<sup>[10]</sup> Therefore, it is essential for parents to have the necessary information. Results of another study in Greece revealed the negative approach of a significant percentage of parents toward psychological drugs and fear of taking

these drugs by their children.<sup>[11]</sup> Also the results of a study that was conducted in the USA indicated that the most common concerns of parents of children with ADHD were incorrect diagnosis of ADHD, the effect of their parental style or home environment on the symptoms of the disorder, the effects of long-term use of drugs, and prescribing too much drug too early.<sup>[12]</sup> Based on the results of the present study, one of the problems of the families of children with ADHD was attention and concentrate deficit; according to Barkley,<sup>[13]</sup> children with ADHD would usually lose or misplace their stuff, would not be able to handle the details accurately, would not be able to follow the instructions, and have problem in organizing their homework. Also they would easily be distracted by irrelevant stimulants and are forgetful in their daily activities. Impulsivity would be observed in children who would answer questions without thinking, would not be able to wait for their turn, and would be disturbing others. In the present study, the opinion of the caregivers was similar to the Barkley's. In a survey that was conducted widely in the Europe, parents of children with ADHD stated that ADHD had a great effect on their child and family and had affected their school work, relations with peers, and family connections.<sup>[14]</sup> Therefore, this disorder would have a significant influence on the parents, other members of the family, and the child him/herself. Also, the mental aspect of the caregivers and their mental and social burnout in general, their psychological condition had repeatedly been mentioned in extracted subclasses and codes. Previous studies about children had clearly stated that children would affect the family environment and their parents' marital status and would decrease parents' mental health and consequently increase the burden of care.<sup>[15]</sup> Chronis *et al.*<sup>[16]</sup> have stated that damage to the parents and their parenting style is one of the important risk factors in the developmental outcomes of children with ADHD; because this damage would in turn affect the child's development cycle and would help the chronic process of the disorder. On the contrary, living with a disordered or disabled child is usually considered a stressful factor for the family and could affect all the aspects of the family and might cause more burnout for the caregivers. Meanwhile, since mothers have more interaction with children, they would become affected more and need more special attention in the three – physical, mental, and social – dimensions. Studies have shown that since parents of disordered children would face more parenting challenges, they might experience more stress than the parents of healthy children.<sup>[17]</sup> Also parents of children with ADHD have more marital problems and report higher levels of stress and interpersonal conflicts. These parents would experience more stress and less satisfaction compared to the parents of healthy children. Shure and Gaue<sup>[18]</sup> in their study which evaluated the domestic factors of ADHD reported that mothers of children with ADHD have more psychological distress and aggressive impulses and would perceive less support from their families; results of the present study were in line with these results.

Also the intensity of this disorder has different effects on family's performance. Gustafsson *et al.*<sup>[19]</sup> in their study showed that families of children with severe behaviors, in comparison to families of children with moderate behaviors of this disorder, would present more ill-performance. Most of these children are emotionally unstable too, meaning that their mood would change suddenly.

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 a level of tension because the family members are always alert, since the child might have an emotional breakdown at any time. Therefore, not only this disorder would affect the child but it would also affect the integrated and wider system of the family. Considering all of these evidence, interventional measures, social support, and other supportive programs for improving the mental health of parents of children with ADHD is more necessary than ever, because trained caregivers would be able to make a better communicate with the child and control themselves and their child. In fact, insufficient information would lead to more damage to the child and the parents.<sup>[20,21]</sup>

The above-mentioned studies have indicated that the needs of caregivers all over the world are similar to the needs of Iranian caregivers. What would separate the present study from other studies is its thorough and comprehensive evaluation of all the needs of caregivers that have led to new findings such as the need for gaining anger management skills, compatibility, and problem-solving, which have not been mentioned in any national or international studies before.

All of these results have revealed the necessity of paying attention to the knowledge and attitude of children with ADHD more than ever. Appropriate and correct use of any of the resulted concepts and approaches in the present study might be helpful in organizing 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 reality-based care.

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

## Conclusion

Caregivers of children with ADHD have different needs and problems and assessing them might decrease the child's problems and consequently the family's problems. It would also increase the sense of control and authority over the child's condition in the caregivers. Since this disorder

is chronic and permanent, ignoring the needs of caregivers not only would cut the process of the child's treatment but would also intensify the family's and child's problems. So it is recommended to conduct further studies about each of the resulted concepts in this study and the obstacles to reaching them.

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## Conflicts of interest

Nothing to declare.

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