Experiences and worries in mothers with children suffering from ADHD: A Grounded Theory Study

Original Article

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Abstract

Background: Children with attention deficit hyperactivity disorder (ADHD) have a lot of emotional and behavioral problems. Life experiences of mothers as primary caregivers are very important due to the direct relationship of them with their children. The aim of this study was to analyze the experiences and worries in mothers with children suffering from ADHD.

Methods: This qualitative research was a Grounded Theory study based on purposed sampling. The study population was mothers with ADHD children in the elementary school of Aligoodarz City of Lorestan Province (Iran) in 2019. They were selected by target and voluntarily. The data reached a theoretical saturation through the interview with 16 mothers. Constant comparison analyses were used simultaneously with data collection.

Results: The studied participants were 16 mothers with ADHD children. Data were analyzed using Corbin and Strauss (1990) method. Open, axial and selective coding methods were used for data analysis. Final research findings could be discussed in four categories including: "Mother's concerns about the child", "family disorders due to the child's behavior", "worries and negative feelings experienced by the mother", and "parenting strategies for dealing with child".

Conclusions: Despite of the complexity of the experiences and worries in mothers with ADHD children, this study indicated multiple aspects of impact of having ADHD children. Living with and caring of the ADHD children bring negative feeling and psychological distress for mothers. Awareness of these mothers' problems and concerns will help the mental health professionals to gain a deeper understanding of their life experiences.

Keywords: Child, Experience, Grounded Theory, Hyperactive Disorder, Mothers

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Introduction

The attention deficit/ hyperactivity disorder (ADHD) is a problematic behaviors that makes the difficult for a child to communicate with the outside world. Based on Diagnostic and Statistical Manual of mental disorders (DSM-5), the symptoms of ADHD are disobedience, theft, lying, fights, misbehavior, destruction, profanity, malice and hyperactivity [1]. There are many factors in the etiology of these disorder including inappropriate environmental stimuli such as child rejection, lack of adequate parental love and support, excessive affection, lack of maternal care and compassion, family's aimless life, coldness of family relations and insecure attachment during childhood [2].

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The most important of these disorders is parental inability to manage child behavior and negative parent-child interaction [3]. A study has demonstrated that mothers who do not have a good parent-child relationship with their children, their children have more sleep disorders, behavioral and maladaptive problems as well as ADHD problems [4]. Sometimes, parents' wrong communication with their children causes behavioral abnormalities in children [5].

Some researchers emphasize that the early treatment of these problems at an early age is a form of prevention and suggest that if these problems are identified and treated during preschool age and early childhood, they will be greatly relieved, leading to improve child's performance in different contexts. In many cases, the mother considered as the main role in child's growth and development in addition to as the most influential factor affecting the child has poor parental self-efficacy so that the poor, inappropriate and retrograde interactions with the child are important factors in the formation and development of the child's disorders [4].

Today, the role of education in enhancing community health is emphasized, and parents' ignorance as well as lack of care and attention to children's health are an effective factor in the physical and mental failure of the child. With proper education, mothers can be enabled to protect their children from many diseases and complications. Given the important role of education in promoting self-efficacy in different areas, the need for mothers' self-efficacy in dealing with risk factors in their children is of particular importance.

The results of Firmin et al.'s study [6] have cited that parents with ADHD children have experienced more distress. McIntyre et al [7]. identified six major themes: [1] getting your head around ADHD, [2] the child takes over, [3] emotional impact, [4] inconsistency of structural supports, [5] ignorance and discrimination, and [6] it is not all bad. In addition, Khodabakhshi- Koolaee et al [8]. expressed that the mothers with disabled child experienced the subjective and objective burden because of caring their child. Therefore, it seems logical that effective therapeutic interventions are needed to decrease the effects of inappropriate parent-child interactions.

In this regard, the main role of preventing such conditions and restoring balance in the family is the responsibility of the parents, especially the mothers considered as the basic foundations of the family.

Parent education programs involve understanding the challenges between parents and children, and this cannot be accomplished except by studying the lived experiences of mothers with ADHD children.

Literature review indicates that few studies have been conducted on the lived experiences of mothers with ADHD children [6-8], and there are very few studies in Iran. Although little research has been done on the etiology and treatment, family outcomes, especially on interaction with the mother, have not been extensively investigated. Therefore, mothers' experiences are very important because of their direct relationship with the children. These experiences cannot be achieved with quantitative research.

But qualitative studies than quantitative ones have significant potential for deep understanding of the phenomenon and explaining real experiences. The former studies are important because service providers can play an effective role in helping parents accept and overcome the problems associated with caring for mothers of children. Awareness of these mothers' problems and concerns will help the mental health professionals to gain a deeper understanding of their life experiences.

Therefore, the aim of the current study was to explain the phenomenology of mothers' experience in living with ADHD children, given the necessity of recognizing the ADHD children by their mothers, supporting mothers and enhancing their quality of life.

In the present study investigated mothers' life experiences, identified the main and sub-elements as well as introduced the phenomenon-based experiences of mothers with ADHD children in Aligoodarz City in 2019. In other words, what are the main and sub-elements that constitute the mother's life and phenomenon-based experiences?

Methods

This study was conducted using the grounded theory (GT) approach. The underlying idea of GT is that, instead of testing the hypotheses, verbal reporting of individuals' experiences was used as data to provide a set of theoretical concepts that best describe the data [9].

The present study described, deeply explained and understood the lived experiences of mothers with ADHD children. Participants in this study were 16 mothers with ADHD children referred to the Education and Mental Health Counseling Center affiliated with the Education Organizationn by schools in Aligoodarz

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City in 2019, and previously the child's disorder was diagnosed via the competent centers by psychiatrist.

Mothers' inclusion criteria were having informed consent, at least one ADHD child in primary school that diagnosed by psychiatrist, a good understanding to answer the questions, fluency in Persian and having no mental illness. The exclusion criteria were divorce or single mothers who had no counseling sessions with psychologist.

Purposeful sampling was used to collect data, and data collection continued until the theoretical saturation stage. Data collection tools were open, semi-structured and in-depth interviews. Each interview lasted on average 1-2 hours. All interviews were accomplished by researcher.

Prior to the start of each interview, the purpose of the research, reason of interview recording, voluntary participation as well as confidentiality of the information and identities of the interviewees were explained, and the participants were given written and oral permission to record their voice. All interviews were conducted in psychologist's room and in mental health counseling center. The data were collected through in-depth interviews at this stage of the research since, in such studies; the main source of data is in-depth interviews between the researcher and participants [10].

Interviews began with a general question “What are your concerns and experiences about having an ADHD child?” and continued with exploration questions such as (explain more, give an example, what does this mean) to expand and deepen the findings. The contents of the recorded interviews were transcribed on paper, and the data were coded and analyzed using open, axial and selective coding method.

Finally, the results were formulated in a paradigm consisting of contextual, causal and intervening conditions, strategies as well as consequences about the central axis. In the present study, the consistency and objectivity of the data were evaluated to confirm the results, robustness and accuracy of the research or acceptability of the data [11].

The validity of the study was verified by referring to each participant and conducting a single interview. At the end, the codes were reviewed by the supervisors, and different comments were summarized in a joint session. This research was approved with the ethical code of 26221602971010 from Islamic Azad University branch of Khomain.

Results

Participants in the ongoing study were 16 mothers whose descriptive information is listed in table 1.

Based on the findings of the current study, 4, 12 and 32 selective, axial and open codes were obtained (table 2), respectively and discussed separately below.

First main category: mother’s concerns about the child

This phenomenon has three sub-categories as follows:

Concern about the future of the child: Concern about who is responsible for the child after the death of the mother. The mother's perception of her child after death is a disaster. According to mothers, after their death, their child is left in the community and no one cares for them. Mothers are also concerned about their child's future maturity, employment and marriage, and feel hopelessness and frustration with their child's future.

"How long am I alive to support him?", "My mind is on its future, who wants to support him?”, “If he gets older, what is his future job and life?, “After my death, I do not like him saying my mother did nothing for me” (Participant 5).

Social concerns for the child: Most mothers feel that their child will be ineffective in social activities and successes.

Concern about the social status of children is that the poor and low levels of social skills in children make them often unable to perform well in social situations. "When I think about the future, I get disturbed”, “I am afraid that she cannot fend for herself in the community”, “I am afraid that she will be a drag of society”, “I am afraid that she cannot defend herself” and “I am afraid that he will not succeed in society in the future (Participant 7).

Feeling embarrassed and ashamed: Feeling embarrassed and ashamed is another consequence of children's behavior in the family. “I am already ashamed of his behavior, I want to die, I have to wash him myself, I am ashamed of others" (participant 4).

Concern about education: Parents are also concerned about their child's educational status. Children are not able to have an appropriate interaction with their teachers and classmates. Calling mothers to school because of their misbehaviors is often unpleasant to mothers, as they have stated that responding to school as well as expressing the dissatisfaction and unreasonable view of school to the child makes mothers anxious and depressed.

“He does his homework hardly", " He starts homework at 7 and ends at 11 o’clock", " His father

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and I are both worried about his education", " He doesn't study at all and I am really worried about him", "He's naughty at school and he was expelled from school several times" and " I'm tired of going to school for my child" (participant 9).

Second main category: Family disorder due to the child's behavior

This phenomenon has four sub-categories as follows:

Communication disorder:

Disrupted relationship with spouse: These relationships are disrupted due to the pressures and stress on mothers and fathers of the family, which in some cases leads to indifference towards the spouse and child, and the father has no responsibility for the child for any reason.

In these families, mothers are constantly in conflict with their spouse, the wives than their husbands more interact with the child. Sometimes, the husbands condemn the mothers because they are not as involved in the child's problems as the mothers and consider them to be the cause of the problem. My husband and I are no longer bored of each other, his/her father does not like him/her at all, and my husband does not accompany me" (participant 16).

Disrupted mother-child relationship: The most tension and conflict is between mother and child. The child's disregard for the commands, rules and personal discipline as well as his/her maltreatment cause resentment in mothers and disrupt the mother-child communication channel. In such a situation, the mothers resort to beating the child and being aggressive. "There is no day we do not have conflict and tension, he does everything that is stressful for me, in the game, he suddenly hit me with a stick and my shoulders became hot, I am tired of him and he bothers me".

The child is in constant tension with other family's children in addition to with the mother because of his behavioral disorders. "He presses her brother's leg and his brother cries, he beats his brother too much (participant 5).

Disrupted child relationship with other family's children: Classmates and playmates (family children, relatives, acquaintances and neighbors) are groups with whom the child quarrels, especially at parties, this is more evident.

"He is so annoyed me at a party, my child hurts my nephew/niece, he had beaten the neighbor's son firmly and his head was bleeding, finally, everybody is bad with us because of his behavior" (participant 8).

Disrupted family relationship with environment: Also, child behavior has limited communication with the family. "I broke up with my father's family due to my child's behavior, my sister said "Do not come to our house anymore because I do not have the patience for your son and I do not go my father's house anymore (participant 16).

Family disorder and disarray: The child is unable to do her job, loses her belongings and disregards home's rules and regulations. In general, irritability, aggressive behavior and immature acts in these children exacerbate the tension and depression of interpersonal interactions in family members.

"She is very disordered in her work, is very messy and leaves her belongings. She has a bad mouth and says you are wrong, the hell you are, when I tell her to take your clothes off, she is stubborn and doesn't" (participant 14).

Negative patterning (Fear of child's behavior imitation by other children in family): Parents are concerned that other children may also become role models by observing their child's behavior "I'm afraid that his behavior will affect my younger son, I'm very worried my younger son will imitate his brother" (participant 1).

Financial pressure: The costs of childcare and medication for taking care of the child, destruction of belongings by the child, destruction of the belongings of family and neighbors' children as well as destruction of neighbors' belongings such as breaking the glass put a lot of financial pressure on the family. Even, some families impose a heavy financial burden on the child's family due to the continuing misbehavior of their child; "He breaks the toys and we have to buy again, as much as you want he destroys the furniture and we must pay extra money, the cost is high and the insurance will not accept it" (participant 15).

Third main category: Worries and negative feelings experienced by the mother:

This phenomenon has two sub-categories as follows:

Blaming experience**:** Blaming experience is one of the issues that disrupt the real life of mothers. The experience includes self-blame, husband's blame and community's blame. The mother is always confronted with blame thoughts and feelings. Some fathers because of their lack of awareness of child's behavioral disorder blame and humiliate the mothers as well as know mothers as the main culprit.

Many mothers expressed the experience of community's blame, "I know everything is my own

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fault, I had to do test, and anyway, I committed a sin that this happened for me. My husband commends his nephew/niece to me every day and tells me it's your fault you don't foster the child well. One day, an old lady on the street told me you committed a sin and now you are penalized (participant 12).

Negative feelings: Feeling guilty and blameful: "When I beat him, I feel guilty and I say how do I respond on Resurrection Day?", Feeling anger and wrath: "His behavior made me very nervous, my blood pressure went up and I had a cesarean section", Feeling disappointed:" I am disappointed with my child's treatment ", Feeling depressed: "I feel that I'm not in the crowd at all, the child gets so annoyed that I'm shaking when hearing the child's name", Forgetfulness and neglect: "Sometimes I forget to pay the fare, I get off the bus several times by mistake", Feeling lonely and helpless: "I feel I can't do anymore, I'm tired," Anxiety and decreased confidence: "My stress has increased, I start the works but not finish" (participant 15).

Fourth main category: Parenting strategies for dealing with child

This phenomenon has three sub-categories as follows:

Child's physical punishment: Some mothers punish the child physically when they are tired of the child's behavior "When he doesn't listen to me while studying, I get tired and beat him …. I burnt him when he was three years old" (participant 6).

Maternal self-beating and crying: One of the parenting strategies for coping with child is maternal self-beating and crying; "When I think that my own behavior has made my child like this …, I get angry, knock my head on the wall and pull my hair many times, and that is my only solution ..., I sit in a corner and cry …" (Participant 4).

Psychotherapy: One strategy for cope with the child is to visit a psychiatrist and counselor; "I have visited the psychiatrist for a long time (for 3 years) but nothing has been occurred …" (Participant 3).

The key elements were identified through data-based theory. These main elements included the mother's concerns about the child, family disorder due to the child's behavior, worries and negative feelings experienced by the mother and parenting strategies for dealing with child.

Each of these categories was incorporated as a phenomenon into a paradigm model. Here, by integrating the main categories of paradigm models into axial coding, a paradigmatic model was made for selective coding and was used for initial formation of the model framework.

In this process, the phenomenon of "family disorder due to the child's behavior" was chosen as the pivotal phenomenon due to its relation to other phenomena and its generalizability, as well as due to incorporating the main elements of all major categories (figure 1).

Accordingly, the present study identified and introduced "family disorder due to the child's behavior" as a pivotal phenomenon.

Table 1. Demographic characteristics of interviewed mothers with ADHD children

Number	Mother's age	Mother's Education	employment	Child's age	Child's Grade	The economic situation
1	28	Bachelor	Employee	8	2	**good**
2	25	Diploma	Housewife	7	1	**good**
3	34	Diploma	Housewife	10	4	**good**
4	47	Elementary	Housewife	10	3	**Weak**
5	49	Elementary	Housewife	11	5	**Weak**
6	36	Bachelor	Teacher	7	1	**good**
7	32	Bachelor	Teacher	8	2	**good**
8	39	Diploma	Tailor	11	5	**Weak**
9	41	Bachelor	Teacher	10	4	**Good**
10	28	Bachelor	Housewife	7	1	**Good**
11	30	High school	seller	7	1	**Weak**
12	45	High school	Housewife	10	4	**Weak**
13	37	Diploma	Housewife	8	2	**Weak**
14	41	High school	Housewife	7	1	**Weak**
15	30	Bachelor	Housewife	12	6	**Good**
16	33	High school	Housewife	8	2	**Weak**

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Table 2. Selective, axial and open codes were extracted from interviews with mothers

Selective codes	Axial codes	Open codes
Mothers' concerns about the child	Concern about the future	Concern about the fate of the child after mother's death
		Concern about puberty and adulthood
	Social concerns for the child	Concern about the child's entry into the community
		Fear of the future and tendency to delinquency
		Feeling ashamed and embarrassed
	Concern about education	Poor educational performance
		Responding to school
Family disorders due to the child's behavior	Communication disorder	Disrupted relationship with spouse
		Disrupted relationship with child
		Disrupted child relationship with other family's children
		Disrupted family relationship with environment
	Family disorder and disarray	Child's disorder
		Child's careless
		Child's aggression
	Fear of negative patterning	Fear of child's behavior imitation by other children in family
	Financial pressure	Increased cost and financial burden for medicine
		Increased cost and financial burden for child behavior
Worries and negative feelings experienced by the mother	Blaming experience	Self-blame
		Husband's blame
		Community's blame
	Negative feeling	Feeling guilty and blameful
		Anger and wrath
		Feeling disappointed
		Feeling depressed
		Forgetfulness and neglect
		Feeling lonely and helpless
		Anxiety and decreased confidence
Parenting strategies for dealing with child	Child's physical punishment	Beating
		Abusing and screaming
	Maternal self-beating and crying	Self-beating
		Crying and hair pulling
	Psychotherapy	Referring to psychiatrist

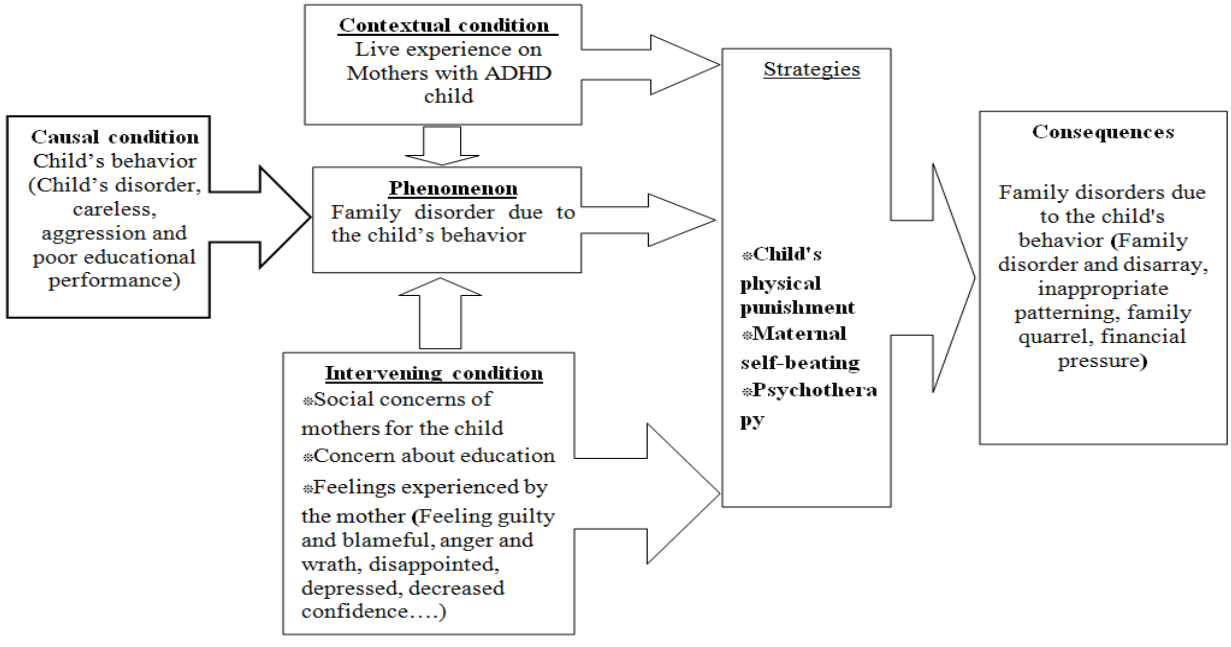

Figure 1. Paradigm model of the process of disorder in the family behavioral-emotional network due to the child's behavior

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Discussion

The results of the present study suggested that mothers with ADHD children encountered with many problems and challenges. One of them emerged from in-depth interviews with the studied mothers was mother's concerns about the child, which is consistent with the finding of Peters et al [12]. Who studied on the experiences of mothers and concluded that mothers were anxious about their child's future and asking for help from the government and educational centers.

The mothers of the ongoing study also reported one of their concerns was social concerns for the child (child's inadequacy, disorder, disconnection with the community and seclusion as well as family's shame and embarrassment for having such a child), which is in line with the study of McIntyre et al [7].

Another concern of the studied mothers was the concern about educational performance (poor educational performance and responding to school). In this regard, Gharibi et al [13] believed that the ADHD children demonstrated poor educational performance in some cases, so the education skill curriculum should be designed with the aim of teaching special and general skills.

Mothers with varying degrees of confusion to cure problems often have few resources other than giving their child medication or are forced to move their children from one class to another and from one school to another so that their children's infamous reputation can be neglected [14].

Another experience of these mothers was family disorders due to the child's behavior. This is important in many aspects, one of which is the disruption of communication. Disruptive subcategories included disrupted relationship with spouse, child, other family's children and environment as well as fear of child's behavior imitation by other children in family.

For disrupted relationship with spouse, khodabakhshi-koolaee et al [8] have argued that the child-parent relationship interacts with each other, in other words, the effects of the child and parent are reciprocal. Studying the interaction between parents and ADHD children has shown that there is a high level of stress, imposition, depression, limitation and frustration in their relationships [15], which is similar to the result of Fischer et al., too [16].

In this regard, Moen et al [17]. Have expressed that the role of the spouse's support and assistance is necessary to help mothers and that paying attention to the maternal mental health is important.

Concerning the disrupted mother-child relationship, Khodabakhshi-koolaee et al [5]. Have represented that the behavior and reaction of mothers with ADHD children are due to their hyperactive children.

Besides, in terms of the disrupted child-family relationship, Gharibi et al [13]. Have explained that the ADHD children are often separated and secluded early in life, and because they have less social interaction than other children, these children cannot develop the skills needed to start and maintain social relationships and friendships; hence, it seems natural that the inability of the ADHD child to maintain social relationships can also lead to a limitation of parental relationships.

Other lived experiences of mothers in the current study were disrupted family relationship with the environment and fear of child's behavior imitation by other family's children.

Like this finding of the present study, Marmorstin [18] has stated that the externalizing disorders conflict with others and their expectations, as a result, invoke negative reactions of others. Misbehavior of ADHD children with other family's children puts a lot of mental pressure on their parents.

Another implication of the present study was financial pressure. Financial pressure is the costs of childcare, destruction of belongings by the child, destruction of the belongings of family and neighbors' children as well as destruction of neighbors' belongings such as breaking the glass.

Even, some families impose a heavy financial burden on the child's family due to the continuing misbehavior of their child. Another finding of the ongoing study was the feelings experienced by mothers including a number of experiences such as blaming experience (self-blame, husband's blame and community's blame) as well as feeling guilty and blameful, anger and wrath, disappointed, depressed, sadness, fatigue, loneliness, helplessness, irritability, impatient and headache as well as lack of enjoyment. Mothers experience these mentioned mental disorders due to the pressures of interacting and living with these ADHD children.

Similarly, Benderix et al [19]. Have cleared that the adverse consequences of children's behavior cause a great deal of anxiety for mothers.

Conflict due to attention to child, possible side effects of medications, blame on child and ambiguity in children's misbehaviors owing to their environmental consequences are an integral part of the life experience of most mothers with ADHD children.

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However, most mothers often feel desperate and helpless because they find themselves alone on the path of treatment and coping with their ADHD children so that some of these mothers are frustrated with their husband's companionship and feel completely lonely and helpless in struggling with their child's problem.

Consistent with these results, Marmorstin et al. have reported that families with ADHD children are more at risk of stressful and conflicting environments than families with normal children. In a study, it has been found that mothers with ADHD children than mothers with normal ones have lower self-esteem as well as feel guiltier and greater isolation [18].

Khodabakhshi-koolaee et al. have revealed that mothers with ADHD children experience stress, psychological problems, depression, limitation, high frustration, imposed relationships and difficult living situations [20]. In general, mothering an ADHD child is stressful and demanding, and mothers feel isolated [12].

One of the limitations of this study was the length of interviews. The second one was lack of available qualitative research on experiences of mothers with ADHD children. Given the important role of father in dealing with an ADHD child, his concerns about having a child with ADHD should also be considered.

In conclusion, mothers are involved in many of the pressures and worries about their children in various psychological, social and family contexts. Many of these concerns and frustrations of mothers refer to the lack of awareness, lack of full understanding of how to educate and communicate with ADHD child, how to cope with their own thoughts and feelings, their personality and attitude characteristics, pressures and misbehaviors of their children as well as lack of social support and government education services.

Investigating mothers' problems and experiences in small communities and cities helps the health professionals better understand how to access specialized support resources.

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