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Disease Process Management Experiences of Parents of Adolescents with Attention-Deficit/Hyperactivity Activity Disorder

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Abstract

Aim: This research aims to investigate the experiences of parents of adolescents aged 12-18 years with attention deficit and hyperactivity disorder in the management of the disease process.

Methods: Parents (n = 10) of children aged 12-18 years who were treated in the Child and Adolescent Psychiatry Outpatient Clinic of Kars State Hospital for at least 2 years were included in the study on the basis of data saturation. Information was collected with introductory information form and semi-structured interview and interpretive phenomenological analysis was used.

Results: In this study, the experience of parents to manage the disease process was examined, and 10 sub-themes were identified under four main themes. These were "reactions of the parents against the disease" (emotional and behavioral), "difficulties in managing the disease process" (managing symptoms, social, and financial), "difficulties in managing the disease process" (assessment, problem-solving, and emotion-oriented), and "inferences about managing the disease process well" (aimed at parents and school staff). When the findings from the themes and sub-themes were evaluated, it was found that many of the parents felt sadness and concern about their child's condition and showed mourning reactions such as denial and shock but also developed positive perspectives and an effort to become stronger after accepting the disease.

Conclusion: The results of the research indicate that the holistic approach is important for the family to manage the treatment process well. When first diagnosed, parents should be allowed to express their emotions, revealing their strengths and strengthening their weaknesses. Emotion and behavior-oriented support programs will be useful for families to cope with their difficulties. Parents talk about the positive effect of information, so information resources and accessibility should be increased. School nurses should be trained to monitor the child's behavior at school. Social support resources of the family should be evaluated and supported.

Keywords: Attention deficit and hyperactivity disorder, Adolescent, Disease management, Phenomenology

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Introduction

Attention deficit and hyperactivity disorder (ADHD) is a common childhood neurodevelopmental disorder characterized by inattention, hyperactivity and impulsivity symptoms.[1] It is reported that it is seen in school-age children with a rate of 3-11%.[2] Considering the results of a study conducted with 5830 participants in more than 30 cities across Turkey, the rate of any psychiatric disorder in the primary school second, third and fourth grade students was found to be 37.6%. In the same study, it is noteworthy that ADHD is the most common disorder in the country.[3] In longitudinal studies, it has been determined that children with ADHD have more negative interactions with their parents than healthy controls.[4,5] In addition, the mutual conflicts between the parent and the child negatively affect the functionality of the child with ADHD. Studies also emphasize that parents who have children with ADHD experience more negative parental feelings and more stress than their parents, and they also have more psychopathological complaints about themselves.[6,7] It has been determined that mothers with children with ADHD have higher psychological difficulties both in general and specific to the maternal role and experience inadequate maternal feelings compared to mothers of children without ADHD diagnosis.[5,8] It is observed that the parents of children with ADHD have poor problem-solving skills and problems in the distribution of roles in the family, and they display more aggressive behaviors and use reward methods less than healthy controls.[6,9]

A study investigating how the difficulties experienced by parents reflect on the clinical picture of children with ADHD focused on the relationship between inadequate parenting skills and ADHD symptom clusters in children in families with children with and without ADHD

diagnosis. As a result of the study, it was concluded that the chaotic structure in the home, critical attitudes towards the child, and inadequate child and parent relationship are related to the negative course.[10]

Parental attitudes in ADHD treatment are an issue that should be emphasized because of its effect on the treatment process. Children and their families mostly live and try to manage this process together. Effective management of the disease process brings many positive results for both children and parents. Parents have an important place in the management of ADHD, which is a chronic disease.[11] The development of parents' ability to manage the disease and cope with the difficulties of the disease will contribute to increasing the functionality of the child with ADHD. Difficulties experienced by parents in managing the disease ADHD in Turkey, the ways of managing the disease or the coping skills they have developed are not the subject of research, and no qualitative research has been found by nursing and other health disciplines.

Methods

Aim

The study was conducted to determine the subjective experiences of parents of adolescents diagnosed with ADHD in managing the disease process.

Design

This research is a qualitative research in phenomenological design.

Study Population and Sample

The study was conducted in the child and adolescent psychiatry polyclinic of a state hospital in the Eastern Anatolia Region of Turkey (Kars Harakani State Hospital). This polyclinic has been in service since the beginning of 2015, and it does not have an inpatient service and has one room for examination. A child and adolescent psychiatrist and a secretary make up the outpatient clinic team. In this outpatient clinic, an average of 75 children and adolescents diagnosed with ADHD and their families receive service for diagnosis, treatment and control per week. Approximately 1/3 of them are at the age of 12 years and over. Control appointments are given to children and adolescents between 15 and 30 days. The sample consisted of voluntary parents and primary caregivers who replaced parents with a child diagnosed with ADHD who applied to the child and adolescent psychiatry outpatient clinic between the research dates. Inclusion criteria in the study were as follows: being parent of an adolescent diagnosed with ADHD, having been followed up with a diagnosis of ADHD for at least 2 years, having come to the child and adolescent psychiatry outpatient clinic of the state hospital where the study was conducted, on the dates of the study, having no communication problems and agreeing to participate in research (Table 1).

Exclusion criteria in the study were as follows: not signing the consent form and not knowing Turkish, based on the data saturation in determining the number of samples, a total of 10 parents or individuals who fulfilled the criteria of the study (nine cases were evaluated under the accompaniment of mother and/or father and one case by uncle) were included in the study. Participants who met the criteria of the study were invited to the study according to the order of application to the polyclinic. Nobody refused to participate in the study or abandoned the interview.

Data Collection

The research data were first gathered in May 2019; after the ethics committee and institution permissions were obtained, the research environment (interview room, cooperation with the polyclinic authorities, etc.) and tools (data collection forms, voice recording device, etc.) were prepared. Parents who met the research criteria were informed about the duration of the study, its content, its benefits and potential problems, the benefits of the confidentiality of the research and the use of a tape recorder, and their names would be kept confidential, and the consent form was signed by those who accepted. The interviews started after the individuals were relaxed and able to direct the subject by chatting on daily matters in the room determined by the hospital management and gradually progressed with semi-structured questions and sounding questions according to the objectives of the research. In order to ensure the reliability of the interview, the interviewer paid attention to the following principles: the participants were informed about the interview and their curiosity was answered. Both verbal and written consent was obtained from the person. Simple, clear and understandable language is used, avoiding

Table 1. Demographics of Participants regarding Themselves and Their Children

Participant no	Age	Marital status	Education status	Income Status	Psychiatric diagnose of parent	Number of children	Psychiatric diagnose of siblings	Parent child relation perception	Child's perception of school success
1	51	Married	Primary	Income = expense	No	4	No	Good	Good
2	47	Married	High school	Income > expense	Depression	3	No	Intermediate	Intermediate
3	42	Married	Primary	Income = expense	No	2	No	Good	Bad
4	39	Married	Primary	Income = expense	No	3	No	Good	Bad
5	34	Married	Primary	Income = expense	No	2	No	Intermediate	Intermediate
6	42	Married	Primary	Income = expense	No	2	No	Good	Good
7	29	Married	University	Income > expense	No	2	No	Intermediate	Bad
8	38	Married	University	Income = expense	No	1	–	Good	Bad
9	40	Married	Primary	Income = expense	No	3	ADHD	Intermediate	Good
10	41	Married	University	Income > expense	No	3	No	Good	Intermediate

ADHD: Attention deficit and hyperactivity disorder

criticism and evaluation. Questions are chosen as neutral, non-judgmental and open-ended. The unsaid has also been taken care of. Individuals were allowed to express themselves comfortably by allocating sufficient time to the interview. In the data collection form, the participant number was used for the participants according to the order in which they were included in the study instead of their names. Data were collected through in-depth interviews, which were planned for an average of 45-90 minutes.

Data Collection Tools

It consists of an introductory information form and a semi-structured interview form.

Introductory Information Form

It is a form consisting of 15 questions in total, 9 questions containing the introductory characteristics of the parents and 6 questions containing the health characteristics of the child.

Semi-structured Interview Form

It consists of alternative and drilling questions based on five open-ended questions prepared by the researcher considering that it will receive an answer to the research question and will be used in the interview. The interview questions, which were finalized with pilot interviews by taking expert opinions, are given below:

1. How did you first notice the symptoms of ADHD in your child?
2. What did you feel/experience when your child was diagnosed with ADHD?
3. Could you tell us about the process after your child is diagnosed with ADHD?
4. What are your current feelings/emotions about this situation?
5. How do you feel about managing your child's illness process from the beginning?

In addition, in order to allow the families to sort out the issue and to state anything they have difficulty speaking, finally their opinions were asked by two following questions: "What are your inferences from your experiences in this process? What would you say if there was a family with a newly diagnosed child?"

Ethical Statements

In the first stage, "Non-Interventional Clinical Research Ethics Committee Permission" was obtained from a university hospital ethics committee for the ethical compliance of the study (81,829,502.903/44). Second, an institutional permit was obtained from the Provincial Health Directorate to work in the state hospital in the Eastern Anatolia region of Turkey where the study will be conducted. Finally, verbal consent and written consent forms were obtained from the participants who volunteered for the study.

Data Evaluation and Analysis

The data of the study were analyzed with the interpretive phenomenological analysis (IPA) approach. This method was found suitable for this study as it involves detailed examination of concepts and phenomena that may be encountered in daily life on the basis of experience. In the analysis, the researchers tried to understand and interpret their feelings and thoughts based on what people said. The phenomenon to be investigated in this study is how the experience of managing the disease process of parents with children with ADHD is experienced on their own front. The interviews with the participants throughout the study were recorded with a voice recorder (sony-ıcd-px240) and a mobile phone. It was then processed into the computer as raw data. First of all, voice recordings obtained through face-to-face interviews were turned into a written text without any changes. Researchers have repeatedly reviewed audio recordings and texts to describe the nature of the phenomenon. Important statements describing how the participants experienced the phenomenon were identified and codes were created. By comparing the code lists of both researchers, categories were created by grouping similar and different codes over the code list that was agreed upon. At this stage, themes were formed after the feedback of an observer (child and adolescent psychiatrist) other than the researchers was also received. The themes that emerged were interpreted to ensure integrity of meaning. In the process of structuring the research and analyzing the data, consultancy was received from a statistician who is an expert in qualitative research.

Results

The experiences of parents in managing the disease process are grouped under four main themes. These themes are responses of the parents to the disease, difficulties in managing the disease process, behaviors of coping with the disease process and their implications/suggestions on managing the disease process well (Table 2).

Theme 1. Parents' Reactions to the Disease

Parents' reactions to the disease are grouped under two sub-themes as "emotional reactions" and "behavioral reactions". Emotional and behavioral responses are considered as two sub-themes: the first diagnosis period and the experiences of the disease during the treatment process.

Emotional Reactions

Emotional reactions at first diagnosis: All parents expressed their opinions, except P7. Emotional reactions of parents when the child is first diagnosed: sadness, surprise, rebellion/inability to accept, worry, inadequacy, inability to understand/describe the feeling and relaxation. One of the parents expressing his sadness said, "*I am so sad that I am very upset. Either they say, the day when the first diagnosis was made, how do you say, the world is falling on your head, or it happened that way*" (P5). Another feeling that emerged when the diagnosis was first heard was surprise and was expressed with the sentence "*We did not expect it at all*" (P5). Difficulty and worries of the parents to accept this situation were clearly observed. "Everyone's okay, why isn't ours okay?" (P5), "Can I deal with it, can't I?" (P3). It is revealed in the following sentences that some parents have difficulty describing their feelings and cannot make sense of it. "*We could not understand what was happening, the tests were done. It turned out that it was ADHD, when we went to the doctor*" (P1). In addition to these negative emotions, some parents stated that they felt relief because the diagnosis was made. "*These have been very good for me, at least because they have been diagnosed or because I know that this child's life will be in order by taking a medicine*" (P8).

Emotional reactions in the treatment process: All parents expressed their opinions. One of the prominent emotional responses of parents to managing the disease process is to be happy. "*Well I am very happy right now Alhamdulillah*" (K1). Another prominent feeling related to managing the illness process is the feeling of anxiety expressed by almost all parents and covering many areas of life. For example "*What will happen next that worries me? Until when will the drug be used? So these are the things that worry me*" (P3) represent worries about treatment, "*How will it be as the school progresses? Will it be fixed? For example, I do not care about primary school now, but how will he do his homework when he passes to secondary school? Now he sometimes writes his homework, sometimes he writes half, I take it from my friends.*

Table 2. Themes and Sub-Themes of Parents of ADHD Adolescents' Experiences of Managing the Disease Process

Theme	Subtheme
1. Parents' reactions to the disease	Emotional reactions
	Behavioral reactions
2. Difficulties in managing the disease process	Difficulties in managing disease symptoms
	Community difficulties
	Financial and business difficulties
3. Behaviors to cope with the illness process	Assessment-oriented coping behaviors
	Problem-solving-focused coping behaviors
	Emotion-focused coping behaviors
4. Implications/suggestions for better management of the disease process	Suggestions/ implications for parents
	Suggestions/ implications for school staff

How will his friends be in middle school? How long will he be behind them? I always think about them" (P3) represent worries about academic life, "*You know, he goes and tells other places something he has in mind, I do not want him to exclude him if someone else finds out, or that he is sick, let us stay away from it*" (P4) represent worries about stigmatization. Few parents also stated that they felt lucky to notice the situation early. "*We had a chance that his mother was very interested. Also, since we were in Istanbul in the early days, we noticed the incident early on. When I realize it early, I mean, let us say 12 years old now, we have known for at least 9 years that he has this disease. In other words, we knew about this disease for about 80% of his life*" (P10). Some parents stated that they did not pay enough attention to the treatment and felt regret, "*I hope I will not do anything like this from now on, I will come to check every 15 days*" (P2).

Behavioral Rresponses

Behavioral responses at first diagnosis: Two parents, P5 and P10, expressed their opinions.

Crying and consoling the spouse are examples of behavioral reactions when first diagnosed. "*At that moment, I sat down and cried so much that I could not recover myself*" (P5). "*When a person is upset, I think other one should comfort. I say to my wife, do not bother, we will overcome, we will overcome*" (P10).

Behavioral responses in the treatment process: Three parents expressed their opinion (P2, P3 and P5). The behavioral reactions of parents in the process of managing the disease process of their children were as insomnia, "*This has done something to me (thinks) I could not sleep, what am I going to do, I will lose my child*" (P2), physical violence to the child, "*There is nothing that can be done but you inevitably hit him*" (P5), verbal violence to the child, "For example, I used to get angry with my son all the time. I was getting angry so he (other children) can do it, why cannot you?" (P3), ignore and walk away from the environment, "*During times of aggression, I sometimes tried to keep quiet. I was ignoring, I was going out and I was afraid that I would beat him until he calmed down*" (P5).

Theme 2. Difficulties in Managing the Disease Process

Difficulties in managing the disease process determined according to the interviews with parents whose children have ADHD are grouped under three sub-themes as "Difficulties in managing disease symptoms, community-related, financial and business difficulties".

Difficulties in managing disease symptoms: All parents expressed their opinions. Difficulties in managing disease were about, child's attention deficit symptoms, hyperactivity symptoms, impulsivity symptoms and difficulties due to drug side effects.

As an example of difficulties related to attention deficit symptoms, "*For example, is there a math class today, he was putting his Turkish book away. school was not important to him, it did not matter... Either he forgot his pen or he forgot his notebook*" (P7) can be given. An example of difficulties associated with hyperactivity symptoms is, "*He was very mobile, he was naughty. The kindergarten teacher did not accept, said I cannot cope. My child used to be like a dog bitten, just like that. Shouting, I mean, God what, what, what would pull my hair, this is something unprecedented. It was a very terrible thing*" (P1) sentence can be given.

Another illness symptom that parents have difficulty managing is impulsivity. "*He cannot wait to throw or something, he jumps once or twice like this, so the children throw it. When he throws himself, he jumps after the ball again*" (P3).

Finally, since all children receive medication, the related side effects are a difficult area for families. "*They told me that my child may be short in length with these drugs. We were using the heaviest dose, I did not give it in the summers. But I had a lot of difficulty in the summers*" (P1).

Community difficulties: Six parents, including parents P2, P3, P4, P5, P8 and P10, shared data about community difficulties. The parent, who stated that she was experiencing environmental questions and difficulty in managing the child's situation, expressed herself as follows. "*Obviously some neighbors are asking; Why is this boy like this? Why is his behavior like that, I say it too, frankly, I say attention deficit or something*" (P4). Another parent shared her concerns about the labeling of her child as follows. "*More precisely, external conversations confused me like this. If you go (to treatment) they will call your child crazy, they will do that, they will do this*" (P2). Another parent complained of isolation and difficulty maintaining relationships with people. "*Also, I left all my friends around me for a few years, except the ones in the apartment. I have never been to anyone. Of course, they did not come when I did not go. The reason is I need to take care of my child*" (P8).

Financial and business difficulties: Parents with code P2, P4 and P6 expressed their opinion. One of the difficulties expressed by parents with children with ADHD is related to the deterioration of financial and business life. One of the parent explain situation as follows, "*He Can't Wake Up. Since I am a working woman, my hours and everything should be planned. I hardly wake him up in the morning, then I'm late for work because he hardly goes to school. Our manager does not say anything again, but this is not good for me*" (P8).

Theme 3. Behaviors to Cope with the Illness Process

Coping behaviors with disease process; assessment-oriented coping behaviors, problem-solving-focused coping behaviors and emotion-focused coping behaviors.

Assessment-oriented coping behaviors: All parents gave their opinions. Participants emphasized six factors in evaluative coping: positive perspective, religious perspective, focus and letting go, accepting the disease, generalizing, and minimizing. "*We were afraid that he had another disease, but thank God no other disease occurred. He was just diagnosed to be hyperactive... If it goes on like this, I hope he will be saved. This is my observation impression*" (P1) is an example for positive perspective, "*If my God is testing us with these, we should be thankful for it*" (P9) is an example for religious perspective.

Another assessment-oriented coping behavior of families is acceptance. "*But I did not know this was a lack of attention yet. Then after I came to the doctor, I stopped doing that much to him. So now I am starting to see normal*" (P3). Generalization and minimization have been observed as two other ideas. "*Often, this is the case with other people. One of the three friends say either mine is attention deficit, mine does not attend class either*" (P6). "*But when I look at him, there is nothing very abnormal in the child. He just cannot grasp some things, so we do not have trouble reading, other things*" (P9).

Problem-solving-focused coping behaviors: Except P2, P6 and P7 coded parents, other parents expressed their opinions. In this subtheme, two factors came to the fore: information seeking and retrieval and the rearrangement of individual life. Some of the parents' statements are as follows. "*Then I did some research. I said maybe it would be good or I thought badly at first, I thought very badly, but then after seeing the doctor, I started to comprehend something. You know, I always thought at home, I started researching all the time*" (P3), "*I have tried so many things, I have adjusted and adjusted everything according to him*" (P4).

Emotion-focused coping behaviors: P1 and P3 expressed their thoughts. "*I said to myself what am I doing? If I collapse, I will have no contribution to this child. God damn blind devil, I will be fine too, my child will be fine too. I gave myself a self-confidence. And I continued like this. I still continue like that now. I got stronger with Gods help and with your support*"' (P1) is an example for emotion-focused coping behavior.

Theme 4. Implications/Suggestions for Better Management of the Disease Process

Two sub-themes emerged in which the participants expressed their thoughts on what to do with family and school staff about ADHD.

Suggestions/Implications for parents: All parents gave opinions. Be patient with the child, be self-confident, be interested in the child, give importance to the treatment (go to the doctor, continue the treatment, follow the treatment), make decisions together in the family, show love for the child, be calm, the child should not be pressured, They stated that they should be directed (sports, music) and conscious as parents. The striking ones of these suggestions are expressed as follows, "*I suggest mothers to be patient. I would also say to families that if you are patient, you will definitely reintegrate your child into society*" (P1), "*You will definitely succeed if you have self-confidence*" (P1), "*This is especially important for working parents so that they spend more time with their children. They should spend a little more time with their children because when this really shows interest, the child is different*" (P2), "*At least if you do not do anything, you can take it to a child psychiatrist. I mean, that way, but be sure to take it to a psychiatry first. We also took the guides, but let a child psychiatrist see you before the guide*" (P3), "*I say, for example, you will not do everything he/she say. You know, by talking, negotiating with the child is always better*" (P3), "*I want them to show their love so give he/her time*" (P5), "*so you have better to change his tune or try to behave like he want*" (P6), and "*Do not put too much pressure on your child. My suggestion to them; direct to sports, direct to music*" (P8).

Suggestions/Implications for school staff: P3 and P8 expressed their thoughts. Participants emphasized "being conscious" and "having a professional attitude" towards school staff. An example of being conscious can be given, "*However, the teachers are very uninterested and ignorant. So my son is studying at Science High School, but the teachers are very ignorant. So I am going to school, I am telling, I am telling you that he is a 4-year university graduate and I am a 2-year associate degree graduate, but I try to explain it with what doctors say and read. My child is distracted, taking medication. Never mind what a distraction, you made these children like that because of that, I do not know what the teacher ignores. So it does not take into account what I say. I mean, he finds every blame in my son. I think teachers should know this issue first*" (P8), The statement of a parent stating that school staff should adopt a professional attitude is as follows, "*When they first looked at it, they spoke such sentences as if this child could achieve nothing. I tried for a month and could not teach anything. You are going to issue a disability report to this kid, but I am against the report too. Well, I said okay, what are we going to do*" (P3).

Discussion

In this section, the experiences of parents with children with ADHD in managing the disease process, the components that make up the structure of the phenomenon and the studies conducted in the field are discussed.

In the study, the theme of parents' reactions to the disease was discussed in two sub-themes as emotional and behavioral reactions. These two sub-themes were examined separately at the time of first diagnosis and parents' feelings and behaviors related to managing the disease processes. In a study conducted in Denmark in which the responses of families whose children were diagnosed with ADHD were measured, it was found that the families showed reactions such as shock and denial at the first stage.[12] In another study, it was found that in the phase of accepting that their child had a psychiatric disorder such as ADHD, parents first showed mourning reactions such as shock and denial.[13] In the first periods after ADHD symptoms were declared as a diagnosis, it was stated that mothers showed avoidance behavior, had difficulty describing their emotions, experienced shock, sleep problems, memory difficulties, anorexia and emotional lability.[14]

The second theme, which is the difficulties of parents in managing the disease process, is examined under three sub-themes: child-related, community-related and financial or business-related difficulties. It was observed that the difficulties of the parents with the sick child were particularly related to the symptoms of attention deficit and hyperactivity disorder. When Ghanizadeh[15] examined the family functions of children and adolescents with ADHD with the family assessment scale, they found that children with ADHD had problems with their families in roles and behavior control. Such problems make it difficult for children to easily learn, understand and adapt to social rules.[16] Children with ADHD experience many problems in relationships. Their movements can be disturbing, and sometimes they can be perceived as deliberately doing antisocial and undesirable behaviors. In addition, it was observed that they may be more introverted, lonely and angry because of the difficulties in establishing and maintaining friendship relations.[16] In a study in which children diagnosed with ADHD were compared with healthy controls in terms of academic skills, it was found that children with ADHD had lower school

functionality compared to the control group.[17] This finding can be interpreted as a result of the low attention paid to academic activities in children with ADHD. Another situation that challenges parents during the treatment process is the side effects seen in stimulant treatment, despite all its positive contributions. In the literature, it shows that the presence of side effects during the use of methylphenidate or atomoxetine in families has an important place in discontinuation of treatment[18]. In our study, parents with codes P1, P5, P8 and P10 stated negative opinions about drug side effects, while other parents expressed their satisfaction with the drug and the treatment.

Another area where parents with children diagnosed with ADHD have difficulty is related to the negative viewpoint and stigma they are exposed to by the society. In this study, too, families' concerns about this issue are felt intensely. In another study on ADHD, it was seen that stigmatizing tendencies towards ADHD were higher than other psychiatric disorders and this could lead to negative consequences in areas related to treatment seeking behavior and social functionality.[19,20] In the study by Klasen and Goodman[21] (2000), approximately 20% of the adults who participated in the study stated that they were reluctant to interact with a child with ADHD symptoms, 22% of those who did not want a child with ADHD to be next-door neighbor, and a child with ADHD. The rate of those who do not want to have dinner is 17%, the rate of those who do not want their children to have a friend with ADHD is 24%, and the rate of those who want a child with ADHD not to be their own classmate is 17%. Again, another finding obtained from the same study was found that older individuals with ADHD are not wanted more strongly than girls, compared to younger individuals with ADHD. A similar result has been reached in this study.

The perception that parents are criticized by the society for mental illnesses in their children is also valid for parents of children with ADHD. For this reason, parents' approach to their children is shaped by stigmatizing thoughts and behaviors from their wider social environment[21]. In a study in which 48 parents whose children were diagnosed with ADHD were included, 77% of the parents stated that they experienced stigma, 44% stated that they were worried about how their children would be labeled by the society, and 40% stated that they felt socially isolated and excluded.[22] In addition to the long-term effects of ADHD, it is known that if it is not treated, it has serious financial and moral burdens on the society. It is also supported by some literature studies that the child's ADHD symptoms cause economic difficulties for the parents, some parents cannot continue working due to the problems that arise, and significant deterioration in the quality of life of the parents is observed.[23]

The third theme, which is the behaviors of parents to cope with the disease process, was addressed under three sub-themes: assessment, problem-solving, and emotion-focused coping behaviors. In a study showing similarity with the research finding in the literature, they found that at the stage of accepting their child's situation, parents tried to make sense of what was told to them after their first reaction. While trying to make sense, it was observed that they made religious point of view, minimize, generalize and try to accept the disease.[23] The over-tolerance of the parents of children who show signs of hyperactivity and impulsivity can be explained in two ways: The first is the parents' inability to cope with the behavior of their children and to let go, the second is the overly tolerant attitudes of the parents perceived by their children as permissive. This can cause symptoms to become more apparent in attitudes. Davis and Fallowfield[16] stated that parents' adaptation to the disease is complex. In addition, they observed that there were important relationships between social support such as obtaining information about the disease, seeing other sick children, talking with other parents, parents' well-being, behaviors towards their children and child's adaptation to the disease.[24] These findings in the literature support the findings obtained in this study.

The last theme of the study, the inferences/suggestions of parents on better management of the disease process, were discussed in two sub-themes as "inferences/suggestions for parents in better management of the disease process and inferences/suggestions for school staff on better management of the disease process". When looking at the literature, a recent study investigating how parents' behavioral patterns affect the problems that will arise in their children with ADHD has found that strict discipline methods, non-consistent parenting skills and non-supportive parenting approaches exacerbate ADHD symptoms by causing emotional regulation problems in children. In addition, it was found that parents' avoidance of physical and emotional violence against their children, consistency in setting limits and determining rules, saying praise words to their children and avoiding behaviors that would exacerbate discussion with the child both contributed to the reduction of ADHD symptoms and may prevent the development of oppositional defiant disorder symptoms.[25] Early diagnosis in ADHD, determination of comorbid psychopathologies and necessary interventions are very important. Generally, teachers and families feel helpless in the face of behavioral problems of children with ADHD, which increases the importance of studies on this subject[26]. Just like teachers, parents' perception of their children's academic skills is more negative when their children are diagnosed with ADHD. It is very important to inform teachers about the difficulties experienced by the child regarding these behavioral problems at school. "When does the child show problem behaviors more?" and "How to ensure that the child participates effectively in the lesson?" Training programs should be prepared for school staff in such matters.[27] Preparing teacher education programs is very important in this sense. In the study of Nicolau et al.,[28] It was determined that the assistance given to parents and teachers such as information and support increased the awareness level of both parents and teachers about the disease and the care of their children. It can be expected that parents who act consciously about the care of their children will help the child with chronic disease to be less affected by the problems caused by the disease.[14]

Limitations and Difficulties of the Research

The limitation of the research: in this study, the results of the research cannot be generalized since the parents' management of the disease process is evaluated on the basis of their subjective experiences.

If we look at the difficulties, it is noteworthy that there are difficulties with children, parents and environment in the data collection process. Difficulties with children: The children in the sample were school-age children and had difficulties such as wanting to return to school after the examination hours, having limited time, applying psychiatric examination with relatives or neighbours instead of their parents, the presence of those who did not come for an appointment despite having an appointment and not wanting to wait while the family was interviewed. Unexpected difficulties with participants in the data collection process are as follows: not wanting to fill in a form again because they have filled out certain forms by the doctor, fear that signing consent will impose responsibility on them, do not want to spend time for the interview because of the low number of car trips, have a limited period of permission from the workplace and demand money for the information given, even if they meet the criteria made it difficult to choose. Environmental difficulties in the data collection process are as follows: making a conversation in an empty polyclinic room, having a telephone in the room, not allowing the phone plug to be unplugged because of internet connection and the ringing of the phone in between may be shown.

Conclusion

In this study, data that are compatible with the literature and showing the parents' views on ADHD, their life experiences and the ways of managing the disease were obtained. In the data obtained, the four main themes that include the experiences of parents with children diagnosed with ADHD in managing the disease process are as follows: implications/suggestions of parents' reactions to the disease, difficulties in managing the disease process, behaviors of coping with the disease process and good management of the disease process. Parents' responses to the disease include both positive and negative responses. When first diagnosed, parents should be allowed to express their feelings. In line with the answers given, positive responses should be pointed out, the strengths of the individual should be revealed, and the individual should be supported and empowered in negative responses. In difficulties in managing the disease process, "the symptoms of the sick child and the difficulty in managing the treatment" can cause feelings of helplessness and exhaustion, and it stands out as an issue that should be emphasized by health professionals. In tackling community-related difficulties, nurses and healthcare professionals should empower parents by enabling them to express their feelings about stigmatization and social isolation and through psycho-education. Support from social workers can be provided for financial and business challenges. In addition to the disease, parents experience difficulties in social environment, school and work relations. Getting and using social support is an important resource for families. Opportunities should be provided to the family in accordance with their needs by utilizing the sources of support.

Although "assessment-oriented coping behaviors" of parents in coping with the illness process are good at cognitive level, "intense anxiety, anxiety, inadequacy and violent behaviors" indicate that there are problems in internalizing and the need for support for coping. The subtheme of "problem-solving-oriented coping behaviors" reveals the importance of getting information and the positive effect of gaining skills to live with the disease. In this respect, a solution may be to facilitate access to booklets and brochures for parents. Parents stated that they managed to live with the disease when they managed their emotions. Psychoeducation programs can be prepared to develop "emotion-focused coping behaviors".

Parents' suggestions for other parents to better manage the disease process are highly constructive and adaptive. This again shows that awareness at the cognitive level develops more easily, and practices that will increase the effect of this in emotional and behavioral areas should be studied. School is another factor that has an important impact on the lives of children with ADHD. Parents stated that they had difficulties in cooperation with the school and that school staff had insufficient knowledge about ADHD. The importance of school nurses for the behavior monitoring of the child in school comes to the fore here. School nurses can be trained on this subject. Research findings indicate that a holistic approach to the patient and his family is important in managing the treatment process in the treatment of children with ADHD. It was concluded that a child with a chronic disease affects the whole family, parents also play an active role in this process, parents' experiences and feelings are very important, and it is also important to inform and cooperate with all persons and parties involved in the child's disease process.

Ethics Committee Approval: Ethics committee approval was received for this study from the Kafkas University Faculty of Health Sciences Non-Interventional Research Ethics Committee (date and number: 29.03.2019– 81,829,502.903/44).

Informed Consent: Written and verbal consent was obtained by the parents who participated in the study.

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