



## An In-Depth Analysis of the Life Experiences of Parents with Children with Autism Spectrum Disorder \*

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### Abstract

Studies report that different aspects of the family structure can be affected when a family has a child who has been diagnosed with Autism Spectrum Disorder (ASD). This study aims to determine the experiences of Turkish parents of children with ASD before, during and after the diagnosis, and how this situation affects both their individual and family lives. In the study, the data were collected using a phenomenological approach that involved the semi-structured interview method. The study sample consisted of 10 parents of children with ASD, including five fathers and five mothers. The data were analyzed using the content analysis technique, from which nine themes were identified. The themes and sub-themes identified constituted the main findings of this study. Accordingly, most of the participants stated that the ASD diagnosis of their children was late as a result of being misled, and that their children were able to develop daily life and self-care skills from the trainings they had received. Participants further reported that they had endured negative experiences, including being forced to take on part-time jobs or to go into early retirement, because of having children with ASD. Yet, in contrast to these drawbacks, the participants also stated that they had experienced positive emotions due to their children's special situation, such as looking at life from a different perspective, feeling stronger and developing different methods of dealing with ASD-related difficulties. From the results of this study, it can be suggested that additional research involving different approaches be planned to gain a better understanding of the experiences that both children with ASD and their parents face as a result of being labeled (stigmatized).

### Keywords

Parents with children with ASD  
Life experiences  
Qualitative research  
Phenomenology  
Labeling  
Posttrauma growth

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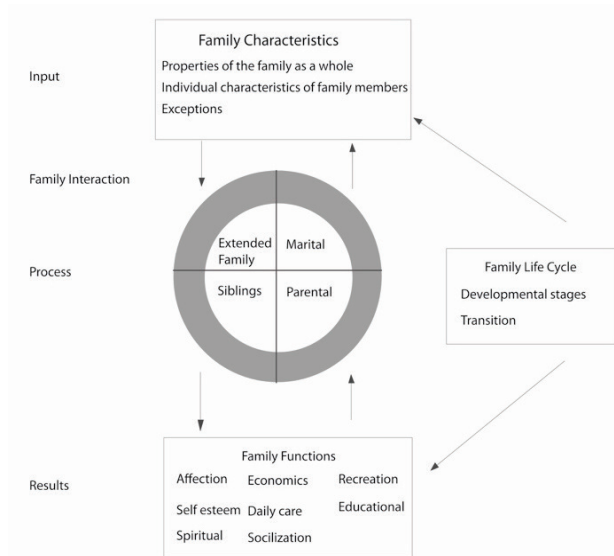
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## Introduction

“Autism Spectrum Disorder (ASD) is a neuro-developmental disorder characterized by deficiencies that began to emerge in the early developmental stages in the areas of social communication and interaction and in repetitive behavioral patterns, resulting in limitations in social and other important functional areas” (APA, 2013, pp. 25-27). Individuals with ASD may have secondary disorders, like intellectual disability, depression, anxiety, attention deficit and hyperactivity disorder, obsessive compulsive disorder, psychotic disorder, bipolar disorder and oppositional defiant disorder (NAC, 2011). All of these characterizing features of ASD adversely affect the quality of life of the individuals with this disorder and their families. Therefore, the educational process of individuals with ASD has great importance in terms of increasing their quality of life and their parents, insofar as it can help to decrease/eliminate the challenging situations specific to ASD and the secondary diagnoses associated with it. In this context, organizations such as the National Autism Center (NAC, 2015) and the National Professional Development Center on Autism Spectrum Disorders carry out various research projects to identify evidence-based interventions related to the education of individuals with ASD. For example, the National Standards Final Report issued by the National Autism Center (NAC, 2015) highlights 14 evidence-based interventions that can be used in the education of individuals with ASD under the age of 22 and recommends these be included as much as possible in the education process of these individuals (Güleç-Aslan, 2013). These 14 evidence-based interventions defined by the NAC are: Behavioral Interventions, Cognitive Behavioral Intervention Package, Comprehensive Behavioral Treatment for Young Children, Language Training (Production), Modeling, Naturalistic Teaching Strategies, Parent Training Package, Peer Training Package, Pivotal Response Treatment, Activity Schedules, Scripting, Self-Management Strategies, Social Skills Package, Story-Based Interventions.

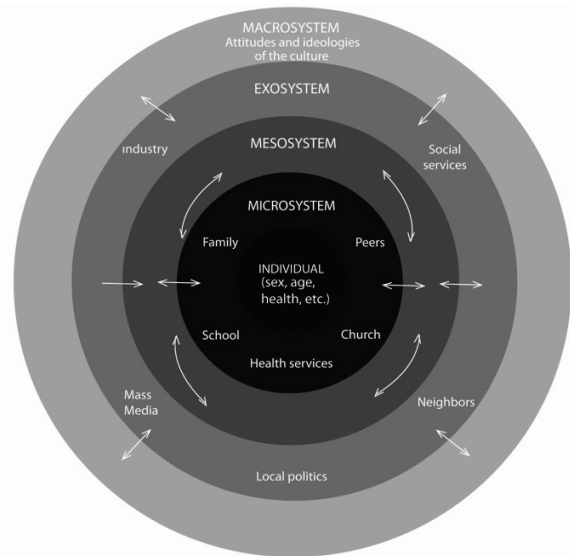
The family system approach and Bronfenbrenner’s bioecological approach, both of which have been spotlighted in studies on family concept and family system structure, should be applied to better understand the processes experienced by families of individuals with ASD or other disabilities. The family can be defined as a group of two or more individuals who perform family functions and refer to themselves as a family. It is not necessary that these individuals who refer to themselves as a family have either consanguinity or marital interdependency, nor are they obliged to live together (Poston et al., 2003; as cited in Turnbull, Turnbull, Erwin, & Soodak, 2007). According to the family system approach (See Figure 1), the best way to understand family interactions is to consider the family as a system. There are two basic assumptions governing the theory of family systems. First, the family has inputs and interacts with these inputs to fulfill their family functions. Second, the family is a whole, and thus cannot be understood by examining only one component of this whole (Can, 2002; Kaner, 2009; Turnbull et al., 2007). Bronfenbrenner’s bioecological model (see Figure 2) describes the family system in terms of the participation of family members in children’s developmental and educational processes, the factors affecting the family system, and the interactions of these factors with each other (Kaner, 2009).

Having a child with ASD can affect the family in different ways. Parents who dream of having a child actually dream of having a healthy child. Therefore, when spouses learn that their children are affected by a disability, they may experience various negative emotions, such as anger, guilt and depression. In addition, other children and the family of the spouses may also negatively contribute to these challenging experiences (Akkök, 2003; Benson, 2010; Bloch & Weinstein, 2009; Cavkaytar, 2013; Gray, 1993; Kaner, 2009; Özdemir, 2012; Öztürk, 2008; Tekin-İftar & Kutlu, 2013; Turan, 2002; Turnbull et al., 2007; Varol, 2006; Wing, 2012). Having a child with ASD can affect the family system in all functional areas, including compassion, self-esteem, mood, economics, daily care, socialization, free time, and education (Turnbull et al., 2007).



**Figure 1.** Family System Approach

Reference: Turnbull, A.P., Summers, J.A., & Brotherson, M.J. (1984)'den akt. Turnbull vd., 2007.



**Figure 2.** Bronfenbrenner's Bioecological Approach

Reference: Diken, İ. H. (2008). Okul aile işbirliğinin tanımı, kapsamı ve önemi (The definition, scope and importance of school-parent collaboration). (Ed. E. Aysın Küçükylmaz). Okul, aile ve çevre işbirliği. Eskişehir: Anadolu Üniversitesi AÖF Yayınları.

The coping process involving the difficulties that parents of children with ASD face until they learn to accept and adapt to the situation may differ from the coping process involving the difficulties faced by parents with healthy children. In cases of families with ASD, parents may need more support to fulfill family functions related to material needs, morale, work life, education and spirituality, to name several. (Turnbull, et al., 2007). A failure to determine such needs in a timely manner may lead to situations wherein parents and children may experience irrecoverable problems that impair quality of life. For example, children with special needs may not be provided with an appropriate educational environment or the families of such children may not get the necessary psychological support. To prevent parents of children with special needs from having these problems or to encourage them to overcome these problems with minimal impact, it is important to understand the process of adapting to children with special needs and to support them with suitable methods when necessary (Akkök, 2003; Ardıç, 2012; Cavkaytar, 2013; Varol, 2006; Turnbull et al., 2007). The adaptation of parents of children with disability to the disability and accompanying difficulties may vary by type and severity of the disability, family characteristics, peer-to-peer communication, and the society's approach to children with disabilities. These factors are common to all families. The literature features a number of approaches that serve to explain the reactions that families with a disabled child have these approaches include the stage model, the continuous sadness model, the personal structuring model, and the helplessness, weakness and meaninglessness model (Cavkaytar, 2013; Gökdağ, 2002; Olcay-Gül, 2012; Özen, 2010; Öztürk, 2008; Turan, 2002; Varol, 2006).

The studies conducted on this subject seem to favor the stage model to explain the processes of adaptation by parents of children with disabilities to the disability and accompanying difficulties. The stage model uses a three-stage system to address the processes of adaptation by parents of children with disabilities to the disability and accompanying problematic situations. The three stages are: (1) shock-denial-pain-depression, (2) contradiction-anger-guilt-shame, (3) negotiation-acceptance-adjustment. Each family may experience these phases in a different order and to different degrees, while in some cases, these stages may not be experienced at all, or a family could be stuck in one of the stages (Akkök, 2003; Cavkaytar, 2013; Kaner, 2009). In the shock-denial-pain-depression stage, a family may exhibit a

variety of irrational behaviors, like intense sorrow, shock and denying the diagnosis of the disability, due to the unexpectedness of having a child with a disability. In the contradiction-anger-guilt-shame stage, a family may go through a sense of confusion regarding the feelings of love and devotion they are supposed to have for their children and regarding the frustration, depression and anger they experience due to the disability of their children. In the negotiation-acceptance-adjustment stage, a family may seek a way to eliminate their child's disability and come to realize the existing problems and produce solutions to them. Families can learn to make progress by developing solutions to all new situations they encounter (Akkök, 2003; Ardıç, 2012; Cavkaytar, 2013; Kaner, 2009; Nurullah, 2013; Özen, 2010; Tekin-İftar & Kutlu, 2013; Turan, 2002; Varol, 2006). As can be seen from the stage model that explains the adaptation process of families to disability, the difficulties experienced by parents of children with ASD in each stage (shock-denial-pain-depression and contradiction-resentment-guilt-shame etc.) can increase their stress levels (Wing, 2012).

Studies report that the stress levels of parents of children with ASD are higher than those of parents of children with disabilities other than ASD (Akkök, Aşkar, & Karancı, 1992; Baker-Ericzen, Brookman-Fraze, & Stahmer, 2005; Boyd, 2002; Cavkaytar, 2013; Esenler, 2001; Estes et al., 2009; Hastings & Johnson, 2001; Kaya, 2015; Krausz & Meszaros, 2005; Küçüker, 2001; Lee, Herinton, Louie, & Newshaffer, 2008; Sunay, 2000; Tekin-İftar & Kutlu, 2013; Weiss, 2002; Yurdakul & Girli, 1997). Regarding the reason for these high levels of stress, studies also report that parents of children with ASD tend to more frequently encounter various stressors, such as limited access to information needed after the diagnosis, social communication problems, the child's insensitivity towards the parents, difficulty in deciding the appropriate education and therapy process, failure of the spouses to provide necessary support to each other, financial problems, lack of social support, destructive behavior of the child due to ASD, lack of or limited language development in the child, and the long duration of the diagnosis (Bilgin & Küçük, 2010; Koydemir-Özden & Tosun, 2010; Marcus, Kunc, & Shopler, 2000, as cited in Kaya, 2014; Mitchell & Holdt, 2014; Uskun & Gundogar, 2010; Wing, 2012). Studies on parents of children with ASD suggest that all living areas of family life, including work life, social life, peer-to-peer communication, future expectations and psychological conditions, are generally adversely affected by this challenge of having a child with ASD (Bilgin & Küçük, 2010; Demir, Mukaddes, Eralp-Demir, & Bilge, 2000; Green, 2003; Koydemir-Özden & Tosun, 2010; Nurullah, 2013; Üstüner-Top, 2009; Wing, 2012). In addition to these adverse effects, studies also suggest that parents of children with ASD often experience labeling/stigmatization (Milacic-Vidgevic, Gligorovic, & Dragojevic, 2014; Werner & Shulman, 2014). Labeling (stigmatization) is defined as the "exclusion of an individual from social approval due to his/her characteristics differentiating him/her from the majority perceived as normal" (Goffman, 1963, as cited in Karabekiroğlu et al., 2009). On the other hand, some studies report that parents may enjoy various positive experiences as a result of having children with ASD, a phenomenon referred to as post-traumatic growth, which is described as positive psychological change experienced as a result of the struggle with a highly challenging life. These positive changes include increased appreciation for life in general, more meaningful interpersonal relationships, an increased sense of personal strength, changed priorities, and a richer existential and spiritual life (Tedeschi & Calhoun, 2004). Within the post-traumatic growth process, social support has been shown to be one of the most important positive factors in helping the families of children with disability to accept the disability of their children and to reduce their stress. Social support is a broad concept, one that involves the need to provide families with necessary information, the need for affection and trust, the need for approval, and needs-based services (Heaney & Israel, 2008; Özdemir, 2012). Another factor is religious coping. Pargament, Koenig, and Perez (1997) defined the concept of religion as "looking for meaning through religious means" and stated that it has five basic functions, namely, (1) meaning, (2) control, (3) comfort, (4) social intimacy, and (5) life transformation (giving up old values and concepts and finding new sources of significance) (Pargament, Koenig, & Perez, 2000). In the process of religious coping, individuals aim to cope with challenging experiences by giving more space to the elements that are sacred and valuable for them. It is important to determine what parents of children with ASD need in terms of taking care of a child with ASD, as determining the needs of parents of children with ASD with

respect to their experiences affects the scope and quality of the education to be given to them. There are quantitative studies that examine the psychological status and levels of social support perceived by mothers of children with ASD (Balkanlı, 2008; Demir et al., 2000; Görgü, 2005; Sencar, 2007), as well as those that compare the stress and perceived social support levels of parents of children with ASD and other disabilities and examine the relationship of these variables with each other (Ar, 2014; Öksüz, 2008). The literature also features qualitative national and international studies determining the difficulties faced by mothers of children with ASD and other disabilities in work life, domestic affairs, social life and the diagnosis process (Bıçak, 2009; Bilgin & Küçük, 2010; Koydemir-Özden & Tosun, 2010; Güleç-Aslan, Cihan, & Altın, 2014). In the international literature, there are qualitative studies investigating how parents of children with ASD are affected by and cope with the situations related to ASD (Gray, 1993; Nurullah, 2013; Ramisch, Onaga, & Oh, 2013; Woodgate, Ateah, & Secco, 2008), while in the national literature there is only a limited number of studies involving the participation of parents of children with ASD (Üstüner-Top, 2009). This study, therefore, was conducted to better understand the experiences of parents of children with ASD, with the hope that the study findings will provide a new perspective for educators, parents and experts working in the field of special education on how parents of children with ASD are affected by the ASD diagnosis of their children. This study paves the way for other studies to be conducted on making a detailed determination of the needs of parents of children with ASD and contribute to making the support they may need more effective and more easily accessible. In addition, this study, which examines the experiences of parents of children with ASD, can give an idea and guidance on the situations that the parents of children with ASD, or to parents under the risk of having a child with ASD, may encounter. In this regard, this study aimed to determine the experiences of Turkish parents whose children were diagnosed with ASD and how their lives are affected by the fact that their children were diagnosed with ASD.

The aim of the present study was to determine the experiences of Turkish parents whose children were diagnosed with ASD and how their lives are affected by the fact that their children were diagnosed with ASD. Based on this objective, the following research questions were posed:

1. What are the life experiences of parents until their children were diagnosed with ASD?
2. What are the experiences of parents when they learned about the diagnosis of their children with ASD and during the initial moments/year of the diagnosis?
3. What are the experiences of parents during the education process of their children with ASD?
4. What are the experiences of parents of children with ASD in different segments of their lives such as career, marriage, and social life due to their children's disabilities?
5. What are expectations of parents for their children with ASD for the future?

## Method

This section describes the study's research model, participants, data collection process, and data analysis.

### *Research Model*

From among the qualitative research approaches, the psychological phenomenology design was used in this study. The key feature that differentiates the psychological phenomenology method from other scientific methods is that the researcher aims to distinguish his/her own views from the view of the research participants as much as possible and to present the participants' views in a consolidated, simple form in order to completely reveal how participants perceive a given phenomenon (Creswell, 2007; Patton, 2002).

### *Participants*

Participants of the study was determined by snowball sampling which is one of the purposeful sampling methods frequently used in qualitative research methods (Ekiz, 2009; Noy, 2008). Table 1 contains information about the direct participants of the study (i.e., 10 parents), five children with ASD who were considered indirect participants in the study so as to understand the experiences of their parents, and their three siblings with typical development. Table 1 demonstrates that the average age of the parents was 43, the average age of the children with ASD was 10, and the average age of the siblings with typical development was 9. It was observed that three out of five families participating in the study had a high socio-economic income level, while one family had medium and one family had low socio-economic income levels; two families had a single child and the other three had two children.

### *Data Collection*

In the current study, data were collected through semi-structured interviews, researcher diaries, and parent information and child information forms.

### *Interviews*

As required by the semi-structured interview technique, interview questions were prepared with the aim of obtaining as much detailed data as possible from the participants to address the research questions. Five expert opinions from experts in the fields of qualitative research and individuals with ASD were obtained for the structured questions, and necessary corrections were made based on the suggestions of the experts. These corrections were made by writing and adding new questions, combining some questions, and so on. Two pilot interviews were then conducted to determine the comprehensibility of the questions. Pilot interview data were not included in the analysis of the study findings. The researcher described the aim of the study for the participants before the interviews and emphasized the importance of the participants' explaining their views and thoughts without hesitation. The researcher and participants signed the research participation agreement, which was prepared to confirm that the participants volunteered to participate in the study prior to the interviews. Furthermore, all participants were informed that the interviews would be recorded with a digital voice recorder to collect more reliable data, and that only one expert other than the researcher would be allowed to listen to the recordings or read the transcripts for reliability measurement. It was also expressed in writing and verbally that the participants could end the interviews if they felt uncomfortable or simply did not want to continue with the interviews. Furthermore, the participants were told that pseudonyms would be assigned for all participants, that these code names would be used for study purposes, and that the participants' real identities would be kept confidential. Interviews with the participants lasted an average of 47 min. The interviews were conducted between 20.02.2015 and 08.03.2015, in a quiet and adequate environment and wherever and whenever it was appropriate for the participants. A total of 466 minutes of voice recordings were collected and transcripts of these recordings were 234 pages.

**Table 1.** Demographical Information on Parents and Children

Family Number	Code Name	Age/ Age of Diagnosis	Educational Background	Occupation	Monthly Income	Number of Kids
01	Mehmet	44	Speciality in Medicine	Dermatologist	Above 2500\$	1
	Fusun	45	Speciality in Medicine	Rehabilitation and physical therapist		
	Cemil*	10/2	Mainstreamed student (Second Grade). Taking swimming, table tennis, and fitness classes in special sport club			
02	Zaim	48	Police Academy	Retired Police Officer	Above 1500\$	2
	Sibel	44	Elementary School	Housewife		
	Ahmet* Ceylan**	21/4 9	OÇEM graduate, continuing rehabilitation center. Fourth Grade student			
03	Kemal	44	M.SC.	Mechanical Engineer m.sc.	Above 2500\$	2
	Fatma	41	University Graduate	Chemistry Teacher		
	Cüneyt*	12/2,5	Mainstreaming student (Fifth Grade). Taking swimming, table tennis, and fitness classes in special sport club			
04	Nilgün	12	Seventh Grade Student		Above 2500\$	1
	Tarık	52	Ph.D.	Retired Academician		
	Şenay Nazlı*	48 12/3,5	Ph.D. Mainstreamed student (Fifth Grade); Taking table tennis and fitness classes in special sport club.	Professor		
05	İsmet	34	Elementary School	Mechanic	500-750\$	2
	İpek	31	High School	Housewife		
	Aras*	9/2,5	OÇEM student			
	Rüya**	5	Nursery Class student			

\*Child with ASD, \*\*Typically developing child

**Data Analysis**

In the process of data analysis, the stages of content analysis, namely description, classification, association, and interpretation (Patton, 2002), were implemented. The researcher utilized a computer program (*Microsoft Office Word*) both to organize and to analyze all data easily and rapidly as described in the literature (Creswell, 2007; Patton, 2002). In the form prepared using *Microsoft Office Word* software, descriptive data, descriptive index, and interviewer comments were described, classified, and interpreted using different text highlight colors.

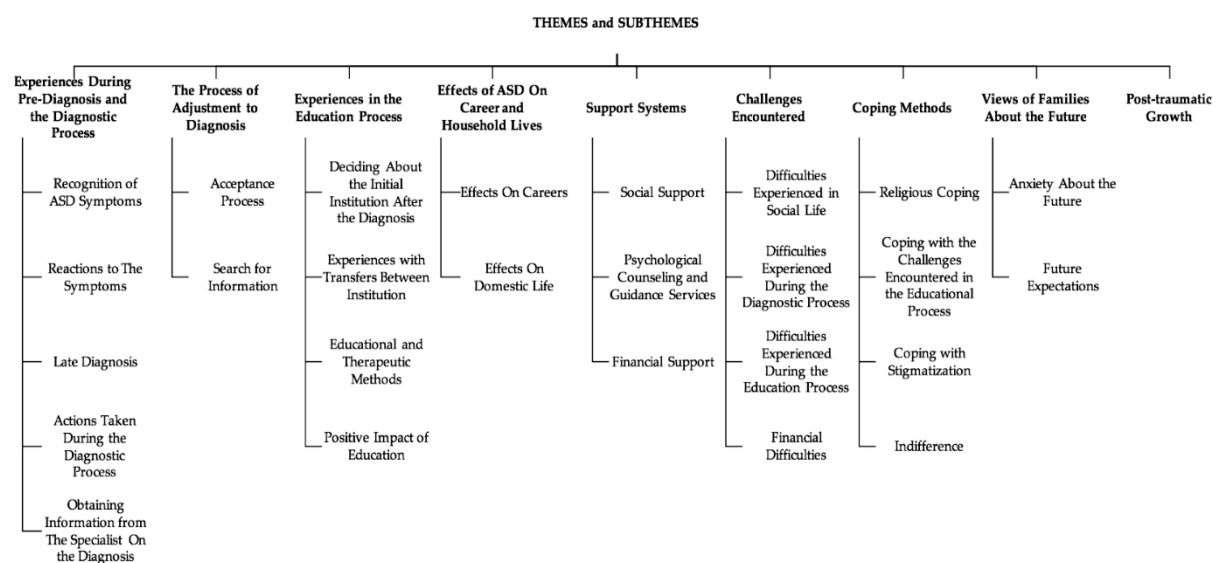
**Validity and Reliability**

The voice recordings of the preliminary interviews were 466 minutes in total. Reliability study was conducted with three interviews which were randomly selected from the first, middle and last sections according to the order in which the interviews were conducted. The three selected voice recordings consist of a 139-minute record corresponding to 30% of the total voice record. The accuracy of the papers prepared by researcher was checked by the voluntary expert by listening to voice recordings.

In the reliability study conducted A special education specialist experienced in qualitative research was employed to conduct reliability checks during the coding phase and a doctorate candidate in the field of special education was employed to conduct reliability checks on the themes and subthemes. The theme and subtheme file that was created before the reliability study was conducted was delivered to the specialist. After the expert worked on this file, the expert met with researcher to review, discuss, and reach agreement on the themes and subthemes. There was no change in the number of themes at this stage.

**Results**

In this section, nine themes and subthemes for each theme, which were the findings of the present study and obtained from the answers given to interview questions by the parents are discussed. These themes and subthemes are presented in Figure 3. In order to facilitate comprehension of the presentation of the findings, only the subthemes are specified in the text, and although the sub-theme content is included in the tables, they are not indicated in the text by titles and explanations. In the writing of findings, another practice for facilitating intelligibility is to use direct quotations during the writing of sub-themes for data which is occasional in the literature and has high-frequency while other data is shared only in terms of frequency.

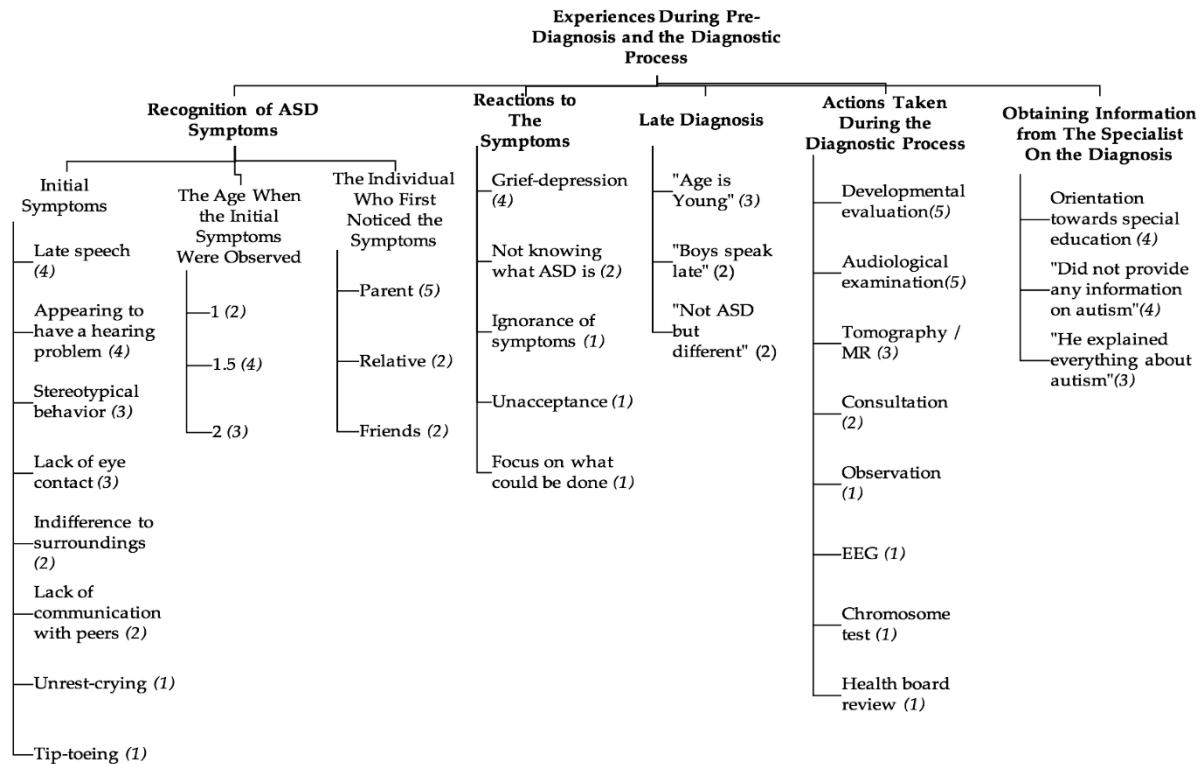


**Figure 3.** Themes and Subthemes



**Experiences During Pre-Diagnosis and the Diagnostic Process**

All the interviewed parents (Mehmet, Füsün, İpek, İsmet, Kemal, Fatma, Zaim, Sibel, Tarık, and Şenay) discussed their experiences before and during the diagnosis process. In Figure 4, the views of the parents, themes, subthemes, and the contents of the subthemes are presented together with frequency distributions demonstrating how many parents indicated each item. The symptoms which the parents observed in their children with ASD were delayed speech, appearance of hearing disability, stereotypic movements, no eye contact, indifference to the environment, inability to establish peer interaction, restlessness/crying, and walking on the balls of the feet. It often appears that frequently parents, and not-so-frequently relatives or friends, identify these symptoms when the children are between the ages of 1 and 2.



**Figure 4.** Experiences During Pre-Diagnosis and Diagnostic Processes

When the parents noticed their children’s symptoms, they stated that they exhibited different reactions such as sadness-depression, ignorance about ASD, denial and unacceptance of the diagnosis, and, at last, focusing on what could be done.

Certain parents (Mehmet, Şenay, Tarık, Kemal, and Fatma) reported that the specialists they consulted avoided a diagnosis claiming, “she/he is still young,” “boys usually start speaking later,” or “she/he does not have ASD but she/he is different,” which resulted in a delayed diagnosis. The procedures performed during the ASD diagnosis of children were identified as developmental evaluation, audiological examination, tomography/MRI, consultation, observation, EEG, chromosome test, and health board evaluation. Participants’ opinions on the information they have received about the ASD after being diagnosed with ASD can be classified as directing to special training, not giving any information about ASD, and telling everything about ASD. Below, direct citations on subthemes and the views of the participants are presented.

### *Recognition of ASD Symptoms*

Fatma said that her son did not respond when he was called by his name, but to the sounds that appealed to him: "... when he did not react to his name, we thought maybe there is a problem with his ear, but we were sitting in the living room for example, and the kitchen TV is on, and when he hears the commercial jingle that he loves and starts running to the kitchen, then we thought maybe there is nothing wrong with his ear..." Zaim explained that their child did not respond to calls of his name: "... I was calling him out, but he was not responding to his name...." Sibel said, "He would not look at me when I called his name." Kemal described his son's compulsive behavior: "He had a toy car; he would roll its wheel and look at it for a long time." Şenay said, "... began to wave her hand towards the age of 2, looked at the wall and started to make such stereotypical movements." İpek said that her friends first realized the difference in her child and said, "I had gone to visit a friend. My friends there noticed that my child did not make contact with the other children" and her husband, İsmet, confirmed: "Later on, they told this to İpek when she visited her friends. That there was something wrong with this kid.

### *Reactions to The Symptoms*

Mehmet explained his feelings in the face of his son's different behavior: "Of course it was a bad feeling;" "you experience a big thing, in general, meaning that you feel depressed." Zaim described his experiences about different characteristics of his son's behavior as follows: "We were not able to recognize it; we were young then. We were not affected much." Şenay explained how she focused more on what she could do against the irregular behavior of her daughter instead of a particular diagnosis: "...maybe we are a little weird, but we did not experience much trouble with her. I always think that we have dough in our hands and it is us who will shape it. So I figured it was not important if she was whole-wheat dough or not."

### *Late Diagnosis*

Şenay said that the diagnosis was delayed because of the young age of her daughter and she explained her thoughts on the issue as follows: "... [the physician] told us that she was too small for a diagnosis." "So, the doctors are still ignorant. And they still let time pass by without a diagnosis. Thus, the diagnosis is not important. I think, for example, as soon as these behaviors are observed ... training should be commenced immediately. Thus, the diagnosis is not important." Kemal narrated the doctor's explanation on the late speech of his son and his thoughts on the issue as follows:

*"We were taking him to pediatricians. We waited for them to say something, but they always told us that this is boy and a boy can develop this skill later than a girl. I told the doctors that it was autism and I said odds were higher in boys. Thus, I said that I read 12 articles, seven-eight of these fit my son. So 2 years and 3 months passed without a diagnosis."*

### *Actions Taken During the Diagnostic Process*

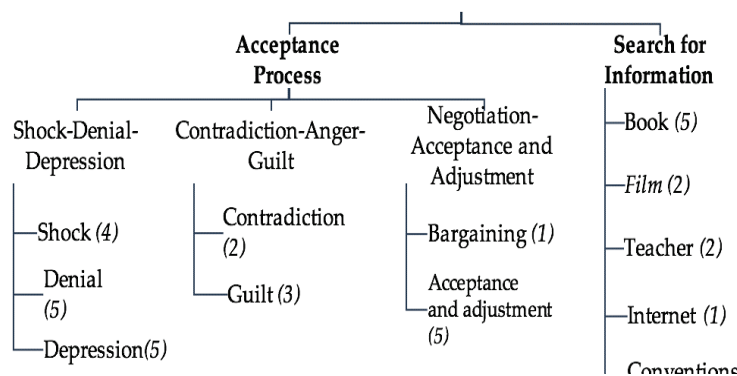
Zaim said the following about the actions conducted during the diagnosis process: "We suspected the ear ...", "... he took the audio test." Kemal said, "He was under, then he had brain tomography." Sibel said, "... MR results were clean and everything was normal ..." and İsmet stated the following: "went through the tomography." Şenay and her husband, Tarık, stated that they went to a university hospital in America for consultation based on a child psychiatrist's recommendation due to their daughter's different behavioral patterns. Şenay explained this process as follows: "At that time there was a friend of my doctor, a Turkish Cypriot doctor. She was at Harvard. Our doctor said that the diagnosis was atypical autism but said it would be perfect if we could take the child to the US for a second opinion. To see whether the child was typically autistic or not. We went with the recommendation..." She also stated that a chromosome test was conducted at the suggestion of a child psychiatrist they consulted during the diagnostic process: "Doctor even asked for further tests. One was a chromosome test ... 13<sup>th</sup> chromosome or 11<sup>th</sup> chromosome, something like that ... The results were good, so the doctor said it is ok, the child can learn."

*Obtaining Information from the Specialists On the Diagnosis*

Zaim said that the specialist who diagnosed his son explained the significance of training in ASD as follows: "We had a child with a disability and we were told that if we educate him enough to get by in his life, we would raise a child who would be able to protect himself and live in the society." Mehmet stated that the doctor who diagnosed ASD did not provide any information about the disorder and since medical knowledge on ASD is already limited, Mehmet thought that he should ask for information from special education specialists rather than physicians: "... child psychiatrists do not provide information. And there is not much information to provide, anyhow; that is the problem. I am a physician, an attending physician; I am fluent in English, I can read the related articles, too. There is no definitive knowledge that the physician could pass to me. The only people who could provide information are special educators."

**The Process of Adjustment to Diagnosis**

All the parents (Zaim, Sibel, Mehmet, Ismet, Senay, Tarık, Fusun, Kemal, Ipek, and Fatma) provided views on their experiences in the process of adjustment to their children’s diagnoses. The views of the parents are presented in Figure 5 including frequency distributions showing the number of parents who expressed views on each theme, subtheme, and subtheme content. Figure 5 shows that parents experienced emotions such as shock, denial, and depression in the process of acceptance of their children’s disabilities, and until they adapted to those disabilities they felt emotions such as contradiction, guilt, and bargaining. Furthermore, the resources that parents used to get information about ASD were books, movies, teachers, internet, and conventions. Direct quotations on the subthemes and the views of the participants are presented below.



**Figure 5.** The Process of Adjustment to the Diagnosis

*Acceptance Process*

Sibel explained the feelings of shock they experienced after the diagnosis in the following statements:

*“Err, the doctor diagnosed him. We went out, took a shared taxi, and got off on the other side where the police station is; it an avenue, and we were a little hazy. The cars were passing by, we were not aware; a car made a sudden brake; the car almost ran us over, a disaster. A lady in front of the police station yelled at us so badly, saying, ‘If you do not feel sorry for yourself, feel sorry for the kid, what are you doing?’”*

Füsun said that she could not accept that the condition was for life and she had perceived it as a temporary situation when she first heard the diagnosis: "We could not accept it at first, as if it was a temporary situation, as if it would not last a lifetime but would go away after a period of time, and my child would get well. At first, you cannot accept it."

Şenay said that her husband Tarik blamed her for their daughter's ASD:

*"In the diagnosis process, the problem is not the child, but from whom she got the disability. The diagnostic process is the time when her father and I blamed each other. Even though there was no diagnosis yet, there was an oddity." "In fairness, I have epilepsy. Tarik put a lot of pressure on me because I have epilepsy. You have epilepsy, that is why your child is like that. This is a brain disorder, and it's a brain disorder as well. It was something like: this would not have happened if you did not have epilepsy. Thank God, I am not a person who caves in easily. If I have epilepsy, so I do, what does it have to do with our daughter? In fact, it runs in your family, your mother looks like she has autism, I said. So, a blame game happened. After that, I really tried to find out if it was related to epilepsy. ... when I asked the doctor, the doctor said to me that the risk of a normal person having epilepsy is the same as the risk of an individual with autism having epilepsy, as a child born from an epileptic mother. So, it could not be said that the child has autism because of that; there is no such thing right now, the doctor said. Then we relaxed."*

Füsun explained that when she was pregnant with her son Cemil, she had an inflammatory disease, and felt guilty for causing her child to have ASD:

*"Now, I got sick with fever when I was 4 months pregnant. I sat on the balcony; we had just returned from abroad, it was cold outside and I sat outside in my clothes ... that evening I fell very ill, on the evening of the next day I came from the hospital and did not call the professor. I got a painkiller. ... I had high fever all day. I do not know if the fever caused the child to become like that." "Maybe if I did not have that fever... I went to Prague; maybe if I did not go abroad, but it is over now. There are a lot of autistic children, so I do not know everyone is guilty."*

#### *Search for Information*

Kemal said that after his son was diagnosed with ASD he started to read books about ASD to get more information about the disorder: *"I started to read things, I mean articles on ASD,"* while Sibel said she tried to obtain information from the teachers: *"... I was asking his teachers, what are you doing and how does it go and what can we do?"*

#### **Experiences in the Education Process**

All participating parents (Zaim, Sibel, Mehmet, Ismet, Şenay, Tarik, Füsun, Kemal, İpek and Fatma) provided their views on the experiences in the education process of their children. The views of the parents are presented in Figure 6 including the frequency distributions showing the number of parents that expressed views on each theme, sub-theme, and sub-theme content. When Figure 6 is examined, it could be observed that after the ASD diagnosis, the parents decided about the institution that their children would attend for education based on psychiatrist referral, psychologist referral, friend suggestion or information they have obtained in the conventions they have attended. Parents' reasons for the switch between educational institutions are listed as being not satisfied with the quality of education, being exposed to discrimination, experiencing problems with institution administrators, graduating from school, turning to socialization processes, seeking understanding teachers, not registering desired program and changing institution with the recommendation of a friend. Educational and therapy methods that parents use for their children with ASD are mentioned as PECS, language speech therapy, ABA-PCDI, music therapy, dolphin therapy, work and occupation therapy, sensory integration and drama therapy. Alternative and supportive therapy methods used by the parents were herbal cures, metal treatment and sports. Parents stated that their children have benefited from education and therapies. Parents indicated that the benefits of education and therapies had benefits for their children such as increased adaptation to social life, acquisition of daily life and self-care skills, readiness for education, calming down, learning to read and write, starting to respond to instructions, increasing eye contact, increase in vocabulary, reduction in problem behavior and increasing the speed of conceptual development. It has also been demonstrated that education and therapy methods benefited the parents in learning behavior control. Below, direct quotes and views of the participants on sub-themes are presented.

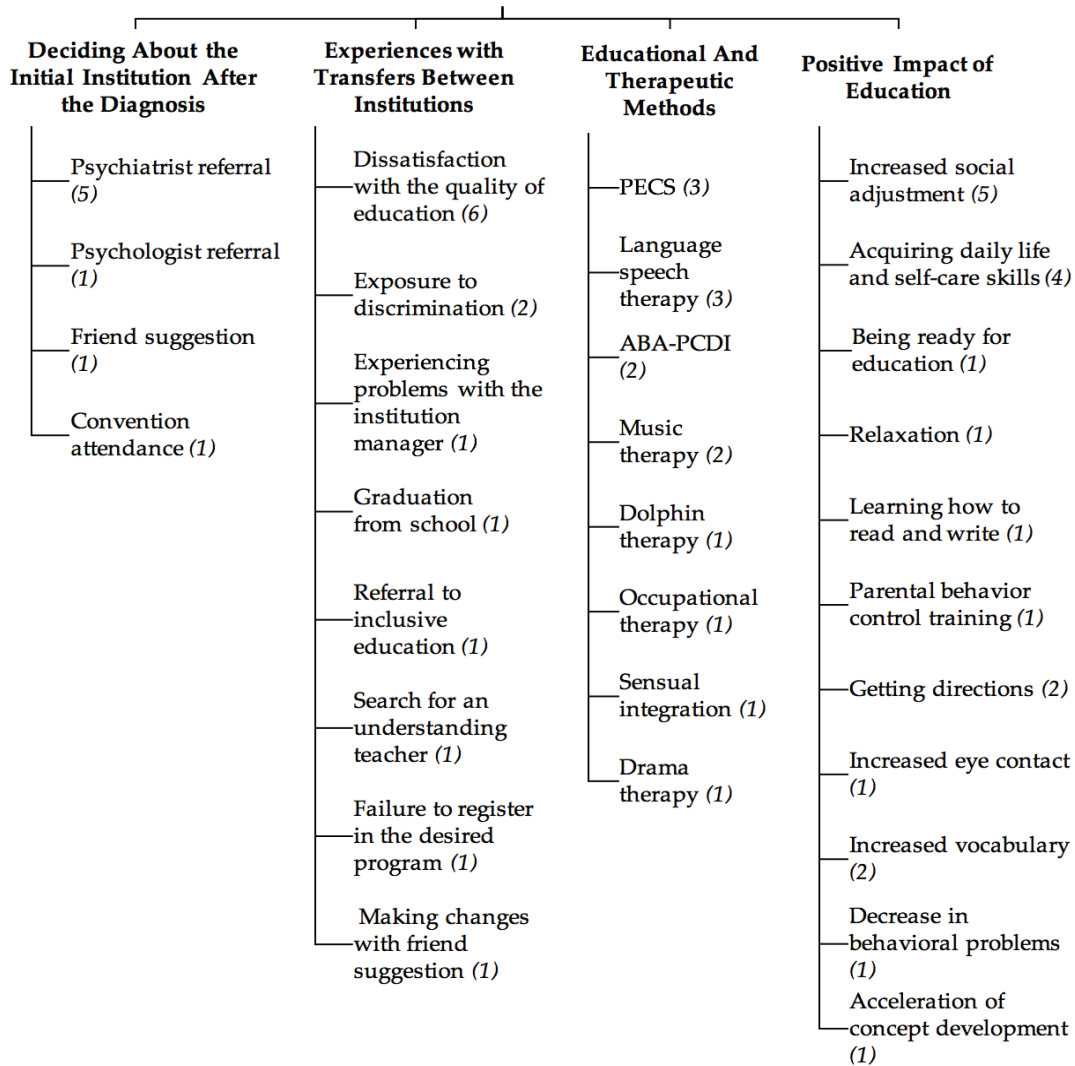
*Deciding About the Initial Institution After the Diagnosis*

Şenay said that her son's psychiatrist referred them to an instructor and they started to get training from that person in the process of deciding on their daughter's education: "We must have been very fortunate in that regard. Our psychiatrist gave us a direct name, and we followed." Ipek said that after the diagnosis, they decided on the institution that her son would attend as a result of references that her friends provided: "I was informed by my sister's friends. They provided references. There are rehabilitation centers, where education is provided for such children and the children reach a good level."

Mehmet stated that he decided on the institution his son would attend and what kind of education his son should receive as a result of the information he received at a conference he attended:

"There were professors from Harvard, and after that I went to the thing and registered, I attended the conference ... I attended certain ABA programs, the courses, and listened to each one of the presentations and talked personally with the Harvard professors. I decided on what to do with my child right there and then, my child must receive ABA during the first 3-4 years, and receive applied behavioral analysis and then one can diversify ... we received ABA at the Behavioral Education Program for Children with Autism (OCIDEP) for 4 years."

**Experiences in the Education Process**



**Figure 6.** Experiences of the Participants in the Education Process

*Experiences with Transfers Between Institutions*

İsmet also explained that his son did not exhibit any progress in the educational environment that he attended, so they enrolled him in the Educational Center for Children with ASD (ECCA): *"Then, we were taking him to the school for 2 days a week, he was instructed for 45 minutes in rehabilitation. He attended these classes for 3 years, 3 to 4 years. We have not observed any improvement. Then, we applied for ECCA."* Füsün stated that, unlike İsmet, she was not satisfied with the education her son Cemil received at the ECCA and that they applied to the special education center where he now studies:

*"He attended ECCA as well, ECCA is very bad ... a teacher for four to five children. No one cares there, he was left hungry until 2:30. The current institution, Mehmet had already heard about. We said let us try it for 6 months. Then my mom and dad stayed with Cemil for a year. We came here a year after because we were reappointed."*

*Educational and Therapeutic Methods*

Mehmet spoke about his son's PECS education: *"They said he could talk if they applied PECS, but he achieved two steps in PECS, but we could not pass to the third step."* Mehmet said, *"ABA was applied,"* while Kemal said, *"But I observed that in the special education center that we attend, I came to the conclusion that the autistic children should not receive one-on-one instruction under 40 hours per week intensively; I thought it was necessary for success, there should be 40 hours of instruction."*

*Positive Impact of Education*

Zaim argued the following about the positive effects of the education his son received:

*"I can describe it with a single sentence, in fact there is nothing much to tell about it, it would tell everything, we have turned a child who could be kept in a closed place with a chain into an individual who could at least adapt to the society."*

Kemal said, *"... then, he started to play a little with his classmates, he ran with them in the breaks, he wanted to go to school to be with his friends when he did not go to the school. Cüneyt keeps a distance from his friends still, but he is not happy when they are not around"* and stated that his son became a more social child after the training he received. Using the following words, Ipek expressed the fact that her son adapted better to the society thanks to the education he received:

*"Positive; for example, we can go out. I relaxed, for example, as I said, we can go to the market comfortably, we can visit our friends, we can go out ..." "we can even go shopping now."*  
*"...socially, it had many results."*

Mehmet explained that his son had acquired various daily life and self-care skills: *"Adapted to daily life, brushes his teeth, folds his clothes and puts them in the wardrobe, puts on his clothes, washes his face ... he went to the bathroom, he told us he needs to go to the bathroom, he pooped, took a leak."* Tarık stated that his daughter, Nazlı, received music therapy when she displayed problem behavior and music therapy was a calming application for her: *"... We took on music therapy every time she was grumpy. We calmed her down with music. And indeed it worked."*

### *Effects of ASD On Career and Household Lives*

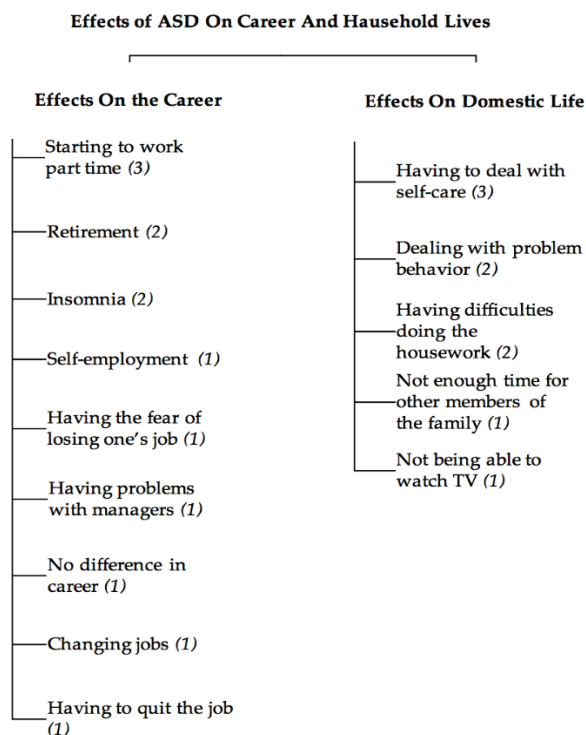
Interviewed parents (Mehmet, Füsün, İpek, İsmet, Kemal, Fatma, Zaim, Sibel, Tarık, and Şenay) expressed the effects of their children's diagnoses with ASD on their household and work experiences in different ways. The views of the parents are presented in Figure 7 including the frequency distributions showing the number of parents who expressed views on each theme, subtheme, and subtheme content.

In Figure 7, the conditions experienced by parents of children with ASD due to this disorder are listed as follows: starting a part-time job, retiring, starting their own business, experiencing the fear of losing their jobs, having problems with their managers, changing jobs, having to quit their jobs, and experiencing no changes in their career. Parents stated that they experienced problems at home such as having to deal with self-care, dealing with problem behavior, having difficulty in doing their household chores, not being able to spend time with other members of the family, and not being able to watch TV. Parents stated that having children with ASD also affected their typically developing children and they defined the effects of having children with ASD on the typically developing siblings as follows: feeling of staying in the background, acting protective toward the sibling with ASD, acting more mature than his age, and rejection of the sibling when he was with friends. Below, direct citations on the subthemes and the views of the participants are presented.

#### *Effects On the Career*

Zaim expressed the following on his experiences in his career due to his son's autism:

*"After I retired, I started working somewhere else, but it did not work. I went to work at 8 am and came back at 8 pm. But the kid ... we are of no help. Thus, we left our concerns for money or career behind ... I work as a driver at a bakery. Just to be near the home."*



**Figure 7.** Parents' Experiences in Their Careers and Domestic Lives Due to ASD

Şenay stated that she could not continue to work full time due to the chores such as taking her daughter to training after the ASD diagnosis and that her manager allowed her to work part time with full-time salary to let her spend time with her child:

*"After the diagnosis, a very difficult period began. Then we had to take her to therapy at least every other day. We had no car, we had nothing; you know Istanbul, it takes hours to go from one side to the other. So, I talked to the dean; I said, 'What would I do?' I never could forget what he told me; he said you would do whatever you should do for your child. And he assigned his own car with the driver to me. They paid me full time but let me work part time. "*

Kemal said he feared that if he lost his job after his son was diagnosed with ASD, his son's daily life would be disturbed and that he might not attend his education and could experience various problems away from the educational environment. For this reason, he explained that he was afraid of losing his job and that he began to concentrate on his job more to overcome this fear:

*"Of course, since our child was autistic, we worked in a private company and we have to be successful to stay standing in a private company ... why am I always trying to improve myself? To hold on ... I mean, if we lose our jobs, we are afraid that we would go back to the baseline when the life of our children would be disturbed. We had one thing in our mind: we found a setting with knowledge on autism, even if it was very difficult. We wanted to stay connected to this environment, and we strived to be positive for continuous success ... 3 or 4 years we had these concerns. The process suffocated me. Sometimes Turkey experiences crises. I was experiencing stress. What would happen?"*

#### *Effects on Domestic Life*

Mehmet explained that his son was not potty trained and wet himself, and thus, they had to replace his diapers or clean him up too often: *"... I was examining 100 patients a day, coming home in the evening. Cemil wets himself and you have to clean it. You take him to take a bath, and then he poops again. I remember him pooping three times in an evening. These were troublesome times."* İsmet stated that his wife Füsün showed more interest in their child with ASD and, as a result, he and his daughter experienced various problems:

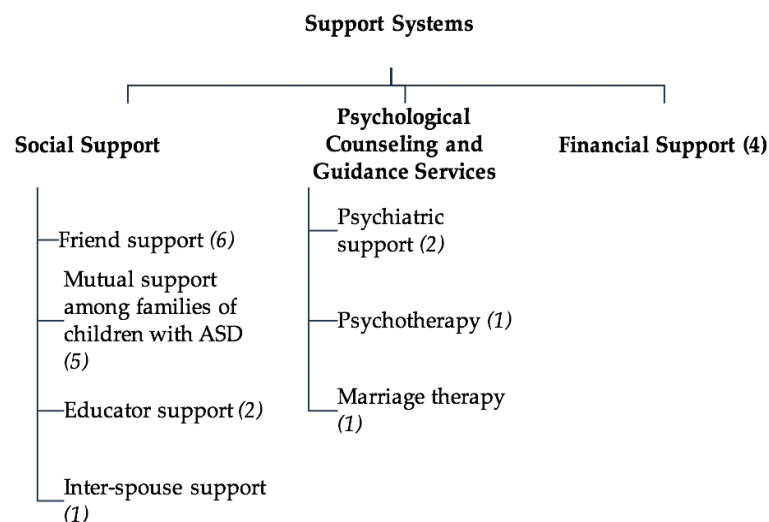
*"Now, when you focus on this child, then the house becomes that, after we had our daughter, since she did a lot to Aras, then I ended up raising our daughter. She is like 12; I prepare her breakfast in the morning, dress her for school, comb her hair, I do not know, get her ready and drive her to school, pick up at 4:00. So, if you do not, the girl would be lost, she would not be able to attend the school, there is nothing to do, properly, so one has to do these chores. Then she complains that her mom would not take care of her, she remonstrates."*

While Zaim stated *"Semihâ understands. It changes from child to child, she is understanding. She protects his brother. She has such an attitude; her older brother is under her hegemony. She gets anything she wants done. She teaches, she applies what she sees from special trainers."* Mr Kemal stated that her daughter did not want her brother Cüneyt to come to the side of his friends after adolescence period and explained it as *"She does not want Cüneyt next to her friends. For example, an event was held today in the school, I said, I will bring Cüneyt, she said do not bring him."*

#### **Support Systems**

Nine interviewed parents (Mehmet, Füsün, İpek, Kemal, Fatma, Zaim, Sibel, Tarık, and Şenay) expressed their experience on support systems they utilized in various ways. The views of the parents are presented in Figure 8 including the frequency distributions showing the number of parents who expressed views on each theme, subtheme, and subtheme content. Figure 8 show that the sources of social support for parents were friends, parents of other children with ASD, educators, and spouses. Psychological support, psychotherapy, and marriage therapy were identified as guidance and counseling services that the parents utilized. Furthermore, some participants also expressed that they had received financial support. Below, direct quotes on the subthemes and the views of the participants are presented.





**Figure 8.** Support Systems

#### *Social Support*

Zaim indicated that a friend of his who understood the difficulties they were experiencing supported him by giving him a job, saying, "There are people who understand it very well. For example, the owner of the place where I work ... my friend is from my neighborhood. He said one day, 'you need to work, I know.' He said, 'come work with me, it is not far from your home, so you can take care of your child easily.'

Fatma, as well as her husband Kemal, also explained that her neighbors were not disturbed by the noise that Cüneyt made:

*"Our neighbors were very understanding; they did not complain about any mishap that Cüneyt might have caused ... Cüneyt sometimes woke up and wept in the evenings ... When we were moving from that house, the neighbors said if we were moving on their account, they would never give us their blessings, and they said, 'We love Cüneyt so much. We are never disturbed by him in any way.'*

Sibel explained how families with children with ASD supported each other: "Then he started his education, and there were always the mothers of children with autism there, a few years older than Ahmet. We asked a lot of questions all the time; we asked many questions." To overcome the stress due to the fact that his son had ASD, Kemal talked with the parents of children with ASD: "Getting rid of that stress ... That is how it happened; I have spoken to people who are living with children with autism above a certain age. It was kind of self-therapy. What did they do? How did they manage?" Tarik stated that, over time, he and his wife started guiding individuals whose children had been recently diagnosed with ASD: "...Şenay, those who have been diagnosed with autism or in the process of diagnosis, for these families we provide guidance ... you will pass through such and such stages ... apply to this physician. Consult that educator. That is what we did ..." Parallel to Sibel, Şenay said that her daughter talked about her problems to her teacher and her teacher supported her: "For example, she said she would refer us to an in-house sister; that helped a lot ... the in-house sister came 5 days a week. She was great, for my psychological condition, someone to support me ... She sat down, and I talked to her ... Sometimes she cried with me, sometimes she was happy when I was."

#### *Psychological Counseling and Guidance Services*

Sibel went to a psychiatrist to cope with the difficulties she faced, but she said her medications made her sleepy so she quit the treatment: "I received it but I quit since they prescribed medicine. Because I was sleepy." Şenay said that she had problems with her husband due to her child with ASD and she received marriage therapy to solve these problems: "We applied for marriage therapy, but she was a well-appointed woman. She managed well. For example, Tarik does not do anything like that, and he calls psychologists charlatans. He came and listened to what she said and finally implemented all."

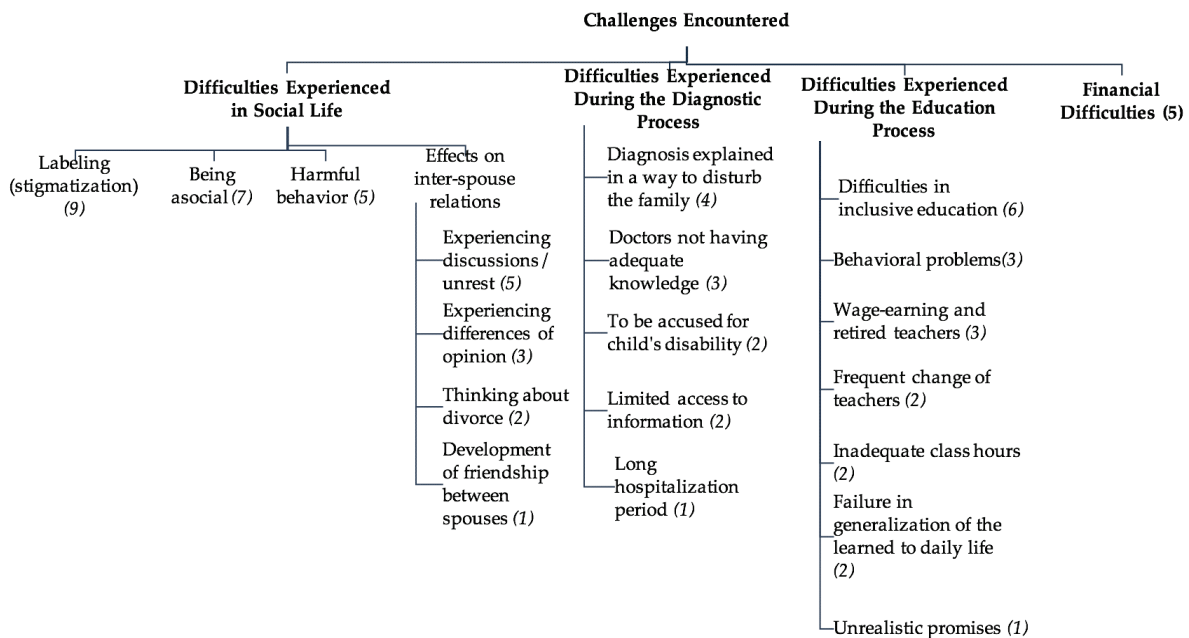
### Financial Support

Ipek said that the amount of the care stipend that the government pays for individuals with disabilities paid for the needs of both her son with ASD and her typically developing daughter: "The positive effect is, to tell the truth, on the financial side. At least he takes care of his own needs. He could also pay for his sister. Yes, it is the money for care." Şenay, on the other hand, indicated that her sister helped with her daughter's education and therapy expenses related to ASD: "That is what happened. My sister started to help Nazlı, with the therapies."

### Challenges Encountered

All the participants (Mehmet, Füsün, İpek, İsmet, Kemal, Fatma, Zaim, Sibel, Tarık, and Şenay) expressed their views on the difficulties they faced due to ASD. The views of the parents are presented in Figure 9 including the frequency distributions showing the number of parents who expressed views on each theme, subtheme, and subtheme content. Figure 9 shows that the difficulties parents encountered in their social lives were labeling, problems in social relations, dealing with harmful behavior, and effects on spousal relationships.

The difficulties encountered in spousal relationships were identified as having discussions/anxiousness, differences of opinion, planning to end their marriage, and developing friendship among spouses. Parents were found to experience problems during the diagnostic process such as information about the diagnosis given to the family in a disturbing manner, lack of adequate information shared by the physician, being blamed for the child's disability, limited access to information, and long hospital stays. The difficulties encountered by the parents during their children's educational process were classified as follows: difficulties experienced in inclusive education, behavior problems, retired and wage-earning teachers, frequent change of teachers, inadequate teaching hours, inability to generalize the learned knowledge to daily life, and unrealistic promises. Furthermore, half of the parents who participated in the study stated that they experienced financial difficulties. Below, direct quotes on the subthemes and the views of the participants are presented.



**Figure 9.** Challenges Encountered

*Difficulties Experienced in Social Life*

Zaim talked about the difficulties he experienced in social life as follows:

*"How should I say, there are some movements that autistic children exhibit, waving hands, shouting, mobility, jumping, and so on, when they exhibit these behaviors outside, people cannot understand what is wrong with them. They look at them not as if they were disabled, but as if they were aliens from space. Well, so, we are uncomfortable as a family; when you are uncomfortable, you stop taking the individual with disability out, you get embarrassed; this is not nice stuff... these individuals are handicapped, not aliens; our people need to be a little more aware."*

Zaim explained that he got angry at labeling (stigmatizing) attitudes that he had encountered and sometimes he could exhibit aggressive behavior due to such behavior by individuals:

*"When I consider it, the things that I have been through ... I pulled the guy out of the subway, sometimes I feel like killing such people. I feel like cursing them, but I cannot, because life for a disabled child, living is very difficult for a disabled child, so I cannot curse anyone. When I do, I do not want their child to be like my son, so we either hold it back or engage in aggressive behavior."*

Sibel described the labeling (stigmatization) attitude she encountered in the apartment where she lives:

*Then at a certain time ... in the government housing ... that is a different story, a family was planning a birthday party for their daughter. They are all my age, with kids at Ahmet's age. There were 16 flats ... they invited everybody, only me and there was another kid who was not well, they did not invite that kid and Ahmet only. I heard about it later and I was upset. Maybe we would not have gone anyway, but we were excluded nonetheless because we were not well.*

Şenay said that her spouse's parents did not understand the situation with their children and displayed labeling attitudes toward them and their daughter:

*His grandmother and grandfather never did anything for Nazlı until, I do not know, until last year or something like that. For a very long time, Nazlı was not considered a grandchild. We even went to visit his relatives once. They asked what was wrong with Nazlı; her grandfather said she was defective. That was his perspective ... considers Nazlı as someone who makes us spend our money. And he says 'It is a pity to invest in her, do not invest in her; instead, renovate the kitchen, the bathroom in your house, renew your car, etc., do things like that. Why are you dealing with this?'*

Tarık stated that a colleague told him, 'Thank God, my child does not have it.' Fatma expressed that she went to a government organization to resolve the issue that her son was not admitted to school and was told the following: "And her own branch is PDR. He said nothing would come out of this child; he said, 'Take him and register at...' He said, 'Why you are fighting for him?' I was petrified.

Şenay explained how she thought about divorcing her husband, Tarık:

*That is how it happened. Now, of course, problems began to arise between us all of a sudden. At that time, my mother was alive and staying with us. Of course, she also had certain needs. There it was, Nazlı was young and with problems and my mom was old. There was nobody to help, there was a lady who came to help me in the daytime, but there was nobody who could support me psychologically. At that time, we started to have problems with Tarık. He was also cranky; he was acting like I was responsible for all these problems. Then I took him to court for a divorce and said, 'I want to get rid of you now. I can either take care of Nazlı or you; since I cannot get rid of her, I've decided to kick you out.' Then, we received psychological support. And of course, the problem came out to be not about our marriage, but about the situation we were experiencing.*

*Difficulties Experienced During the Diagnostic Process*

Tarık expressed his thoughts on the statements that the child psychiatrist used while explaining the fact that their daughter had ASD:

*... lady is a very good physician. But she does not understand much about family psychology. She automatically tells it all. Your daughter is autistic. Then she even told my wife that she should quit her job and she should devote herself to Nazlı ... 'There is nothing you could do. She is with autism, you quit your job and then take care of her training. This disease has no chance of recovery. She will always be autistic.'*

Füsün also stated that the doctor who diagnosed their child with ASD explained the situation with rather crude expressions:

*Now, back then, the doctor was never interested, even asked us to seat our child, Cemil, next to us because he could harm the plasma TV. Mehmet had a sister, Aylin, and she also came with us, and she asked if he would be fine. The doctor said he would be fine. Aylin asked, 'Is he always going to be like this?' The doctor replied, 'Is he always going to be like this?' I mean, by repeating, the doctor was trying to explain echolalia to me. The doctor said, 'what if he speaks? Even if he talked, he would speak like that.' Then she would not deal with the child even for 10 minutes. He asked if this had been done, if that had been done, if chelation therapy was conducted, you know. No, it has not. He said it is too late now. He said the metals, heavy metals have settled in, there is nothing that can be done. Finally, when I asked what would happen, he said, 'Have you ever seen a carcass on the street?' just as we were leaving ... We were in shock.*

Zaim stated that psychiatrists do not have much to do as doctors and that, first of all, consultation with an education specialist might be better:

*Of course, there is a lack of experts and information flow. But when the developmental stages of the event are considered, I mean, I am a physician as well; when I consider the medical perspective, a child psychiatrist is the last resort. I mean, it would be fine if you never consult a child psychiatrist. Because, they have a name but there is not much they can do about autism, so maybe they can be consulted once for a diagnosis ... sometimes when my friends say, 'your child is like that, what can we do,' I never suggest, then, to take the child to a child psychologist or child psychiatrist. I tell them to first consult a special educator and receive a performance assessment..."*

*Difficulties Experienced During the Education Process*

Fatma narrated an incident they experienced with her son's teacher related to the problems they experienced in the inclusive education process:

*The first day in the adaptation process, the teacher brought Cüneyt to me, holding his arm, said, 'He is like this and that and he did like that using his hand, bla bla bla... he talks nonsense, disturbing children; other children said, 'What will happen?' I said, 'Dear teacher, Cüneyt is an autistic child.' I said, 'He is a special child; if Cüneyt could speak he would not talk nonsense,' I said.*

Similar to Kemal and Fatma, Şenay also stated that she had difficulty in finding a school that would admit her child and she had to lower her expectations from inclusive education to merely socialization:

*Inclusive education is a problem in itself. We could never have our child 'included.' As much as we aimed for inclusion, inclusive education became ... we had to tell everyone one by one that our aim was socialization. We said, 'We do not want him to learn anything but just to socialize.' As a teacher, I am very sorry to have said that, but I had to, to make them admit my child.*

İpek stated that her son was in the class of wage-earner teachers all the time in the school where she was educated:

*We never came across the special teacher of this department. We always came across the thing, wage-earner teacher. I was always unlucky with teachers ... the teacher does not have a feeling for my child in the class ... Aras does not like when someone speaks loud; for example he cries, gets out; I bring him back very calm and happy after the break. But once he is in the class, the same problem happens. I could not solve this with the teachers.*

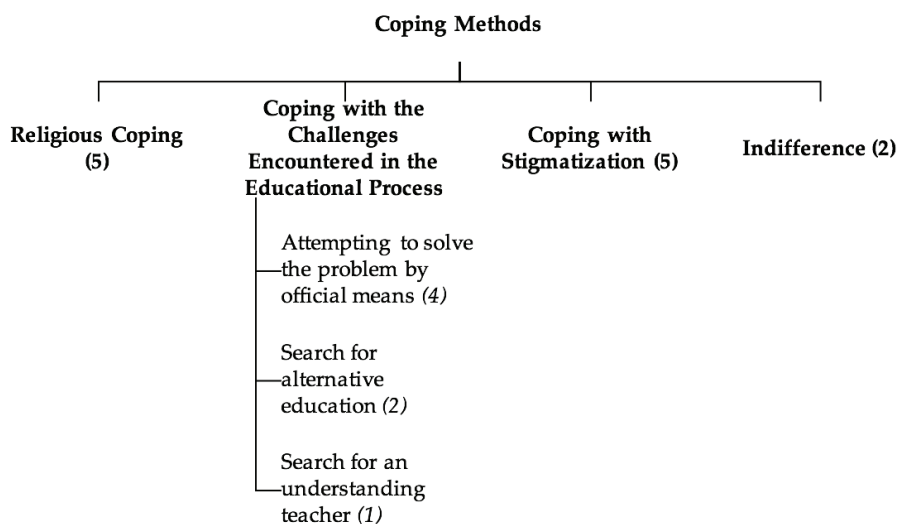
Fatma stated that the number of classes her son took was insufficient: *Two hours a week, nothing, maybe that was the reason for the little progress he showed, or maybe that was why I perceived that there was no progress; 2 hours a week.* Kemal said that he observed the teacher utilizing inappropriate methods in most classes: *He takes Cüneyt on a trampoline; he lets him bounce, gives him a tambourine to play. I am a mechanic, but I have no doubt that this has nothing to do with special education.*

#### *Financial Difficulties*

Şenay stated that education was very costly and that the doctors were very expensive as well: *I swear we had big financial problems in special education. Doctors also charge a lot of money. Your appointment lasts for 45 minutes, they just talk to you and just watch the child from a distance. I spent a lot of money and got nothing in return.*

#### *Coping Methods*

Eight parents (Zaim, Kemal, Şenay, İsmet, Tarık, Fatma, İpek, and Füsün) expressed their views on how children coped with the difficulties they faced due to ASD. The views of the parents are presented in Figure 10 including the frequency distributions showing the number of parents who expressed views on each theme, subtheme, and subtheme content. Figure 10 demonstrates that half of the parents used religious coping methods to deal with the challenges they encountered. It was determined that the methods parents used to cope with the problems they encountered in the education process included trying to solve problems with official means, seeking alternative education, and searching for an understanding teacher. It was also observed that half of the participating parents had to cope with stigmatizing experiences. It is understood that a small number of parents were unresponsive to the problems they faced. Direct quotes on the sub-themes and the views of the participants are presented below.



**Figure 10.** Coping Methods

*Religious Coping*

Kemal explained that he considered his son a reward since Allah granted disabled children to his beloved and astute subjects:

*... this ... a friend of mine told me. ... said, 'you are a very cherished person,' so I was dumbfounded. He was so happy when I told him Cüneyt had autism, so it seemed strange to me. He said, 'Allah grants such children to His beloved subjects.' Thus, he said, 'you are people that Allah loves.' He said that this is a reward given to you in this world. 'You have the capacity to endure such children, if you recognize this prize, if you spend efforts to preserve and raise this trust,' he said; 'These children, for sure, will end up in heaven. Then he said that his parents would be called to heaven when they go to heaven.*

Şenay stated that she believed that her daughter is entrustment of God and that she experienced many good things since they care for their child well:

*I think it is because of Nazlı, I think that Nazlı is a trust; I believe that Allah is also favoring us as long as we take good care of His trust. I mean, good things are coming our way. Good people are coming our way ... There are always some people who make our life easier.*

*Coping with the Challenges Encountered in the Educational Process*

Tarık expressed the fact that they were not satisfied with the quality of inclusive education in Turkey. He said that he and his wife tried to adapt an inclusive program that was being implemented in America to Turkey with his wife and he described the difficulties they faced in the process:

*Of course, now we've gotten used to most of it. We are familiar with the perception of society. Also, we know the education system in Turkey. I conducted projects in Turkey to bring a good STAR program to Turkey, which is great according to my views. For example, the state does not pay for it. Then, we continued to struggle with a number of issues. They are ready to implement the American STAR program in Turkey. Turkey does not spend any effort to accept. Financially. The state's attitude is if you want it, you need to pay for it.*

*Coping with Stigmatization*

Zaim stated that to prevent stigmatization of the society, they avoided public transportation and crowded settings: *To resolve this, we do not use public transportation. We use our own vehicle. We do not want to be in places where there are too many people. Because we are bothered, so what happens is that we automatically exclude ourselves from society.*

Şenay stated that she had to enroll her daughter, Nazlı, in a village school to avoid the labeling (stigmatization) they encountered in the schools to which they applied:

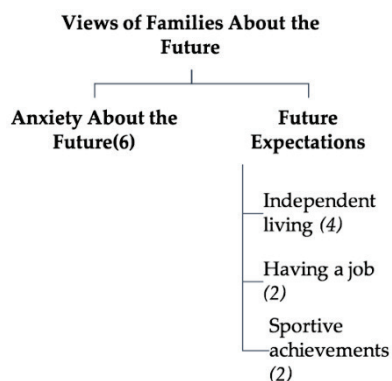
*Why the village? Because people on the periphery can accept individuals as humans. I mean, they do not discriminate. The village children have not made fun of her that much. She never had such a problem at school. I know because there is always someone who accompanies her to school. If there was an incident, we would have learned about it ... It's not like the big city people. Yes. For example, they do not say she cannot talk even if she cannot talk; they say, 'she talks but we cannot understand ...'*

*Indifference*

Zaim stated that he tried not to think about it in the face of some problems they experienced and he had to act indifferent: *"We try not to think. Because, thinking is like a bottomless well; as you think you fall more and more, it is an endless fall. We act dumb; that is the only thing we can do. Ipek said that she could not solve certain problems and let them go: I do not know how I would live tomorrow. It is going to be as it would be.*

### *Views of Families about the Future*

Nine parents expressed their views on the future (Zaim, Kemal, Sibel, Mehmet, Füsün, İpek, Şenay, Tarık, and Fatma). The views of the parents are presented in Figure 11 including the frequency distributions showing the number of parents who expressed views on each theme, subtheme, and subtheme content. Figure 10 demonstrates that more than half of the parents were concerned about the future of their children. It was observed that parents expected their children to live independently, have a job, and achieve success in sports in the future. Direct quotes on the subthemes and the views of the participants are presented below.



**Figure 11.** Views of Families About the Future

#### *Anxiety About the Future*

Zaim expressed the following concerns about how his son would maintain his life after he and his wife are gone:

*I swear to God that the only thing we do not want is to die before him. What will happen after we die? Here we are raising our daughter so maybe she would take care of her brother after we are dead. All we can do is to provide private education for him, to have a good standing in society. After I die, for example, although the state does not pay my pension to my son, they pay it to my daughter, so she can take care of her brother with these funds. That is how we think.*

Kemal explained his anxiety about his son's future and his initiatives on the issue:

*That is what happens in the mind of every father and mother: what would happen to this child if we die. We sat down and started to think about it; that is, this child will always be dependent on someone. Then, what would he need to maintain his life? At least he should own a couple of houses. He has a sister. On one hand, I expend efforts for the academic success of his sister. If his sister is successful in life, at least in financial terms, I do not want anything else, so his sister could look after him. Separately, I want both to live their lives. But I thought that she should have the financial power to support him. In order not to leave the whole responsibility on her shoulders, if they own a few houses, the leasing income they could earn could form a channel. That is how we started... "*

In addition, Mehmet said that if his son had to live alone, he invested to make sure that he would be cared for: *Of course, there should be a house; the child has to own things so that after we are gone, because they say the Darülşafaka [secondary school trust for orphans – translator's note] would establish such a place, but they ask for a trillion Turkish liras. Nothing is cheap.*

#### *Future Expectations*

Fatma said that she wants her son to stand on his own feet in the future: *In addition, he should be able to stand on his own feet, he should be able to go to a shopping mall and come back. Or he could go to his training in sports, or go to a bazaar. He could go to work out and come back using public transportation, he could*

come back home alone. Şenay defined her future expectations for her daughter, Nazlı, as her being able to live an independent life:

*... I always think that there will be a system where she can live on her own. Because I see the examples in America, that is why I think about that. If it can happen there, it can happen here as well. She could cook her food, she could take a bath, keep her house clean. I think she demonstrates that she is a kid who can do anything. We experience troubles in the family; we cannot make her do things. Why? Because we think she cannot. As an example, I prepare the table myself at home. Nazlı eats at a restaurant, they go together with three or four teachers. I went to pay the bill one day, she clears the table, puts the garbage out, puts the dirty dishes in the sink. I said, 'How did you do it?' They said, 'We told her to do it and she did it.'*

Kemal explained that his son Cüneyt believed that he could have a job in the future and he expressed the following considerations on the issue:

*... Cüneyt is 20 years old, almost, but he could go on to live his own life, even on his own, and even take on a job. I say this statistically ... even the job that he could do in the future. I have it in my mind. Cüneyt could easily work as a pharmacist's assistant. Also, he could work at packaging in a retail store. He could organize shelves at a market. These are my main goals for Cüneyt other than sports.*

### **Posttraumatic Growth**

Three parents (Kemal, İpek, and Şenay) reported that they achieved positive results as a result of their experiences related to their children with ASD. Direct quotes on the themes and the views of the participants are presented below.

Kemal described the positive effects he experienced as a result of having a son with ASD:

*Well, of course, there are. For example, the positive effects, we, I have to say that our approach to life has changed. For example, before that I used to say ... 'Everybody to his own, no matter what happens, all to his own.' Now there is no such thing, we forgot about 'me,' we learned to become 'we.' I say we should do this or that; I never say I should do this; we should do this, we should do that. They say, 'it is OK, we can accept Cüneyt.' I say, 'no. I say, 'all autistic people should be allowed.'*

İpek stated that she has become a stronger with experiences after her son being an ASD:

*A positive aspect, at least, how should I say, I got stronger and more clear. My struggle in life is different; I have come to this world once and I have a child as well. If I say 'yes' to all, what would I do with this child in the future? His disability, your struggle for life makes you stronger.*

Şenay also stated that the fact that her daughter had ASD completely changed her perspective on earth:

*I think we experienced very positive things, so I think our perspective on the world has changed completely. ... at least I can say that I am friends with my husband. Maybe we could have argued more about 'you looked at her,' 'you have done that.' We did not have such a stress after Nazlı. First of all, patience and thankfulness, the most important being thankfulness. We learned to be grateful for small things. However, you always know that, it is human psychology, you want more, you want to hit the jackpot. But the little progress in Nazlı taught us to be grateful. We should be grateful for all; life does not always offer these to people. You could have to fight for it. And you can only get it once in a thousand. For example, I think, I was very happy to have bought a house. But then I said what was in this world would stay in this world, what is important is the kind of life that Nazlı would experience ... I think we have improved, that is, I think it contributed to the development of our personality.*



## Discussion and Suggestions

This study determines the experiences of Turkish parents of children with ASD in the pre-diagnosis, diagnosis and post-diagnosis periods, especially in terms of educational processes after the diagnosis and how their lives have been affected by the fact that their children were diagnosed with ASD.

Studies report that the first symptoms of ASD, such as lack of eye contact, failure to respond to one's name despite having normal hearing, non-verbal communication, social limitations and behavioral problems, are generally observed between the ages of 1.5 and 2 years old or before the age of 4 (Arslan, 2011; Bıçak, 2009; Midence & O'Neill, 1999; Selimoğlu, Özdemir, Töret, & Özkubat, 2013) by parents or health personnel (Sayan & Durat, 2007). In this study, the statements made by the participants on this subject are similar to those reported in the literature. The participants stated that they questioned themselves as parents before and after the diagnosis of their children with ASD, rejected the idea that their child was different, and had a sense of failure and excessive stress. Relevant findings in the literature also suggest that parents of children with ASD have similar problems before and after the diagnosis (Farrugia, 2009; Nealy, O'Hare, Powers, & Swick, 2012). Regarding this finding, some of the participants stated that the greatest distress they experienced before the diagnosis was the late diagnosis of their children with ASD. They added that the physicians they consulted during the diagnostic process made statements like "your child is still under age", "boys mature slower", "boys speak later" and "your child does not have ASD but rather, symptoms specific to ASD". Studies with comparable findings determined that some physicians misguided the families who had suspicions of ASD for their children and caused a delayed diagnosis by saying things like, "your child is below the age for the diagnosis" and "boys speak later" (Ailing-Moh & Magiati, 2012; Bıçak, 2009; Karagöz, 2010; Mitchell & Holdt, 2014; Selimoğlu et al., 2013). The finding from the present study indicating that participants did not experience every phase of the stage model as it related to having children with ASD is parallel to the findings from studies that employed the stage approach in examining the experiences of parents of children with ASD (Arslan, 2011; Bıçak, 2009; Bilgin & Küçük, 2010; Bloch & Weinstein, 2009; Gray, 1993; Karagöz, 2010; Midence & O'Neill, 1999; Nurullah, 2013; Selimoğlu, et al., 2013; Üstüner-Top, 2009). However, there are also studies reporting that some of the families expressed that they had relaxed after the diagnosis of their children with ASD because they got rid of the uncertainty they experienced before the diagnosis (Bloch & Weinstein, 2009; Farrugia, 2009). No similar data were obtained in this study. Studies have further determined that parents whose children were diagnosed with ASD used a variety of methods to get information about the disability, such as reading books and articles, doing internet research, meeting with other families of children with ASD, attending scientific meetings, conferences and congresses, and asking questions to teachers of their children (Green, 2007). The participants in this study stated that they used similar methods to obtain information. NAC (2015) report that the scientific-based practices that participants used for the education of their children with ASD who were under the age of 22 are language speech therapy and ABA/PCDI, whereas the non-scientific based practices that participants used for the education and treatment of their children with ASD are dolphin therapy, occupational therapy, sensory integration, drama therapy, herbal cures and metal treatment. In parallel with the findings from this study, Nealy et al. (2012) reported that the methods that the parents of children with ASD used for the education of their children were school-based special education, sensory integration therapy, language and speech therapy, occupational therapy, dietary treatment, drug use, and food support.

The present study findings suggest, as emphasized in the bioecological model and the theory of family systems, that parents of children with ASD encounter a variety of adverse factors in different areas and with different people, such as work life, siblings, relatives, social life and marital life, because of having children with ASD. There are similar findings in the related literature. For example, parents of children with ASD have been shown to encounter problems in business life, such as having to quit work, work a part-time job, or seek jobs with flexible working hours, to be able to meet the needs of their children (Arslan, 2011; Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010; Hutten & Caron,

2005; Koydemir & Tosun, 2010; Kuhlthau et al., 2014; Lee et al., 2008; Nealy et al., 2012). There are different findings in the studies on how children who have siblings with ASD are affected by having siblings with ASD. Some studies report that a sibling with ASD has positive effects on the normal developing sibling (Bloch & Weinstein, 2009; Dillenburger et al., 2010; Kuhlthau et al., 2014), whereas other studies report that a sibling with ASD has negative effects on the normal developing sibling (Gray, 1993; Myers, Mackintosh, & Goin-Kochel, 2009; Nealy et al., 2012). On top of those, there are also other studies reporting both positive and negative effects (Tekin-Iftar & Kutlu, 2013; Tokuç-Öztürk, 2009; Wing, 2012). The findings from the present study match those in the literature, in that they suggest that a sibling with ASD has both positive (acting mature, being protective, etc.) and negative (a sense of playing second fiddle, feeling shame etc.) effects on the normal developing sibling. One participant (Aynur) expressed her concerns about the future, stating that she was afraid that her daughter would have problems both in puberty and in marriage because of having a brother with ASD. Gray (1993) also found a similar finding.

More than half of the parents who participated in the study stated that they received support from their friends when they faced challenging situations related to having children with ASD, and half of them received support from their spouses, other families of children with ASD and experts who were interested in their children's education. In the literature, there are studies reporting that parents of children with ASD receive social support mostly from their spouses, friends and relatives (Özdemir, 2012; Twoy, Connolly, & Novak, 2007; Yurdakul & Girli, 1997). In addition, most of the participants stated that the number of social activities they could participate in was limited because of having children with ASD. This finding is parallel to the findings in the literature reporting that the social lives of parents who have children with ASD are limited (Arslan, 2011; Bıçak, 2009; Dillenburger et al., 2010; Farrugia, 2009; Green, 2007; Koydemir & Tosun, 2010; Kuhlthau et al., 2014; Lee et al., 2008; Nealy et al., 2012; Sencar, 2007; Tokuç-Öztürk, 2009; Woodgate et al., 2008). The participants indicated that they experienced problems because of having children with ASD, such as disagreements with their spouses, interparental conflicts/agitations, thinking about divorce, and trouble maintaining a friendship with spouse. In the literature, there are conflicting findings in the research focusing on this subject, with some studies reporting that the problems caused by having children with ASD led to unrest and divorce (Hutten & Caron, 2005; Koydemir & Tosun, 2010; Myers et al., 2009), whereas others report that the process of fighting against the problems faced by their children with ASD brought the spouses closer and strengthened the marriage (Kuhlthau et al., 2014; Ramisch et al., 2013). Parallel to the findings in the literature, some of the participants in this study stated that they had problems in their marriages, while others stated that as spouses they supported each other and as a result their relationship was strengthened. To cite an example of a problem that was mentioned in this study, two mothers (İpek and Sibel) expressed that they were accused by their husband or their husband's family of being responsible for having a child with ASD.

The current study found that most of the participants and their children were exposed to labelling (stigmatization) because of having children with ASD. This finding supports the findings in the literature showing that having a child with ASD can result in labeling (stigmatization) (Bilgin & Küçük, 2010; Gray, 1993; Gil & Liamputtong, 2011; Green, 2003; Karabekiroğlu et al., 2009; Koydemir & Tosun, 2010; Kuhlthau et al., 2014; Üstüner-Top, 2009; Werner & Shulman, 2014; Woodgate et al., 2008). When the studies on the experiences of parents of children with ASD in the diagnosis process are examined, there are findings supporting the findings from this study. For example, Siklos and Kerns (2007) conducted a study on the experience of parents of children with ASD in the diagnosis process and reported that more than half of the participants were not satisfied with the diagnosis, defining it as a stressful process. The present study suggests that doctors do not have enough knowledge about ASD. Similar to this finding, Selimoğlu et al. (2013) also stated that the evaluations made by the experts in the diagnostic process were not sufficient, and that the general attitudes of the experts were not humanistic. The majority of the participants stated that although their children benefited from the inclusive educational practices, their children nonetheless still had difficulties, such as not being admitted to school, being exposed to discrimination, and not being wanted in the classroom by other parents. For

example, the parents reported that their children were taking lessons from persons who were not specialized in teaching the mentally handicapped. In parallel with this finding, Selimoğlu et al. (2013) determined that half of the participants' children took lessons from persons who were not specialized in teaching the mentally handicapped, and that therefore, they were uncomfortable with this situation. Gil and Liamputtong (2011) found that parents of children with ASD were labeled (stigmatized) by their normal developing peers in school. In addition, similar to the present study findings, there are also results from other studies showing that parents of children with ASD have problems associated with the quality of education provided to their children (Hutten & Caron, 2005; Selimoğlu et al., 2013).

Similar to the findings from this study, the results of other studies focused on the types of coping methods used by parents of children with ASD also suggest that they mostly use religious coping methods to deal with the difficulties they face in having children with ASD (Güleç-Aslan et al., 2014; Kara, 2008; Karagöz, 2010; Tarakeshwar & Pargament, 2001). In the present study, half of the participants stated that they used various methods to cope with the labelling (stigmatization) they encountered, such as not using public transport, pursuing legal proceedings, and limiting their social life. Similarly, there are also studies indicating that parents of children with ASD prefer to isolate themselves from the community in order to protect themselves from the labeling attitudes of the society (Gray, 1993; Woodgate et al., 2008). Three of the participants described the variety of positive experiences they had as learning to see life from a different perspective, feeling stronger, and being grateful even for small things. In the literature, there are similar findings showing that parents of children with ASD feel stronger and more patient than they had been before, are more thankful for everything that life offers them, and have more empathy for people (Bloch & Weinstein, 2009; Karagöz, 2010; Myers et al., 2009; Üstüner-Top, 2009; Woodgate et al., 2008). In this study, when asked what they thought about their children's future, more than half of the participants stated that they were concerned about their children's future. The participants were generally worried about what would happen to their child after they (the parent/parents) died, and how their child would sustain his/her life on his/her own?" In the literature, there are studies reporting that parents of children with ASD are concerned about how their children can continue to live their lives after they die (Bıçak, 2009; Bilgin & Küçük, 2010; Mitchell & Holdt, 2014; Morgan, 2009; Nealy et al., 2012; Üstüner-Top, 2009). Furthermore, the participants in the present study also hoped that their children would learn to live independently, acquire a job, and achieve success in sports in the future. In parallel with these findings from the present study, other studies suggest that parents of children with ASD want their children to be able to meet their own needs in the future (Bilgin & Küçük, 2010; Diken, 2006).

In conclusion, it is quite clear from the finding of this study that parents of children with ASD experience a stressful process before and during the diagnosis of their children with ASD, have negative experiences in these processes, and face negative situations, such as discrimination, rejection and even labeling in the education process of their children, both from normal developing peers and other environmental-related factors. These negative situations create serious problems in their private lives as well as their social lives. To cope with these problems, they sometimes prefer to rely on evidence-based practices and other times prefer to use religious coping for religious or spiritual support. In addition, the parents of children with ASD are very concerned about the future of their children, worrying what will happen to their children after they die.

In line with the present study findings, the following application-oriented recommendations can be made: Seminars, conferences and awareness-raising activities to raise public awareness about ASD can be carried out across the country to eliminate the stigmatization of children with ASD and their parents in society; an information campaign should be organized for relevant medical and education staff to better their understanding about the importance of early diagnosis in ASD; with the cooperation of the Ministry of National Education and the Council of Higher Education, new strategies and policies should be developed to solve the current problems related to teacher trainings on dealing with students who have ASD; a variety of studies can be conducted by the relevant ministries to increase the training hours and education and therapy services provided for children with ASD; legal arrangements should be made to ensure relevant institutions provide children with ASD and their parents with respite care so that they have more spare time to socialize; to gain further insight into this subject, studies should be carried out using different research approaches on how healthy siblings of children with ASD or their grandparents are affected by having a sibling or grandchild with ASD; studies can be planned using different research approaches to compare how parents of children with ASD are affected by the situation of having children with ASD; finally, in-depth studies should be planned to better understand the labelling (stigmatization) experiences of both children with ASD and their parents, particularly qualitative and quantitative studies, in order to identify the challenging situations, like peer bullying and stigmatizing individuals with disabilities in inclusive environments, and to improve the conditions of such environments.

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