Life Stories of Parents with Autistic Children

Oya Onat Kocabıyık[1], Yeşim Fazlıoğlu[2]

[1]Trakya University, Faculty of Education, Department of Guidance and Psychological Counseling, Edirne, Turkey

[2]Trakya University, Faculty of Education, Department of Preschool Education, Edirne, Turkey

Correspondence: Oya Onat Kocabıyık, Trakya University, Faculty of Education, Department of Guidance and Psychological Counseling, Edirne, Turkey.

Abstract

The major aim of this study was to determine how children diagnosed with autism shapes their parents' lives by specifying parents' life stories. The study group consisted of 10 parents who have children with autism. Parents who have participated in the study were determined through a preliminary interview prior to the study and in-depth interviews were conducted with volunteer parents. In the study, "Life Story Interview" list was implemented to examine the content of life stories that shape parents' lives. The data obtained from the research were analyzed using data analysis phases of interpretative phenomenology which is one of the qualitative research models. By analyzing the data obtained in the research, 10 major themes emerged. These major themes include; diagnosis, feeling, hopes and plans, concerns and questions, social reactions / stigmatization, parenting roles, coping with, sensitivity to disease, meaning of life and development. Analyses revealed that parents with autistic children undergo through a wide variety of emotions, challenges and difficulties during their daily lives and also that good coping skill is the key to normal functioning within the family which had an autistic child.

Keywords: life story, autism, interpretative phenomenology

1. Introduction

Autism Spectrum Disorder (ASD) is a broad term that covers social-communicative deficits (e.g., deficits in social-emotional interaction, non-verbal communication, building and maintaining relationships), repetitive interests, and behaviors (e.g., stereotyped and repetitive motor movements, sameness, ritualistic, restricted and deep interest, more or less sensory stimulation) (DSM-5, 2014). Symptoms typically are apparent before the age of 3. Along with this, there might be cases where all stated criteria are not observed. For example, an individual who does not have language development disorder might have difficulties in social communication (Haesen et al., 2011). The risk, anomaly or syndrome that is noticed at birth or shortly after the birth is generally a condition in which families do not know or are not ready for. Many families experience emotional strains, lack of information about the child's condition, health problems due to the child's disability, necessity to consult many specialists about treatment and education, difficulties in describing the situation of child to the others and concerns about the future of child (Küçüker, 1997; Neely-Barnes, Hall, Roberts & Graff, 2011). Having an autistic child affects a family's view of life, their interactions with each other, and expectations of future in a variety of ways (Nealy et al, 2012). Most of the time, families may blame themselves or each other for the state of the child. Moreover, families are faced with a burden and long-term crisis that exceed their adaptation capacities because of more time, energy, and money requirements (Küçüker, 1997; Neely-Barnes, Hall, Roberts & Graff, 2011). Therefore, these families have stresses and these stresses spread through various dimensions of family life. Families of children with autism often experience certain challenges such as anxiety, depression and low self-esteem, communication problems within the family that can lead separation or divorce and social isolation feelings (Shapiro, Blacher, & Lopez, 1998; Pelchat, Jocelyn & Nicole, 1999; Manuel, Michelle, Rajesh & Beth, 2003).

Having a child with autism may be associated with the inability to fully meet the daily needs of other family members and it can also be linked to stress and poor interpersonal relationships within the families (Woodgate, Ateah, & Secco, 2008, Neely-Barnes, 2011). Family stress may be influenced by the age, gender, type and the severity of the child's disability. Furthermore, stress can be linked with the family's socio-economic status, as children with autism need more specialized services which come with a certain price. Other challenges that may arise while taking care of a child with autism include; spousal conflicts and increased responsibilities of child care which may be linked to parents not be able

to have their own time alone as a couple. Research has shown that the families having a child diagnosed with autism do not copy easy with the diagnosis when compared to parents of children diagnosed with other disabilities (McAndrew, 1976; Beresford, 1994; Neely-Barnes, 2011). Parents who are constantly involved in the care and education of children with autism after a while, they normally withdrawn from their old social environment and sometimes they take a break from their professional careers. These changes lead to differences in the emotional state of the family, change of parenting roles, requestioning of the meaning of life and their problem-solving skills. Along with these changes, the families have to rearrange their lives once more. These rearrangements include acceptance of the child in the affective domain and restructure of interfamilial interaction, informing about the state of child, re-adaptation to the social environment, continuity of education, care and sharing of responsibilities (Kogan, Strickland, Blumberg, et al., 2008; Smith, Hong, Seltzer, et al., 2010). Nevertheless, the way the family of cope with this problem can be closely related to their cultural background. Therefore, it is also important that when planning the coping strategies or research the culture of the families whom their children have autism should be taken into consideration (Skinner, & Weisner, 2007).

This study's aim was to determine how children diagnosed with autism shapes their parents' lives by examining the parents' life stories. For this reason, this research identified common themes that could help clarify the functioning of families with autistic child. Clarification of common themes on this topic may be important in helping parents with autistic children to improve their psychological understanding and improve their abilities to cope with it. This study is different from other studies because it is a qualitative in nature. Our research as an in-depth study differed from other studies in terms of the aspects that was explored like; the feelings of families with autistic children, how this situation affects their daily lives and also how they cope with it.

2. Method

This study adopted Interpretative phenomenological analysis of the qualitative research as a method, the objective of the interpretative phenomenological analysis (IPA) is to elaborate the experiences of individuals in details and to reveal how they build perceptions about their individual and social worlds (Smith & Eatough, 2007). In interpretative phenomenology, there is an experience among people with the phenomenon (Miller, 2003). In order to define and interpret experiences, the focus is on the implications of written out experiences, and on the description of phenomenon through perceptions of participants (Motherlls, 2006). Thus, the common meanings underlying the phenomenon that was experienced by the participants are discovered (Baker, Wuest & Stern, 1992). This method is relevant to this study because it enabled the parents of children with autism to tell their daily stories in relation to their children's conditions from their own point of view.

Interpretative phenomenological analysis (IPA) is connected to hermeneutics and theories of interpretation (Smith & Osborn, 2007). According to Smith, Flowers, and Larkin (2009) IPA is "an approach to qualitative, experiential and psychological research which has been informed by concepts and debates from three key areas of philosophy of knowledge: phenomenology, hermeneutics, and ideography" (p. 11). Smith and Osborn (2007) have described "IPA has a theoretical commitment to the person as a cognitive, linguistic, affective and physical being and assumes a chain of connection between people's talk and their thinking and emotional state" (p. 54). It is said that the process of interpretive phenomenological analysis is a dynamic process. In this process, the researcher has an active role. The researcher is trying to get close to the participant's personal world and the researcher's own conceptions are required in order to make sense of that other personal world through a process of interpretative activity. Thus Smith (2004) refers to "double hermeneutics: The participant is trying to make sense of their personal and social world; the researcher is trying to make sense of the participant trying to make sense of their personal and social world" (p, 40).

2.1 Participants

In the interpretative phenomenological analysis, the general tendency towards selecting the participants is to select a small sample group which is homogenous and purposeful. This choice allows for the examination of similarity and difference in a small sample group and also it makes possible to obtain a sufficient perspective on the topic being investigated. We used a homogeneous group selected by a "purposeful sampling" method because interpretative phenomenological studies aim to examine closely of the experience of a particular group related to the phenomenon (Smith & Osborn, 2003).

In this study, the participants consisted of parents who have children diagnosed with autism. We had a pre-interview to determine the parents. In this pre-interview we gave information about our study to parents who came to a special education center for their children's education. Interviewed in-depth with 10 families who indicated that they were volunteering at this pre-interview. The study group consists of 4 fathers and 6 mothers. Their aged between 28 and 37 years old, and their children's age between 3 and 7 years old. In order for the participants to answer the questions sincerely, it was declared to them that their names were coded and kept hidden and all the conversation during the interviews would be confidential.

2.2 Data Collection

Through semi-structured interviews, parents were asked to think about their lives and to tell what the most important thing that changed their lives was and what they experienced in this process. Open-ended questions generate more answers that may be difficult to analyze unless one groups the answers into themes. In the research we used the "Life Story Interview" list developed by McAdams (1995) in order to overcome these problems. "Life Story Interview" list was used to examine the content of life stories that led and shaped the lives of the parents. Life stories provided us a chance to see the multiple facets of life of the parents who have children with ASD.

The Life Story Interview list consists of nine sections: 1. Life chapters, 2. Critical events, 3. Life challenge, 4. Influences on the life story, 5. Stories and the life story, 6. Alternative future, 7. Personal ideology, 8. Life theme 9. Other. In this study we used the sections; critical events, life challenge, alternative future, personal ideology and life theme sections. We did not use other sections because they were not intended for the purpose of this research. In the critical events section, about having an autistic child we asked the parents to tell us about special moments when they felt happy, as well as when they felt unhappy and desperate and the events that caused a change to themselves. In the life challenge section, we asked the parents what the biggest difficulty that they have faced was and how they managed. In the alternative future section, we asked, "If there is a positive or negative future for you, what needs to happen in the future?" In the section of personal ideology, we asked the parents what the main beliefs that guide their lives were for them, and finally in the life theme section, we asked, "Let's say your life was a book or a film, what the theme would be? What would be the title of this story?" We recorded on each interview a voice recorder based on volunteering and with permission from the participants. Each interview lasted approximately 60 minutes.

2.3 Data Analysis

After transcribing all 10 interviews, we analyzed each interview using the interpretative phenomenological data analysis (IPA) steps used by Smith, Jarman, and Osborn (1999). We used MAXQDA 12 computer program in the analysis steps. Utilizing the computer program in analyzing the data contributed to the efficient creation of themes and sub-themes. At the same time, recall feature of the program enabled us to establish a link between themes.

Step 1: Looking for Themes in the First Case

First, we read carefully the transcripts and we read them again at different times to avoid misunderstanding and we determined units of meaning what the participants said. We divided the text into meaning units and assign a comment for each unit. We identified and listed the units of meaning that capture the essence of the participant's words. We continued this process for the whole of the first transcript. Then we returned to the beginning of the transcript, and we used other margin to document emerging theme titles. We continued transformation of initial notes into themes for the whole transcript (Smith, Jarman, & Osborn, 1999).

Step 2: Connecting the Themes

We searched for connections among the themes and grouped related themes in clusters. Some of the themes were clustered together, and some of the themes were listed as superordinate concepts. We checked whether these themes represented participants' expressions in comparison to what they said in the text. During this process, we dropped certain themes because they not fitted well in the emerging structure (Smith, Jarman, & Osborn, 1999).

Step 3: Continuing the Analysis with Other Cases

We started the analysis of each case, as though it was the first. After analyzing each transcript with an interpretive process, we constructed superordinate themes. We read each interview list together and consolidated the list of master themes. At this step new themes emerged in subsequent interviews and we tested them against earlier transcripts and then modified them (Smith, Jarman, & Osborn, 1999).

Step 4: Writing Up

In our last step, we translated the themes into a narrative account. We explained and illustrated themes (Smith, Jarman, & Osborn, 1999). We use mapping feature of MAXQDA 12 computer program because it enabled drawing a diagram.

In the study, we used an expert review in order to ensure validity. In the expert review, the data analysis was controlled by three academic members. Two of the experts were the authors of this research, and the other was faculty member actively working in the field who voluntarily accepted the role of expert reviewer. As a result of data analysis by the experts, consistency among data and themes were examined and if the obtained themes were suitable or not (Baker et al., 1992). In addition, the obtained data consistently converted into themes and associated with the results for providing consistency in the study. In order to provide reliability, authors of this research compared and controlled the obtained judgments, interpretations and recommendations with raw data (Corbin & Strauss, 1990).

3. Results

These are the themes determined in accordance with the purpose of research, respectively: 1. Diagnosis, 2. Feeling, 3. Hopes and plans, 4. Concerns and questions, 5. Social reactions / Stigmatization, 6. Parenting roles, 7. Coping with, 8. Sensitivity to disease, 9. Meaning of life, 10. Maturation. The themes and sub-themes were shown in Figure 1 on the findings section and explained in detail by direct quotation of the parents' statements to provide transmissibility (Baker et. al., 1992).

By analyzing the life stories of parents, the themes and sub-themes were reached in interviews conducted with parents who have children diagnosed with ASD. The themes and sub-themes were shown firstly in Figure 1, and then each theme and sub-theme was explained by making direct quotations.
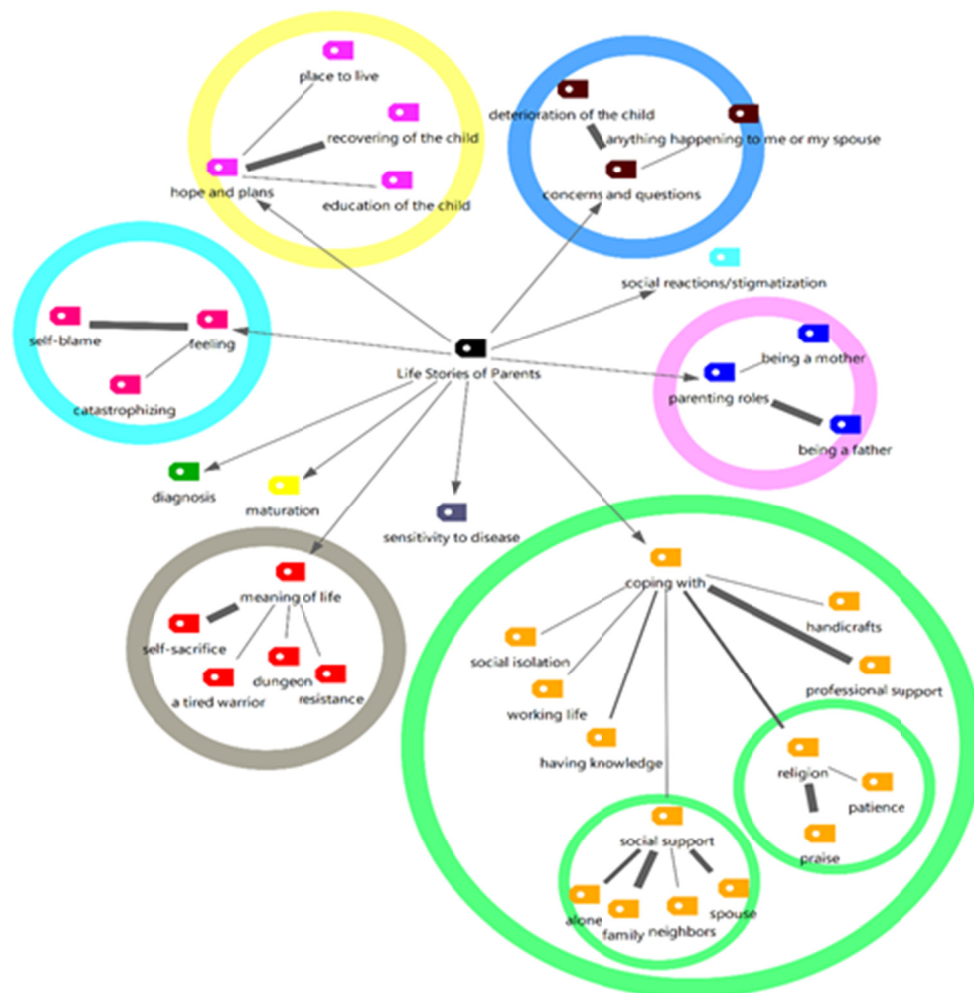

Figure 1. Themes Related to Life Stories of Parents Having Children Diagnosed with ASD

Theme 1: Diagnosis

In the in-depth interviews, it was determined that one of the most frequently expressed themes in the life stories of parents was "diagnosis" theme. In the theme of diagnosis, parents talked about distress, ambiguity and misdiagnosis, especially while their children were diagnosing about the disorder. Some of the parents' statements related to the diagnosis theme were cited below.

> "Because the associate professor said so. That moment was like the tagline of a movie. The doctor showed a pink ball to the child, the child was staring blankly of course; he/she was only 40 days old. The doctor said that the visual area of brain was probably damaged. The child might be cerebral palsy. We asked what cerebral palsy was, the doctor said paralysis of the brain. Then we asked if it was recoverable, he/she said no, it was not. Then we went to another doctor and told what the other doctor said to us. The new doctor said no. The doctor was taken the clothes off the child and tested from sacrum. He said no again, who diagnosed the baby as cerebral palsy. We were at a loss for 24 hours".

Theme 2: Feelings

By analyzing the life stories of parents, "self-blame" and "catastrophizing" sub-themes were reached out under the main theme of "feelings". The parents stated that they blamed themselves for the incident they had experienced could be due to themselves and that they did not fulfill the task of falling down during the treatment process. The self-blame theme was expressed as follows;

> "I could not struggle with Alperen's state, I had not known what it was. You were shocked. I blame myself what if treatment process started in a shorter time. That devastates you."

In another sub-theme, "catastrophizing", the parents expressed the devastation they experienced and its effects in the process of finding out their children's states and after they found out as following:

> "While we were dreaming many good things about our child, the child devastated us. It affected badly our relationship as husband and wife, our family relationships, my attitudes and behaviors towards my spouse".

Theme 3: Hope and Plans

As a result of expressions of parents about their hopes and plans for the future, "hopes and plans" theme was reached and with this theme, parents expressed that they had positive ideas about the future, both their lives and everything would be better. Under the "hopes and plans" theme, "places to live", "recovering of the child" and "education of the child" sub-themes were reached out.

With "places to live", the related physical environment was defined as a peaceful place, with "recovering of the child", it was emphasized that the child got well again, with "education of the child", it was highlighted that the child could go to public schools with his/her peers. These themes were expressed respectively as follows:

Places to live

> "My spouse, my child and an eternal green place. And maybe a sea".

Recovering of the child

> "If he/she becomes an agreeable child, I will be happy. Because his/her happiness is my happiness".

Education of the child

> "Recovering of Asya. Going to a normal school. How can we decrease the difference between Asya and her peers?"

Theme 4: Concerns and Questions

It was emphasized that parents had concerns and questions about the future as well as hopes and plans for the future. "Concerns and questions" theme was reached by analyzing the statements obtained through interviews. Under this theme, "deterioration of the child" and "anything happening to me or my spouse" themes were reached. With concerns and questions, mostly unhappiness, worries and anxieties that emerged from the current situation of the child were determined. The questions were also stated that if the problem of child would be overcoming or not in the future. With the deterioration of child, his/her health would be worse in the future, and with "anything happening to me or my spouse", the expressions were stated as the child would be alone in the future. Respectively, these themes were expressed as follows;

> "For sure, I have fears. Will Poyraz have a difficulty for adaptation? How will he be in primary school, will he be accepted by the others?"

Deterioration of the child

> "I fear that Beren will become introverted"

Anything happening to me or my spouse

> "If something happens to me or my spouse"

Theme 5: Social Reactions / Stigmatization

By analyzing the narratives obtained through interviews with parents, "social reactions/stigmatization" theme was also reached. With this theme, when people noticed the state of the child, they stare at the child and the impact of it on parents was emphasized. The question of this situation was expressed as follows;

> "I became skeptical towards people; when someone looks at Cinar, I ask myself is he/she looking at him with bad intentions or not."

Theme 6: Parenting Roles

By analyzing the statements, "being a mother" and "being a father" sub-themes were reached out under the main theme of "parenting roles". While the fathers relate the reason why the mothers have been more concerned about the development of child is "being the mother", the mothers relate the reason why they search more for treatment and they are more confused is because of being the mother. In short, being the mother requires more concern and more research for treat the child in the eyes of fathers and mothers. This theme was expressed in the following sentences (the first sentence expressed by father, the second sentence by mother);

> "Everything was settled when the baby was 12 months old ... Yes, while I was trying to be a little more relaxed ... it did not happen and I thought he was right as a mother."

> "Yes, I am a mother, reading a lot, maybe I am in a huge confusion. Even I have said recently. For example, if it is right to put the glasses here or there. I brought the photos of the room, I had some questions to ask you about the arrangement of it."

Being a father was only expressed by fathers in the life stories. It was stated that being the father was harder than it was thought, he must be strong all the time and he had responsibilities for both the child and the other family members. The expressions related to this theme were listed below.

> "I was affected negatively, but you had to be a little bit stronger, because you are the father ... it is worse ... well, unfortunately I also wanted to cry and say that I dried up milking, but I did not (laugh)."

Theme 7: Coping with

By analyzing the statements, the theme of "coping with" was reached. Under this theme, the themes of "social isolation", "working life", "having knowledge", "social support", "religion", "professional support " and "handicrafts" were reached. With social isolation, the parent emphasized that he/she coped with these problems by escaping or by avoiding things that were not good for him/her. With working life, they stated that actively working made them feel better; with having knowledge, they feel happy and comfortable by having knowledge about the status of the child. Under the "social support" theme, "alone", "family", "neighbors" and "spouse" themes were reached. With "alone" theme, it was pointed that being alone during this process, especially not supported by the family, led distress and anger on parents. The importance of receiving support from the spouse through coping with was underlined with spouse theme. With family theme, the importance of family support, especially the support of mother and also the support of neighbors were emphasized. With the theme of religion, it was mentioned that especially the destiny, divine justice and relief from the moral point of view. Under the religion theme, "praise" and "patience" themes were reached. With "praise", the relief was mentioned by comparing the state of child with other children and other diseases. With patience theme, waiting, waiting for the time to come and thinking positively were expressed. With expert support, the importance of having this support on coping with was emphasized. Especially fathers underlined that their wives should get expert support. The significance of handicrafts on coping with was highlighted by mothers under this theme. When these themes were examined respectively, they were expressed as follows;

Social isolation

> "Overcoming this process was really hard for us. At those days, I did not accept anyone harmful for me, for my spouse and my child; rather harmful, anything distressful for my soul. I went to the places that are good for me and for my child".

Working life

> "I hold on to working life and my mother".

Having knowledge

> "The machine (different work of mind) of my child works differently. He/she expresses hunger by crying, by throwing something. A normal child say "this" when he/she wants something but when our child throws something, we should know that he/she is thirsty. Understanding him/her took my six months. Well, indeed, it exhausted me too much".

Social support

alone

> "We felt that we are alone. We took the child and went home. At the first evening, there was no one around us. How we could manage, how we diaper the child we did not know. Something like that."

spouse

> "I would like to thank my spouse for that issue. He said, no, there is nothing bad, we have a long way ahead".

family

> "All of the family supports us."

neighbor

> "Our neighbors support us. If you are alone, it is hard."

Religion

> "I believe that there is divine justice. Do what you can and leave the rest to the God. If there is a difficulty, so is there a solution".

praise

> "There are very special children here. They are better than our child. Sometimes I feel ashamed of the families of these children, there is nothing exaggerating in our situation".

patience

> "Philosophy of life, generally I try to think positively. I believe everything will be alright when we are patient and the time comes. It will be".

Professional support

> "We did not receive any professional support at the beginning. I learned everything by asking myself, such as he did this, what can I do; he behaved like that, how can I figure it out".

Handicrafts

> "I like gardening with flowers. I would like to work on this issue in handicrafts".

Theme 8: Sensitivity to the Disease

The theme "sensitivity to the disease" was reached in accordance with analyzing the statements in life stories of parents with autistic children. Sensitivity to the disease implies the sensitivity especially the process after finding out this disease. This theme was expressed as follows;

> "I have become more aware of disabled people."

Theme 9: The Meaning of Life

By analyzing the statements of parents during in-depth interviews, "self-sacrifice", "resistance", "a tired warrior" and "dungeon" sub-themes were found out under the main theme of "meaning of life". To move into another city, they live for changing something, to give up activities they like and habits, to do things that the child likes and to live for the child were expressed with self-sacrifice. With "resistance" and "a tired warrior", it was underlined the struggle for life and also the tiredness of this struggle. What emphasized by "dungeon" was everything apart from the individual oneself might turn the person into a limiting factor. The themes reached out were respectively expressed as follows;

> "After this, I began to live for the child. We all set our lives according to him/her".

Resistance

> "Resistance is my life."

Tired warrior

> "A tired warrior, I get both tired and still fighting for something. Struggle for life".

Dungeon

> "The dungeon for human, namely, a human is not free when he/she is doing something. His/her environment and culture affect everything. And this may be the dungeon for that human".

Theme 10: Maturation

Lastly, in the life stories of parents, the maturation effect on the parents was mentioned. Therefore, maturation theme was reached and expressed as follows:

> "It will be a bit distressful, otherwise we cannot mature".

4. Discussion

With different incidents, life stories of individuals are diversified, enriched and colored. Sometimes starting to a new school may be the reason; sometimes moving to a new city or sometimes the birth of the child may become the reason. In particular, examining the life stories of parents with autistic children could be important to determine how this

situation shapes their lives. For this reason, it was tried to be examined the life stories of parents who have children with autism. As a result of interviews conducted with parents, it was determined that one of the most frequently expressed themes was "diagnosis". In the theme of diagnosis, parents especially talked about the difficulties they experienced during the diagnosis process of the disease of their children, the uncertainties they faced with during this process, and the misdiagnosis. After the diagnosis, parents expressed that they could not accept the situation and felt themselves or their spouses responsible for it. Especially, it was pointed out that the diction of diagnosis to the family by experts and the inadequacies in guidance after diagnosis led them to an ambiguity and chaos in parallel with this reseach (Haldane &Craword 2010). They had explained their feelings in the article as being the family, "The diagnosis came from a psychiatrist. In a small room with toys she takes notes. Pensively, rhythmically the woman writes. She looks up then takes more notes as Lula climbs around the bookshelves, humming and singing like a whale, fixating on pencils, rocking and roaming, all cheerful obliviousness. We sit anxiously, wanting to direct our daughter, wanting to explain a few tricks we know that make her seem less weird. We are not supposed to. We are here to have the weirdness categorized, and we are supposed to answer the occasional questions the doctor asks and nothing more. We are here for a diagnosis. Finally, with a soft voice, there it is: autism. Like a bomb. " Also, when literature is examined, it is expressed that this research supports the findings, it is important that the time of the first explanation of diagnosis to the family and the diction of it by the experts help the family to cope with problems and to accept the status of child in the early period and then reorganize their lives. Psychological and educational supports after the explanation of diagnosis to the family by the child psychiatrist is also important in terms of reducing the problems that they face with in the future and starting education of child in the early period. As far as the families can overcome these feelings, they understand better themselves and others as well as their children. For this reason, even the birth of a normally developed baby causes a crisis in the family; the birth of a disabled baby can lead to radical changes in the emotional and behavioral dimensions of the family. For this reason, it is very important to have a multidisciplinary approach for the family (Yukay & Erturan 1998).

The other theme that was obtained by analyzing the life stories of parents is "feelings". Thinking that the incident they experience is because of them led parents to experience self-blame, thinking that they do not fulfill their duties in the treatment process led them to experience devastation. In similar studies (Yukay & Erturan 1998; Gray 2004; Courcy & Rivières, 2017), it was stated that one of the most intense emotions that families with autistic children experience was guilt. It was emphasized that families with autistic children often blame themselves; especially fathers feel themselves intensely guilty about the diagnosis supposing that this incident was because of them (Courcy & Rivières, 2017). Besides, it was stated that in the families that became aware of the deficiency of their children, their expectations and hopes for their children fell apart. At the first stage that they faced with the diagnosis; they might undergo shock, denial, grief or depression in most of the times. The reactions of families experienced in the second stage were anger, guilt and shame. The sense of guilt is one of the most intense emotions of families who have an autistic child. The guilt of having a child who develops differently is perhaps the hardest emotional state to overcome for the family. Families constantly try to find out the reason why autism has emerged. Sometimes they might think that they are punished by the God. Sometimes they think that this has happened because they are not good parents. Only when the families reach the third stage, they can adapt and accept this new situation (Yukay & Erturan, 1998). Adaptation and acceptance of this new situation can lead to look to the future hopefully. Supporting this finding, "hopes and plans" theme has been reached in this research indicating that parents believe everything will be better in the future and their lives will be better as well. Parents have mentioned that they will live in a peaceful physical environment; their children will be healthy and go to public schools with their normal peers in the future. In this research, "concerns and questions" theme was also reached out by the parents expressing that they had concerns and questions about the future, as well as hopes and plans for the future. Also in this research, Concerns and questions are often associated with autism and uncertainties in the future. The families highlighted that sometimes they are very pessimistic about the future expectations. These concerns were stated as; worsening autism or being lonely of the child if loss or absence one of the spouses. In addition, the parents stated that the society does not accept children with disabilities look at them differently in social environments and label them their despair and anxieties.

By analyzing the life stories of parents, "social reactions / stigmatization" theme was also reached out in this research stating that people who are around start to stare at the child when they realize the situation. Similarly, Kearney and Griffin (2001) found in their research that families who had children with disabilities expressed discomfort with the way the people looked at them and their children in any social environment. In another study (Barnes et al., 2011), it was stated that families with autistic children were perceived as bad parents by the society. The parents stated that people usually regard the families as responsible for the problematic behaviors of the autistic children. They emphasized that it is very difficult to tell the society what autism is because it is an "invisible" problem rather than visible as any physical problem. In addition, parenting roles, feeling as if they are not good parents, striving for being better parents and sometimes being described as uninterested parents by other people are another stress sources for parents. This creates anxiety in the families who have children with autism.

Having an autistic child can have negative effects like stress and depression on families; however, it has positive effects on internalizing parenting roles better. Another theme that was obtained by analyzing the life stories of parents is "parenting roles". While "being a mother" in parenting roles was defined separately by mothers and fathers, "being a father" was defined only by fathers. According to fathers, having more concern about the development of child is related to be the mother. In short, being the mother requires more concern and more research for treatment of the child in the eyes of father and mother. In a research supporting the findings of this study, it was stated that mothers were more affected by the behavioral problems of their children than by their fathers. The reason was that mothers' participation in the care of their autistic children was getting to increase than their fathers (Hastings, Kovshoff, Ward, Degli Espinosa, Brown & Remington, 2005, Benson, 2017). Similarly, in the study of Rodrigue, Morgan and Geffken (1992), it was stated that fathers were less involved in this process than mothers and this led to more difficulties for the mothers. Another finding in this study is that being father is more difficult than thought for the fathers. It was stated that they were responsible for their children and other members of the family and they have to be strong. Supporting the findings of this research, in another research (Hastings, Kovshoff, Ward, Degli Espinosa, Brown & Remington, 2005) it was pointed out that one of the reasons that led to differences between mothers and fathers was that fathers use different strategies to cope with the behavioral problems of their children. The reason of it might be fathers using compatible strategies for coping with the stress by diminishing its effect on them. In another studies (Essex, Seltzer & Krauss, 1999; Gavidia-Payne & Stoneman, 1997), it was found that parents of children with developmental disabilities have adopted different strategies for coping with. The research conducted by Montes and Halterman (2007) supports the findings of this research. It was also stated that after the diagnosis of autism, there is an association between the parents and children; besides, families started to search, read and consult the experts to cope with this problem for being better parents.

In addition, by analyzing the findings obtained in this research, the theme of "coping with" was reached. Under this theme, the parents especially mentioned about the factors such as social isolation. Parents stated that they avoided things that were not good for them to cope with this problem by using social isolation (Courcy & Rivières, 2017). Moreover, it was emphasized that being active in working life and even spending time with handicrafts are important for coping with it. It was expressed that having information by researching the state of child is relieving and makes them happy. In other studies (Skirton & Barr, 2007; Bilgin & Gözüm, 2009), the importance of informing families was mentioned and it was highlighted that lack of knowledge is an important stress factor. House (1981, 1986) mentioned the importance of the availability of support services for parents of children with disabilities such as providing support for services and including information about disability.

In the context of this support, providing health and social services are particularly vital. For this reason, lack of information on these issues causes discomfort and anxieties in parents. The expert support and the importance of receiving it for coping with was also emphasized in this research. Parallel to the findings of the study, it was found that families who received professional support had similar inter-parental relationships to those who had normally developed children (Brobst et al., 2009). In the study of Montes and Halterman (2007), they found that after the diagnosis of autism, there was an association between parents and children; besides, families started to search, read and consult the experts to cope with this problem for being better parents.

Underlining the importance of environmental support for coping with this problem, distress and anger were mentioned in this study especially when not supported by the family. Families emphasized the importance of support received from their families and neighbors for coping with their concerns. Similarly, Barnes et al. (2011) indicated in their research that some families were not understood by their extended families. One of the families who participated in their study said that their mother sent a book to them about how to raise a child and the family of his/her spouse did not understand this situation at all and criticized why their 8-year-old autistic child was not polite. It can be said that it is difficult to cope with this situation if you are not understood and supported by your own family. Along with family, the importance of support received from the spouse was also highlighted in this research. Brobst et al. (2009) investigated in their research that how having autistic children affected the relationship of couples with each other Families with autistic children were stated that they were more dissatisfied with each other in their relationship than those who had normally developed children. At this point, this finding revealed that there is a need of more support with each other for the parents. According to Baltaş (2007), what aims with environmental support is not the solution to the problem that causes stress. It was stated that even if it does not cause a solution, this support reduces the individual's anxiety about the problem, leads the individual to look more optimistic to the problem and causes encouragement for coping with stress. In this sense, it was emphasized that environmental support has also an important influence on making the individual self-controllable.

In this research, parents also talked about the importance of believing in divine justice, praising by relaxing in spiritual aspect and being patience for coping with this problem. They mentioned the benefits of being thankful when comparing

the state of the child with other children and other diseases; and being patient by waiting the time to come. It was stated that religious belief has a significant influence on positive thinking for coping with the situation they have. Supporting the findings of the study, it was pointed that especially in searching for spiritual support in coping with the problems and seeking for creating a new framework for the problem, receiving support from religious officials is a positive religious method of coping with (Ano & Vasconcelles, 2005).

"Sensitivity to disease" theme was reached because the parents with autistic children mentioned in their life stories that their sensitivities to the disease increased especially after they had faced with this disease. Moreover, parents mentioned about the maturation effect of the state of their children on themselves in their life stories. After facing with this problem, the families expressed that they became more sensitive to the disabled people and involved in support groups related to this issue. Similar to this study, Altiere and Von Kluge (2009) found that families stated that having an autistic child increased their life satisfaction; they became more patient and had a strong social network. By analyzing the life stories of parents, the final theme that was reached was "meaning of life". Under this theme, sub-themes such as "self-sacrifice", "resistance", "a tired warrior" and "dungeon" were reached. With self-sacrifice, giving up habits and living only for the child as a parent were expressed by the parents in order to progress in a positive way about the development of the child. With resistance against the problem and tired warrior descriptions, the struggle for life was underlined. With dungeon description, the families stated that sometimes the encompassed feeling around them made them feel trapped. According to Neely-Barnes and Dia (2008), one of the most important needs of families who have children with disabilities is to determine the meaning they give on disability. Weakness in family functions, interpersonal problems in the family are usually because of having a disabled child. However, "what if you did not have a disabled child" question was not answered by the parents and it presented that it was impossible to be understood whether this factor was the problem or not. The problem is to take disability as the center of the problem and the solution is, for the families, to accept that they have a typical family characteristic. For this reason, it is possible to say that the meaning parents give to disability has a decisive role to determine the meaning of life.

In this study, we also had the chance to learn from the life stories of families with autistic children that the problems they experienced after they encountered this situation, their experience and how they coped with it. This research gives clues about the importance of understanding better the experiences of families and to offer them a holistic support. As the research is limited to the families having autistic children, comparative samples can be used in future studies. It may be considered as a limitation of our present study.

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