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A QUALITATIVE RESEARCH ON THE ANXIETY AND STRESS CONDITIONS OF FAMILIES WITH SPECIAL NEEDS CHILDREN

ÖZEL GEREKSİNİMLİ ÇOCUĞA SAHİP AİLELERİN KAYGI VE STRES DURUMLARINA DAİR NİTEL BİR ARAŞTIRMA

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ABSTRACT

In this study, based on the experiences of mothers with special needs children between the ages of 3-6, it is aimed to reveal the anxiety and stress conditions concerning their children, which are formed by individual, familial and environmental conditions. Mothers of thirteen individuals residing in Sakarya province and having different disability types were included in the study. A working group in accordance with the purposive sampling method was formed. The study is a descriptive research created in a qualitative design. The semi-structured interview technique was employed in the data collecting process. In consideration of the reliability of the study, the statements of the participants were included in the form of "direct quotation" without any change in terms of spelling and grammar. The participating parents in the research were informed by the authors about the purpose and content of the research. No limitation was applied to the age of mothers. A parenthetical coding technique was used. In the study, the anxiety and stress situations that parents experienced when they learned that the families would have special needs children in the themes of uncertainty and exclusion were revealed. The anxiety and stress conditions that families suffer vary as per their experiences and differ from each other. The first moment of confrontation and the ambiguous process afterwards seemed to create more stress and anxiety in families. On the other side, it was demonstrated that, in some cases, the exclusion is due to the family and in some cases, is from the outside. The fact that stress and anxiety experienced in cases where psychological health and well-being deteriorates can lead a person to suicide is another finding of the research.

Keywords: Family, special needs, anxiety, stress.

ÖZ

Bu çalışmada 3-6 yaş aralığında olan özel gereksinimli çocuğa sahip annelerin yaşantılarından yola çıkarak çocukları ile ilgili bireysel, ailesel ve çevresel koşullarla şekillenen kaygı ve stres durumlarını ortaya koymak amaçlanmıştır. Çalışmaya Sakarya ilinde ikamet etmekte olan ve farklı engel türlerine sahip on üç bireyin annesi dahil edilmiştir. Amaçlı örnekleme yöntemine uygun çalışma grubu oluşturulmuştur. Çalışma nitel desende oluşturulmuş betimsel bir araştırmadır. Verilerin toplanmasında yarı yapılandırılmış görüşme tekniğinden faydalanılmıştır. Çalışmanın güvenirliği de dikkate alınarak katılımcıların söyledikleri "doğrudan alıntı" şeklinde imla ve dil bilgisi açısından değişikliğe gidilmeden aynen aktarılmıştır. Araştırmaya katılan ebeveynlere araştırmanın amacı ve içeriği hakkında yazarlar tarafından bilgi verilmiştir. Annelerin yaşları belirlenirken herhangi bir sınırlamaya gidilmemiştir. Parantez içi kodlama tekniği kullanılmıştır. Çalışmada ailelerin özel gereksinimli çocuklarıyla birlikte ilk yüzleşme anı ve sonrası, belirsizlik ile dışlanma temalarında yaşadıkları kaygı ve stres durumları ortaya konmuştur. Ailelerin yaşadıkları kaygı ve stres durumları, yaşantının özelinde çeşitlenmekte olup birbirinden farklılık göstermektedir. İlk yüzleşme anı ve sonrasındaki muğlak sürecin ailelerde daha çok stres ve kaygı oluşturduğu görülmüştür. Dışlanmanın ise bazı durumlarda aile içi, bazı durumlarda aile dışından kaynaklandığı tespit edilmiştir. Psikolojik sağlık ve iyi oluş halinin bozulduğu durumlarda ise yaşanan stres ve kaygı durumlarının kişiyi intihara kadar götürebileceği araştırmanın başka bir bulgusudur.

Keywords: Aile, özel gereksinim, kaygı, stres.

A QUALITATIVE RESEARCH ON THE ANXIETY AND STRESS CONDITIONS OF FAMILIES WITH SPECIAL NEEDS CHILDREN

INTRODUCTION

Being a family and walking to the future with healthy steps hand in hand are the basic values that have a unique significance in each individual's world and make life meaningful. The family, which is the core institution of society, has many qualities that it provides to its members. Functions such as love-to be loved, taking responsibility, fulfilling social roles, and being active in decision mechanisms are just some of them (Kaytes et al., 2015). The complementary element of the marriage of every parent is having a child (Varol, 2005). The family's expectation in this process is to have a healthy child. Notwithstanding every family has dreams about their child, the accompanier of this process is anxiety. Nobody dreams of a child with a disability or inability in his/her dreams about their child. In fact, even thinking over this generally discomforts parents (Arı et al., 2012). When parents come to know that they have children with disabilities, they experience different moods (Yates, 2012). This is an unexpected situation and the confrontation process begins when parents fall in despair of a normal child. Similar and common stages that begin with the rejection response are afterward accompanied by understanding and controlling the situation (Howard et al., 2010; Featherstone, 1980; Turnbull and Turnbull, 1985). According to Kübler-Ross (1997), the mourning process, which consists of five stages of denial, anger, bargaining, depression and acceptance, are similar processes experienced by families with children with special needs (Luterman, 1979; Gören, 2016). When families face their special situation for the first time, many stages such as shock, guilt, embarrassment, hovering door to door in hopes of finding a cure, miracle search, bargaining, refusal, wrapping logic accompany this process. In these experiences, the depth and length of the stages differ according to the anxiety and stress situations of the families (Seligman, 1989; Varol, 2005; Guerin and Fay, 1988; Sardohan Yıldırım and Akçamete, 2014).

Children with special needs take place below or above norms in terms of both physical and learning abilities. Therefore, they need individualized training programs in their educational processes (Hallahan and Kauffman, 1997; Özsoy et al., 2000). Although specially talented individuals fall within the scope of this term, in practice, individuals with insufficiency in this term come to the fore (Heward, 1996; Akkök, 2000). Therefore, individuals with special needs phrase was used for individuals under the norms that differ significantly from their peers as individual characteristics and competencies in the study.

Stress and anxiety are the two main facts reflecting the emotional state of families in these differences seen below the norms. Stress can be defined as the state of reaction that creates both social and psychological effects on the person as a result of threats or strains of the organism (Baltaş and Baltaş, 1984). In the event of this strain, many differences and changes occur with the individual and environmental farters in order to overcome the threat perceived by the individual (Mason, 1980; Parker and Decotiis, 1983). Anxiety is the mental and physical reactions of the body when the person experiences fear and tension (Morgan, 1991). In addition to being a chronic and complex emotional process, it also includes negative experiences of social processes. It is a universal life situation that can affect a person in such a way that he / she cannot see and work in private life situations where serious tension is experienced (Drever, 1969; Spielberger, 1976; Nemiah, 1975). Studies on families with children with special needs reveal that stress and anxiety are higher in these parents than in other parents (Dyson, 1993; Hallahan and Kauffman, 1997; Aydoğan, 1996; Kavak, 2007; Akkök, 1989).

Disability is not solely a process with emotional or psychological impacts such as stress, anxiety, social exclusion and isolation. In addition to these, it is a very complex process that involves long health care services according to the type of disability, and also with an economic aspect in so far as families with children who need intense care through special education and rehabilitation processes face a reality like impoverishment (Ali et al., 1994; Veisson, 1999). Besides the material needs, information needs are among the needs of families. When these needs are not met, it is observed that children lock themselves in the house and repeated routines result in problematic behaviors over time (Toker et al., 2019). The emotional confusion that emerges due to learning of the baby's condition brings along the changes in expectations (Yıldırım-Doğru and Arslan, 2016). These changes vary after the child joins the family. When it is considered within the context of system theory, these changes are observed in the structural and functional dimensions of the family as well as in their developmental dimensions (Duyan, 2005). Cases such as self-accusation due to the situation of the child, feeling inadequate in dealing with the type of disability, being dependent on professional services arising from feeling compelled more than necessary for specialist guidance, excessively protecting the child and in this way making child dependent on the parent, rejecting child's inability affect all these structural and functional dimensions (Özgür, 2000). Supporting families in these emotionally complex circumstances and bringing down the unfavorable situations experienced by them is the main target of determining the needs of families (Durualp et al., 2011).

The responses and approaches of parents towards children with disabilities may differ (Danış, 2006). Researches put forth that the mother traditionally plays the role of protection while the father is not so sensitive in meeting the special needs of the child with disability, and his interest is less than the mother's (Alptekin, 2004; Lillie, 1993). The selection of mothers as participants in the research has provided access to healthier and various data regarding the realities, anxiety and stress levels experienced by families. In addition to determining the needs, revealing the ambiguities, inadequacies, and hence anxiety and stress situations that families feel and experience concerning the future will also diversify and qualify the services to be provided. These qualitative data, which are needed and making a contribution to the development of sustainable services, make the research more meaningful and demonstrates its importance.

In the study, based on the experiences of mothers with special needs children between the ages of 3-6, it is aimed to determine the individual, familial and environmental anxiety and stress situations that mothers experience due to their disabled children. The anxiety and stress situations that families experience vary according to their lives and differ from each other. Only the quantitative revealing of the problems experienced by families with children with special needs leads to the missing of the subjective parties regarding the problem and the sensitivity of the developed solution proposals decreases. In this context, in the research conducted on mothers, answers to the following questions are sought.

- What are the anxiety and stress situations felt during the first confrontation and afterwards?
- What are the anxiety and stress situations about uncertainties?
- What are the anxiety and stress situations on exclusion?

METHODOLOGY

Research Model

The research was carried out as a case study in the qualitative research design in order to reveal the future concerns of parents with children aged 3-6 with special education needs. The semi-structured interview technique was employed in collecting the data. Thanks to the qualitative studies performed in order to examine the sample thoroughly, the depth of the inner feelings regarding the subject has been reached. (Bogdan and Biklen, 2003; Yıldırım and Şimşek, 2006). The interviews were performed bearing these dynamics in mind.

Sample Group

Mothers of thirteen individuals residing in Sakarya province and having different disability types were included in the study. A working group suitable for snowball and chain sampling, which is one of the purposeful sampling methods, was formed. Purposive sampling is the process of evaluating the rich information situations in detail, remaining loyal to the aim of the study (Yıldırım and Şimşek, 2006).

The participating parents in the research were informed by the authors about the purpose and content of the research. No limitation during determining the ages of mothers was applied. The average age of mothers is 35.5. Children with special needs suffer from a delayed milestone (mental deficiency), autism spectrum disorder and Down syndrome. Only 1 parent works, the remaining 12 participants are housewives.

Table 1. Demographic Information of Children and Mothers in the Study

Child's Codes	Child's Gender	Date of Birth	Child's Diagnosis	Mother's Age	Number of Children	Education Status	Occupation
MD	M	21.06.2016	Autism	31	2	Secondary School	Housewife
TG	M	28.07.2016	Autism	29	1	High school	Housewife
ZK	F	13.02.2016	Down Syndrome	40	3	Primary school	Housewife
SH	M	08.02.2016	Mental Deficiency	28	1	High school	Housewife
YMO	M		Autism	28	1	High school	Housewife
AÇÜ	M	27.05.2015	Down Syndrome	27	1	Secondary School	Housewife
ÖD	M	04.01.2014	Mental Deficiency	36	1	Secondary School	Housewife
DD	F	04.01.2015	Autism	46	4	Primary school	Housewife
BB	F	27.09.2016	Physical and Mental Deficiency	37	2	Secondary School	Housewife
AA	F	20.10.2014	Physical and Mental Deficiency	39	1	High school	Housewife
ABV	F	12.07.2016	Down Syndrome	49	2	Secondary School	Housewife
KD	M	12.02.2016	Autism	35	2	Secondary School	Factory Laborer
YEK	M	05.06.2014	Down Syndrome	37	3	Primary school	Housewife

Data Collection Tools

In the study, in order to determine the views of mothers with special needs children regarding their anxiety and stress conditions and their diversities, the semi-structured interview form created by researchers, to which field specialists also contributed, was used. Open-ended questions were asked to the mothers, such as when they learned about the special situation of their children, what they experienced first, the reactions they received from the environment, and the emotions they felt in their uncertainty. According to Stewart and Cash (2014), the interview is "A mutual and interactive communication process based on the form of asking and answering questions, performed for a predetermined and serious purpose." According to Karasar (2015), interview technique is the quickest way to learn about possible underlying reasons for information, thoughts, attitudes and behaviors of people on various topics.

Data Collection

Study data were obtained from thirteen mothers of special needs children. The semi-structured interview questions were determined in order to reveal their views on the anxiety conditions they faced. A voice recorder was used to ensure a detailed quotation of the interviews. All the mothers participating in the research were informed about the purpose and scope of the research prior to the interview, and interviews were conducted on a voluntary basis with the permission from the mothers. Since the subject is special and sensitive, researchers always considered the ethical principles regarding unconditional respect and acceptance so that the mothers participating in the study could be comfortable. In addition, during the meeting, care was taken to ensure that the mothers were relieved and that the interviews were carried out spontaneously. The interviews ranged from approximately 15 to 50 minutes and were held in a quiet classroom environment at the school where their children get educated. When an answer given by the mother was also an answer to another question, the question was not addressed again. The interviews were ended by thanking the mothers.

Data Analysis

Interviews performed with the semi-structured questions were carried out on a voluntary basis. Descriptive analysis technique was used in the analysis of the data obtained. The obtained data were coded line by line in a special form. The main concepts were generated from the coded pages one by one and then transferred to the analysis pages. Interview transcripts were presented under the themes and categories related to the problem with direct quotations (Cohen and Manion, 2007; Yıldırım and Şimşek, 2006).

As Creswell (2016) emphasized on the validity and reliability of the study, the interview transcriptions were checked by comparing them with the recording. In qualitative research, validity and reliability are the most basic feature that is sought for the impartiality of the research and accurate measurement of the case (Yıldırım and Şimşek, 2006). For this purpose, the interview transcripts were both confirmed by the participants and checked separately by two separate experts who are field experts. The general framework in the analysis of the research consisted of three components (*reduction, presentation, inference*) and three operations (*coding, note-taking and suggestion development*) that were hold in the Qualitative Analysis Model of Miles and Huberman (1994).

A parenthetical coding technique was used. As in the example of "AA, 39, H, HS", the initials of the names and surnames of the children are in the first space, the age of the mothers is in the second space, the first letters of their jobs (H: Housewife, FL: Factory Laborer) in the third space, their graduation level (PS: Primary School Graduate, SS: Secondary School Graduate, HS: High School Graduate) is coded in the last space. Following the analysis of the data, the findings were described, interpreted and evaluated on three main themes as inadequacy, ambiguity and sense of exclusion. In the theme of inadequacy, the sense of inadequacy that the mothers felt when they first learned that their children were disabled and later was considered. In the theme of ambiguity, the inability to predict the disability and the future of the disabled children was addressed. The theme of exclusion focused on the social acceptance and social support.

FINDINGS

The data obtained from the analysis performed were presented by directly quoting the contents of the interviews with the mothers, and divided into codes, themes and categories. The study focused on three themes experienced by mothers with special needs children between the ages of 3 and 6. These themes are sense of inadequacy, ambiguity and sense of exclusion.

Findings Regarding the Anxiety and Stress After the First Confrontation

The anxiety, stress levels and reactions of mothers to disabilities they faced regarding their children differ from each other. While some consider the situation, she experienced as the whole world collapsed her ears, some stated that she was very unfair in her reactions to her husband and thus she would first change this situation if she had a chance to return those days. Some mothers, on the other hand, stated that they felt anxious and fearful in so far as the financial impossibilities concerning the education life of their children. All these stress conditions faced are diversified specific to the experiences of families:

> *"What am I going to do now?" I said. When I learned that I was living something that would last a lifetime while I was waiting to end at 3 years old, I said, "What am I going to do? How do we live this life?" I got stuck. I couldn't find a queue, I went directly to the psychiatrist's door and started to cry, I said, "There is a danger for my child to have autism and I cannot get an appointment." They said okay, they scheduled an appointment for after 1 month. I said, "I have not slept for two nights, how I will wait for a month" (TG, 29, H, HS).*
>
> *"We caved in, you are looking at the child and, helplessly, you are able to do nothing, we did not want to eat and drink. Our sleep is disturbed"(BB, 37, H, SS).*
>
> *"I was extremely bad when I first heard it. The psychology at that moment is inexpressible that the whole world collapsed on my ears. I couldn't go into the hospital" (AA, 39, H, HS).*
>
> *"D.'s father has already left us. I had to struggle against the situation alone with my children. I don't have a family here. I have no one I can get support from" (DD, 46, H, PS).*
>
> *"When we were in the hospital in Sakarya, there was constant sleepiness in Ö. We asked for a referral from the doctor. They did not allow. So, my husband took us out of the hospital by force. On the way to Umut Tepe, Izmit, he opened his eyes. When the doctors there saw that we came with our own means, they were very angry that we did not come via an*

ambulance. Then they started examinations. They suspected that there was something syndromic. Then we took it to Istanbul Çapa. We were always in search for 2 years" (ÖD, 36, *H, SS).*

"It was said that it was innate in the family, he resembled his grandfather, and the child was naughty. He would cry until we arrived home. While everyone was living a happy and beautiful motherhood, I had long sleep problems. Crying, not going anywhere, not getting out of the house, I had a hard time" (TG, 29, H, HS).

"Frankly, I am so worried financially. Schools are very limited. How the families suffering from financial impossibilities will afford the education of their children". (AÇÜ, 27, H, SS).

"It's not blame, but I expected so many things from my husband, materiality has a limit and spirituality too. Until we learned about Ö's illness, we said to each other not even once to get up and sit there. But I wore away my husband too much, asking for more than my husband could do. My husband tried to provide my child and me with all the support he could. However, I have never found it enough. Despite all this, I usually prefer my husband when I go to the hospital. Because I have difficulty in experiencing my feelings among others, I cry if I have to cry when I am together with him, stop if I have to stop. If I could go back to those days, I wouldn't have put the squeeze on my husband" (ÖD, 36, H, SS).

"I can't cope with it anymore. When he cries, when he asks for something from me, and if I cannot do it, I feel very bad" (TG, 29, H, HS).

"Early on, I thought that if I make him had private lessons in addition to rehabilitation, I supposed he would get better promptly. But despite all the intense lessons, it was not what I expected. Yet we still continue the lessons. It is not easy but rather costly. Both my husband and I are working overtime for this. I scheduled my shift to the time that K. came from school. Only my manager and chief know the condition of my child. I did not share it with my other colleagues. I see him as a normal child. I explain to him everything at home as if I explain a normal child" (KD, 35, FL, SS).

"Sometimes I think he seems like learning something right away, I say okay, but such a thing is happening that even though I say something very simple over and over again, he is giving a blank stare, I think that he will not learn anything at that moment, I feel that my effort is meaningless. All my energy is run out of, I feel my hands are tied, I always cry. It sounds like he will never get better. I think I still couldn't accept my child's special condition. I do not know what I will do. Will he be able to learn like his friends when he starts school? What if he can't learn and fall behind? What if he can't go to school together with his friends? My brain is occupied by these questions constantly. I can't sleep at night, I have severe headaches. I had an anxiety disorder. I do not want to use pills given by psychiatry for life, they stupefy me. When my husband comes home, I want him to take care of T. a little, teach him something, but it is useless, he is playing a little and he gets tired and lies on the sofa. From time to time, I storm at my husband. But I am aware that my husband has to work too, thus he gets tired. I have to do something all the time, so I get very tired because I think it can't be recovered if I don't. Sometimes I maltreat both the child and myself. I don't know what to do" (TG, 29, H, HS).

Findings on Anxiety and Stress about Ambiguity

According to the information obtained from the mothers who constitute the sample group, anxiety and stress conditions stemming from ambiguities vary significantly. At this point, where ambiguities regarding their past and upcoming experiences form a concern for the future, it is observed that issues such as the education process, marriage and social life of their children with special needs come to the fore as a source of stress. On the other hand, not every family feels the same concern. Families who accepted the situation have less anxiety for the future. The presence of mothers who had fainting and crying fits in so far as their fear and anxiety and even suicide thoughts shows how important psychological health and well-being are. When the ambiguity experienced by the families is resolved and becomes more predictable in this extraordinary process they face, it is observed that the families feel better and even use the expressions that those days are not as bad as they expected later on. In fact, there were families who emphasized that this special situation of their children had a special place in their own family relationships and that they became a family thanks to it:

> *"Our minds were always occupied by thoughts as, god forbid, if something bad will happen in the future. This ambiguity of the child has worn us out so much as to what will happen in the future" (BB, 37, H, SS).*
>
> *"We raised my first child with my mother-in-law. So I did not figure out much. It was the first time I was raising a child on my own. Doctors in Izmit sent us to Istanbul for a test or something. After the results, I cried a lot, I was very scared. Since the time was limited, we couldn't talk to the doctor. I entered into the internet on the phone and searched. When I read horrible things, fear haunted me. I was sorry, how it will progress, what will happen. The examples I saw on the internet frightened me a lot. I thought the worst. I wondered if there will be a death" (BB, 37, H, SS).*
>
> *"When the doctor in Eskişehir said so, I jumped out of my skin. I searched afterward. She can't speak but thank God, she is not bedridden. It was very difficult to accept, I even thought about suicide sometimes. I had a psychological treatment then" (DD, 46, H, PS).*
>
> *"I did everything said. I think a lot about whether I had a lot of stress during pregnancy. Or something happened after the baby was born, and the idea that I couldn't notice it hit me a lot. Did something happen during pregnancy? Or did I have eclampsia, and but I was not aware of? Is it my fault that this happens? I questioned a lot. When I think about it, I become sad" (BB, 37, H, SS).*
>
> *"I took care of Y.M for the first 9 months he was a very normal baby. When he was 9 months old, I turned back to work, whatever happened took place after that. I wish I hadn't started work, maybe it wouldn't be like this" (YMO, 28, H, HS).*
>
> *"I was constantly thinking that will my child be able to love someone? Get married? Study? Will he be able to make friends? I started having fainting fits then" (KD, 35, FL, SS).*
>
> *"He is three years old today. Every time when I went to control for nine months; they said 'we can terminate it if you want, you have such a right. That is, nothing happens legally. I refused it at every examination. They showed that paper to me. At that time I had many psychological problems" (MD, 31, H, SS).*
>
> *"They performed progeny testing or something. They examined everything. Yes, there was retardation. Test results as to whether there is a chromosomal disorder or not in terms of having syndrome come after 3 months. Three months became like a prison to me. You know, always, I cried, I thought about what will happen, how it will go, how it will be, how this child will read, how to marry. I was always sad, crying" (SH, 28, H, HS).*
>
> *"I talked to my brother's wife, she asked about my child's problem. As far as I understand, I said that my child does not look in my eyes, if it does, I will understand the problem but my child does not see me. She said, well, I don't want you to scare, but she said it's a symptom of autism. I said what autism is. Then I started searching on the internet. Then I figured out that this is one of the autism symptoms. The phone fell from my hand, I started to cry. I went into the crying fit, called my husband, I said come home urgently" (TG, 29, H, HS).*
>
> *"In that period of time, whenever I entered the internet, I always came across articles about autism providentially. I think a few signs fit my child. Then I talked to my husband. I searched on the internet for what autism is, but one is very afraid when not know what it is. What will happen and what will be done" (YMO, 28, H, HS).*
>
> *"Now my daughter is 3.5 years old, I still haven't searched for it on the internet. Because, there were some rumors*

> *regarding earlier die of these children. I also asked these rumors when I went to the doctor in Izmit. The doctor said to me 'Only God knows when and who will die, no one can tell when anyone will die. These children need love, raise her with your love", at that moment I relaxed" (ZK, 40, H, PS).*
> *"You get away from it all, you just engaged in the child. You have no connection with the house anymore. There was only A. in our lives; we were thinking about 'what we can do' but we were not worried about the future" (AA, 39, H, HS).*
> *"Without it, we wouldn't be a family. It is the basis of our home. We would not be without him" (AÇÜ, 27, H, SS).*
> *"I just want it to be with me, be healthy, be recovered. At the moment, I don't care 'will he be able to join the army for military service?', rather, 'will he be able to outgrow the diaper, say mother?' I think of them" (ÖD, 36, H, SS).*
> *"He went to kindergarten for 6-7 months. They, from Serdivan Guidance and Research Center, said this school. We took a lot of tests. Finally, it was said atypical autism. Then we came to this school. It was not as I scared" (TG, 29, H, HS).*
> *"M. wouldn't hold my hand. Now, he is holding my hand for 2-3 days. We've been traveling outside constantly for two days. He never held my hand, just with his fingertip. Even this made me very happy. Its communication is in that way. He makes eye contact for close to 1 minute. He stares when someone says something" (MD, 31, H, SS).*

Findings on Anxiety and Stress about Exclusion

Considering the anxiety and stress conditions of the participating mothers in the research, it is observed that most of them mainly have anxiety about "what if they don't like my child, if they exclude him". In addition, the unfavorable situations experienced in public transportation, the insistence about the termination of pregnancy, the acceptance of the siblings each other, being more proud of the other grandchildren, the fears as to what will happen in my absence, come to the forefront as general sources of stress in exclusion. Differently from this, some mothers particularly stated that they can take away their children anywhere, they do not hide their children from anyone, and the power in so far as their husbands give them a back and support them. It can be observed from the statements that the anxiety and stress conditions that these families have about their children are less than other families:

> *"My husband's family is at an advanced age. They are obviously not very knowledgeable, but we haven't benefited from anyone, its aunts, etc., all of them are far away and also my husband is always on the roads, thus I care for my child. I am very lonely in this regard and the child should get support from everyone. People should not hesitate to get help from around, and we should explain this to our around and ask for support. Particularly in public transportation vehicles, people should be more sensitive, etc. Negative looks shouldn't be given on us, please" (ABV, 49, H, SS).*
> *"While I was talking to my children about the special situation of their siblings, I opened an autism video on television. The children were surprised. But my 13-year-old daughter figured out, she said mom did something happen. My other daughter and son found it hard to accept. I explained to them later therefore the relations are good now" (DD, 46, H, PS).*
> *"You see, you know, why they are doing this all the time. Let's terminate it, let's get it out. I was always sad about that. I was stuck in this hospital environment. They said let's terminate even when there were last three days. They said let's make a needle. We also visited pediatric surgery. Those three days passed to me as if it was 9 months" (MD, 31, H, SS).*
> *"You get reactions from outside. For example, when I went to a hospital and sat down, a mother looked at us and said "very strange child", "why this child is so different". But I do not know, perhaps I am a mother of a disabled, I have never*

said "this is so strange" to any child ... You cannot call a child "what a pity". It's his specialty. Everyone has their own skills and abilities. They shouldn't call my child a pity either. When a normal child shouts, I cannot say pity as well" (ÖD, 36, H, SS).

"My family, my sisters-in-law are all sweet on my child, yet I am anxious that, in my absence, what will happen to my child, worried about the future" (YEK, 37, H, PS).

"There are a few, you know, in the neighborhood. But they are disabled, not autism or anything. I wonder will it be like that. They came to my mind. I wonder if they were like that. I thought of them. If so, what are we going to do then? I said. As you know, things are a bit excluded in this way in society. I was very afraid that he will be excluded" (YMO, 28, H, HS).

"My mother-in-law, for example, shows her other grandchildren proudly because they are healthy. They kiss when you say "kiss my hand son", and you know, they say welcome when you say "say welcome my daughter". When you look at Ö. and say him say welcome, in fact, he shows his love in another way. But another eye is needed to figure out this" (ÖD, 36, H, SS).

"I never hid my child. It is too sad that there were those who did not even come to say congrats" (ABV, 49, H, SS). "My husband was constantly afraid that if they don't like our child and exclude when he goes to school one day" (AÇÜ, 27, H, SS).

"By saying that we have nothing to do, my husband was both supporting and giving me a back. That was good to me. God forbid, what if he thought negatively too! I don't know what would have happened if he said why it came to this" (BB, 37, H, SS).

"Her older sister is protecting him by usually speaking to her cousins like don't shout at him, he is sick already. Say something 2-3 times. He doesn't understand. You will be more to him" She is only 8 years old. Her brother is the same. They try not to batter while loving in order to protect him. While we think as to whether she will be jealous, since she was also our daughter, she does more than we do. Asks his mood, likes and takes care. When she goes home, she asks, "What are you doing M.? For example, he cried a lot in the evening. His older sister said to him 'Why are you crying? I can't understand you, my brother. His father is in shock. She also cares about his school. She is far beyond our expectations" (MD, 31, H, SS).

"There are some who ask about Ö. without hurt. Without mentioning his illness 'how is Ö.?" The circle of friends made me relax. It made me socialize. Socialize absolutely" (ÖD, 36, H, SS). "I have never got strange reactions. Everyone came near us and loved him, I react if I get strange reactions, I guess I'll walk away from that place. I behave a little hard, maybe I can't help myself saying something" (AÇÜ, 27, H, SS).

"People generally love him. There are not so many people we have already met outside. But if we are going to go somewhere, a wedding, an association, etc. I take him too. We take him wherever we go. We go to dinner together with my husband and children. Z. is whatever our other children are for us" (ZK, 40, H, PS).

"My grandmother takes care of my son because I work. She brings it to school every day and waits at school" (KD, 35, FL, SS).

DISCUSSION AND CONCLUSION

The study was designed in order to determine the stress and anxiety conditions based on the disabilities, and the feelings and thoughts, causing to these feelings, of the thirteen mothers who have special needs children from different disability groups between the ages of 3-6. According to the results of the study, it was found that almost all mothers experienced great sadness and depression when they learned that their child would be/was disabled, they gave stress responses due to grief process such as severe crying fits, insomnia, eating disorder, thinking constantly about the situation in their mind, etc. It is understood from the expressions and the intensity of their stress responses that two of the mothers of special needs children diagnosed with autism spectrum disorder are still unable to accept their disability. Regardless of whether the disability in a child occurs due to congenital causes or at any time of the development period causes families to experience intense sorrow and grieving (Fışlıoğlu and Fışlıoğlu, 1997). The fact that child has disability while waiting for a healthy baby causes families to experience a process in which they are confronted with situations such as shock, denial, anger, fury, anxiety, embarrassment, chaffer, from pillar to post, waiting for a miracle, rejecting child, and rationalization (Deniz et al., 2009; Varol, 2005; Ataman, 1997; Özdoğan, 1997; Seligman, 1989). Researches carried out with parents of a disabled child are to be such as to reveal that the type and degree of disability of the child is an important factor predicting the stress of families. For instance, some studies have demonstrated that having autistic children instead of educable children is a factor that increases stress (Akkök et al., 1992; Şengül and Baykan, 2013). In studies performed on stress perceived by mothers and fathers of disabled children, it was recorded that parents with children in the preschool period had higher stress levels (Yurdakul et al., 2000; Kaner, 2004).

Some of the participating mothers in the study also expressed stress factors in relation to family functionality. It is understood that the mothers who mentioned that they devoted all their energy to their disabled children with the thought that they had more duties in taking care of their children, therefore they could not allocate private time for themselves, also stated that they could not be supported by their spouses at the desired level. Within this context, it was recorded that mothers constantly used expressions of fatigue, low energy, burnout, and helplessness during the interview. Deformation of family functionality in families with children with disabilities is another cause of stress. In the care of children with disabilities, more duties fall to mothers mostly therefore it causes mothers to fully devote themselves to their disabled children. Due to being continuous characteristics of the needs of disabled children such as constant care, attention etc., and mothers cannot allocate time for themselves, and the fatigue of the process and the excessive responsibilities of mothers cause them to have conflicts with their spouses (Doğan, 2001). A few of the participating mothers in the study stated that they received emotional support from their spouses in the process of accepting their child's disability and that this support had a positive impact on coming through the grieving process. It was predicted from the sentences of the mothers participating in the study who stated that they received adequate spouse support that they were more acceptive for their children's disability and their anxiety and stress levels were lower by comparison with those who stated they couldn't get that support. In studies performed for the families with mental disabilities, it is revealed that helping spouses each other reduce stress and this leads to healthier family functioning (Kaytez et al., 2015).

It was determined that the anxiety and stress conditions of the mothers, who participated in the study, arising from their children's disabilities, were concentrated under three main headings. The first of these was the anxiety and stress situation that developed due to the feeling of inadequacy that the mothers felt when the first moment of confrontation and after they found out that their children were disabled. It was determined that the sense of inadequacy due to disability grows out of the mothers' lack of/unable to have the knowledge regarding the disability, the thought that their efforts are not sufficient for their child, that they did not find the educational opportunities in their place adequate, that the financial opportunities are not sufficient for the intensive special education of their children and the poor support from the spouse. Parents' inability to have sufficient information about the child's disability and/or lack of adequate information support from the field specialists following the diagnosis process has commenced can lead families to stress. Mothers with disabled children show negative psychological indications and may be more sensitive to stress, particularly when they do not get support from fathers in the care of their children (Özokçu and Canpolat, 2013). Families with disabled children confront emotional disorders as well as stress. Efforts to find a proper educational institution for children with disabilities, needing more money for special education, difficulties in explaining their child's condition to their family or other individuals in the society, engaging in different searches for their children, needing more time and energy for their children's care and emotional disturbances in families can be the causes of emotional weaknesses, tension and conflicts as well as social deterioration (Kavak, 2007; Aydoğan, 1999; Aslan, 2010; Lusting, 1999; Sarısoy, 2000; Özokçu and Canpolat, 2013).

It can be suggested that the second important factor regarding the anxiety and stress conditions of the mothers who participated in the study, arising from their children's disabilities, is ambiguities. These ambiguities are rather composed of inability to predict the course of the child's disability and anxiety and stress conditions stemming from concerns about the future of the disabled child. Having a disabled child not only increases the stress, anxiety and concern levels of the parents but also unfavorably affects their future expectations (Cin and Kılıç, 2005; Uguz et al., 2004). It was recorded that some of the participating mothers in the study had concerns about the future care of their disabled children, while others experienced anxiety and stress on matters such as whether their child's future education life, friendship and emotional relationships could be, whether they could get married. Ambiguity as to what children with disabilities will encounter in the future, and ambiguities as to how their disabled children will continue their lives, especially after their parents aged or their death, can cause mothers to experience constant anxiety (Coşkun and Aktaş, 2009). Some of the participating mothers in the study expressed that they experienced a positive change in their family dynamics after the disabled child became a member of the family. It can also be stated that the stress arising from the change in the family has positive impacts on some families. In some studies conducted, the spouses mentioned that after having a disabled child, their marriage gained strength, they constantly made a "collective effort" for the development of their children, and this effort further united them and strengthened their relationship (Kazak and Marvin, 1984). In another study, it was recorded that with the participation of the disabled child to the family, a kind of mother-father-child triangulation was formed, and the spouses construe other family problems as more insignificant thanks to directing all their interests to the disabled child. In other words, disabled children act as the "walking stick of the relationship" in the family (Doğan, 2010; Yıldırım and Akçemete, 2014).

A few of the participating mothers in the study expressed that they initially questioned/blamed themselves for their child's disability. Several of the mothers stated that they questioned whether they had a part in their children's disability for a long time and still they felt bad when they remembered this situation from time to time.

It can be suggested that the third important factor regarding the anxiety and stress conditions of the mothers who participated in the study, arising from their children's disabilities, is the sense of exclusion that the disabled child may confront. It can be stated that the underlying thought at most that worry the great majority of the mothers participating in the study is the feeling that their disabled children cannot be accepted and supported by the social circle. Social support is identified as a concept of how much the individual is loved and respected by others (Sarason et al., 1983; Kaner, 2003; Yamaç, 2009; Kaner, 2010; Aksel, 2018). Most of the participating mothers in the study expressed that after the birth of

their disabled child and/or the diagnosis of the disability, at the first level, they got social support from the nuclear family members, their close relatives and friends, and at the second level, that they did not get adequate social support from neighbors, distant relatives, and friends. Most of the mothers, on the other hand, stated that they took social support from social institutions. Social support points out to the emotional, instrumental, or informational assistance provided by the family members, relatives, friends, and other relationships existing in the society (Şahin, 1999; Sungur Bozdoğan, 2011).
In the study of Karadağ (2009), it was demonstrated that there was a negative relationship between the despair levels and social support factors of mothers with children with disabilities, and as the level of social support perceived by the mothers increased, their despair levels decreased. Again in the same study, it was also recorded that the social support levels of the mothers are low, who always feel uncomfortable from the perspective of society to the disabled and always have problems within the family, anxious about the future of their children, feel disappointed and guilty, have difficulties in the treatment process and express that their child brings an additional economic burden to the family. In their research, Altuğ et al. (2006) revealed that families with children with mental disabilities do not get adequate social support, families who find social support from the environment unsatisfactory express more living drawbacks and experience intense anxiety about the future of their children. In other studies conducted with mothers, it has been revealed that mothers with children with disabilities have more financial and moral difficulties and need more support when compared to other mothers, that mothers who get support are emotionally more engaged in their children, mothers who perceive high levels of social support have high self-esteem and low levels of stress and depression (Deveci and Ahmetoğlu, 2018; Kaytez et al., 2015; Şentürk and Varol Saraçoğlu, 2013; Boyd, 2002; Yıldırım-Doğru and Arslan, 2016; Deniz et al., 2009; Canaslan, 2014; Weis, 2002; Karakuş and Kırlıoğlu, 2019).

Suggestions

- The couples who are at risk of having a child according to the tests carried out pursuant to the procedures of marriage should be informed about the disability conditions that may occur as a result of possible pregnancy, as well as a follow-up system should be developed for these couples,
- The personnel of primary health care institutions should provide adequate information to the expectant mothers who have a risky pregnancy about possible risks and refer them to the relevant units,
- Field specialist health personnel should inform families about the disability adequately,
- Prenatal parenting education should be planned in order to increase the prenatal level of knowledge for the purpose of developing the strategies of parents with disabled children to cope with the problems of the disabled child.
- Long-term parental education should be provided by specialist staff, including the post-natal care of children with disabilities, developmental characteristics, possible risks, etc.
- Families, especially mothers and baby-minders, should be educated on the education and care of disabled children.
- Education programs should be prepared in order to enable parents with disabled children to cope with their psychological and educational problems.
- Social support should be provided to families with disabilities by means of informing the close relatives and friends of parents with disabled children by specialists.
- Social network systems should be developed in order to enable families with disabilities to communicate with other families of children with disabilities, and families should be supported in accepting their disabled children.

- Families should be informed about the functions of special educational institutions around them and be encouraged to start special education in early childhood.
- Early childhood units and special education kindergartens should be opened for children with disabilities across the country,
- Social sensitivity should be improved by means of preparing public service announcements, publications etc. that will inform the society about disability,
- In order for families with a disabled child to cope with the difficulties they encountered in matters such as childcare, education, treatment and raising, the necessary support should be given to the families by the social institutions.
- Units providing services to families should be generalized in order to reduce the family burden of families with disabilities,
- Families with children with special needs should be provided with lifelong guidance and psychological counseling, covering family education, directing families to the services they need, providing them with the necessary information, providing them with various problem-solving skills when necessary.
- Ensuring that families with disabilities create value, gain social skills and awareness with the help of getting group guidance services, works should be carried out through local governments and schools in order to provide assistance to families in other learning areas.
- Government assistance for children with disabilities should be enhanced and education, rehabilitation, and medical services should be as accessible and sustainable as possible,
- Solutions and activities that provide psycho-social relief for families of children with disabilities should be taken into account by local and central governments.
- Public and non-governmental organizations should take a more active role in social work processes with the society on disability and its continuity should be ensured,
- Measures should be taken in order to implement social support projects that will enable the development of family members with disabilities,
- In order to get benefit from their guidance, empowering and counseling roles in terms of approaching families with children with disabilities, employment of specialists who communicate with families with disabilities such as social workers, psychologists, psychological counselors, doctors and nurses should be intensified.

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