3-6 YAŞ ARASINDA ÖZEL EĞİTİM GEREKSİNİMLİ ÇOCUĞU BULUNAN AİLELERİN İLK DENEYİMLERİ VE YAŞADIKLARI ÜZERİNDE NİTEL BİR ARAŞTIRMA

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Research Article

ABSTRACT

The lives of special needs children and their families significantly differ from the lives of children with no special needs and their families. Many variables are affecting the quality of life and processes related to the inability field, starting from the first years of life. The study aims to reveal the experiences and needs of families with special needs children from birth to age 6, starting from the early childhood period and to contribute to the structuring of special needs education processes with the suggestions put forward. The data obtained in the study were analyzed qualitatively, employing the inductive approach. 13 mothers of special needs children between the ages of 3 and 6 participated in the study. According to the findings, the first response of mothers when they first learned the special needs of their children is usually traumatic reactions. The study found that the pillar of strength for them was their spouses, they experienced social exclusion as well as social integration, most of them needed psychological support but didn't have the opportunity to start to receive this support. Besides, most of them had regrets about the past and anxiety for the future. It was found that these families usually know their legal rights. In addition, the mothers participating in the study suggested that other families should accept their special needs children and immediately provide education opportunities. Suggestions have been developed based on the experience of the special education processes and experiences of families.

Keywords: Special education, early childhood, special needs children.

ÖZ

Özel gereksinimli çocukların ve ailelerin yaşamları, özel gereksinimli olmayan diğer çocuk ve ailelerin yaşamlarından oldukça farklılık göstermektedir. Yaşamın ilk yıllarından başlayarak yetersizlik alanına dair yaşam kalitesini ve süreçlerini etkileyen birçok değişken bulunmaktadır. Bu çalışmanın amacı, özel gereksinimli çocuğu bulunan ailelerin, erken çocukluk döneminden başlayarak 0-6 yaş aralığında yaşadıklarını ve gereksinimlerini ortaya koymak ve geliştirilen önerilerle özel eğitim süreçlerinin daha istendik şekilde yapılandırılmasına katkı sunmaktır. Çalışmada elde edilen veriler, tümevarım yaklaşımı kullanılarak, nitel olarak analiz edilmiştir. Çalışmaya yaşları 3 ile 6 arasında değişen özel gereksinimli çocuğu bulunan 13 anne katılmıştır. Araştırmada elde edilen bulgulara göre, annelerin özel gereksinimli çocuğa sahip olduğunu öğrendiklerindeki ilk tepkileri genellikle travmatik tepkiler olmuştur. Annelerin en büyük destekçilerinin eşleri olduğu, sosyal dışlanma yaşamanın yanında sosyal bütünleşmeye dönük yaşantılarının da olduğu, çoğunun psikolojik desteğe ihtiyaç duysa da başlama fırsatı veya şansları olmadığı, yine çoğu ailenin keşkeleri olduğu, gelecek kaygılarının bulunduğu görülmüştür. Bunun yanında ailelerin yasal haklarını genellikle bildikleri anlaşılmıştır. Ayrıca katılımcı anneler diğer ailelere özellikle çocuklarını çabuk kabul etme, eğitim imkanlarını acilen sunma gibi öneriler sunmuşlardır. Araştırmanın sonunda ailelerin özel eğitim süreçleri ve yaşantıları göz önünde bulundurularak öneriler geliştirilmiştir.

Anahtar Sözcükler: Özel eğitim, erken çocukluk, özel gereksinimli çocuk



INTRODUCTION

Child, the most important common value between mother and father, facilitating the formation of a common view of life, is also the primary and most precious common value in their lives. Thus, anything causing of loss of this value can be a cause of mourning for parents. Special needs child is, basically, the loss of an *ideal child* in the minds of parents (Gören, 2016). Thus, when the families face this loss of ideal and afterwards, quality support from both in the family and outside of the family is a necessary and expected service for the treatment (Sardohan Yıldırım and Akçamete, 2014). The birth of a special needs child isn't a normal routine for families. Facing the loss of "normal child" expectation arises as a process. The expectations and reactions of families usually follow similar steps. This process, starting with the rejection of the situation, is an experience, out of the routine, accompanied by the reactions including the confusions in understanding the situation and controlling it (Howard et al., 2010). Families of special needs children experience the mourning process classified by Kübler-Ross (1997) as the five-stage as *denial*, *anger*, *bargaining*, *depression and acceptance* (Gören, 2016). Various stages such as guilt, shame, seeking for a miracle, going from door to door, rationalization can be added to these steps. While most parents experience similar stages, not all parents necessarily follow the same stages. The length and depth of stages differ in their experiences (Varol, 2005). There are different meanings for families and individuals shaped by different experiences and perceptions for even *time* concept. This reveals the existence of subjective sides and subjective meanings in the lives of parents and children (Yıldız and Özgedey, 2018).

The effect of the inability of the child, regardless of the type, is usually the despair and the increase of anxiety level in family members. The anxiety may change depending on the age of parent (Daniş, 2006). Apart from these, conflict may arise in the family, the family may become estranged from neighbours and relatives, and lastly, spouses and family elders may blame each other. All these experiences and changes affect the development of the child as well the relationship, solidarity and functions of family members (Özekes et al. 1998; Özşenol et al, 2003; Hatton et al., 2010; Köksal and Kabasakal, 2012). While their reactions may be similar, the anxiety levels and life quality may vary in the families of special needs children. Yıldırım Doğu et al. (2006) found that this difference was significant in their study on the families of children with hearing impairment and mental deficiencies.

Starting from the early childhood, special education of special needs children is a support service process including the critical applications for increasing the life quality of families, decreasing the negative effects and some developmental delays (Howard et al., 2010). It may take many years for the families to recover from the trauma they experience when they learned about the special condition of their children (Yaman and Atasayar, 2014). The difficulties the parents face especially in the education years of their children make life more difficult for them. The perceptions and qualifications of the experts, taking the responsibility for the special education of the children, about the special education directly affect the educational experience of these children. Aksakal Kuc et al. (2019) revealed the significant relationship between the perceptions and qualifications of special education teachers and their professional experience. It is known that the academic life of a healthy student, who takes education in more favourable conditions compared to the special needs children, is affected by some variables such as the marital status of parents, the number of siblings, the grade, etc. (Abay and Keleşoğlu, 2016). The effect of these variables cannot be ignored in the special education processes of special needs children.

The *appropriate behaviour perceptions* of family and surrounding people about the behaviours of special needs children may differ. In addition, the approaches may also differ from each other (Mermer, 1993). It is observed that most of the time mothers experience the harsh living conditions in the families with special needs children. Mothers are alone in many subjects requiring continuity such as daily living skills and organizing the life of children (Crnic et al., 1983; Kazak and Marvin, 1984). The mothers of children with mental disabilities experience the most difficulty and have the highest stress level among the mothers of special needs children. Mothers, taking the responsibility of the care for their children, experience more burn out compared to the mothers with healthy children (Cummings et al., 1976; Kazak and Marvin, 1984; Hayden and Goldman, 1996; Rodriguez and Murphy, 1997). Therefore, the fact that the sample of the study is composed of mothers increases the importance of the study.

The reactions of the family members, especially the mothers, give when they first learned about the special needs of the children and the emotional upheaval periods directly affect the trauma the children experience (Erkan, 1991). Besides the support services presented to the families for overcoming the adaptation problems they experience with the birth of their children with special needs, the presentation support in other subjects such as care, treatment and education is a necessity for these families due to the special needs of their children (Özşenol et al., 2003). The studies have shown that divorce or separation in these families is more common compared to other families. Besides, the risk of suicide and alcohol addiction increase in parents of special needs children (Eripek, 1993). This study describes the needs, difficulties and demands of families directly with the qualitative methods, enabling a deeper investigation and systematic analysis of the experiences of families. It is expected that the outcomes of the study will contribute to the professionals who serve or will serve the families with special needs children.

METHODOLOGY

Research Model

This research is a descriptive study employing the qualitative design to put forward the difficulties of the parents of children with special needs between the ages of 3 and 6 experience as well as their needs.

The semi-structured interview technique was employed in the data collection process. The fundamental aim of the qualitative study is to investigate the sample in a more detailed way and to reach the emotional depth of the participants' inner world (Bogdan and Biklen, 2003; Yıldırım and Şimşek, 2006). The interviews were conducted towards this aim.

Sample Group

This study was conducted with 13 parents of children with special needs in the Sakarya province. The researchers gave information about the aim and content of the study to the parents participating in the study. All of the parents (100%) were women, and the average age was 35.5. Their children suffer from down syndrome, delayed milestone or autism spectrum disorder. Only 1 parent works, the remaining 12 participants are housewives.

Data Collection Tools

Semi-Structured Interview Form, developed by the researchers based on the views of the field experts, was used for data collection.

Data Collection

10 questions, aiming to reveal the first reactions of mothers when they learned about the special condition of their children as well as the difficulties, obstacles and needs they experience afterwards, were posed to the 13 mothers of children with special needs. The interviews lasted between approximately 40-50 minutes and they took place in the educational institution of the children.

Data Analysis

Semi-structured interviews were conducted with the permission of parents. The obtained data were coded line by line to a special form. Main concepts were inferred from the form by reading line by line and then transferred to the analysis pages (Cohen and Manion, 2007). Considering the reliability of the study, "direct quotations" were used in the opinions of mothers. In this way, the concepts and relations were obtained, which are necessary for the explanation of the obtained data. The first letters in the parentheses denote the initials of the children, the numbers denote the age of mothers, the following letters denotes the occupation of mothers (HW: Housewife, FW: Factory Worker), and the last letters denote the education level of mothers PS: Primary School Graduate, SS: Secondary School Graduate, HS: High School Graduate).



FINDINGS

Qualitative data obtained from the analysis of the interviews are presented below with codes, themes and categories by directly quoting the mothers.

Findings about the time and emotions when they learned about the special condition of their children

All of the parents learned about the present condition of their children when their children were between the ages of 0 and 3. They went to the doctor with the information acquired from the people in their environment. Some parents had limited financial possibilities but still managed to go to the doctor. Besides, while some of the parents try to be strong regarding the condition of their children, they have felt uneasiness, sorrow and depressive. "I learned about the condition when I was 4.5 months pregnant. I was a little upset. They said the baby wouldn't live. My husband was inevitably upset. He lived his sorrow on his own, he tried to conceal. I cried a lot for nine months, I felt so sad (MD, 31, HW, SS). "I learned about the condition when my baby was nine months old and I cried a lot. I felt so alone. I said my child couldn't get better. When the doctors said "genetics", I said 'My baby would never recover" (ÖD, 36, HW, SS). "When we learned about the condition, my child was 1 month old. The results of the genetics test came in 35 days. When I came home, my husband explained the results. But God gave me such strength and power at that moment like I knew the results and I got prepared, even my husband was surprised (AÇÜ, 27, HW, SS). "I was losing sleep over the crying crises of my baby when the baby was two months old. I was upset as I didn't understand the reason for my child's crying. The crying crises lasted until T's (the child) first birthday. We got T vaccinated when T was two years old. The nurse asked me if the baby had started talking. I said T couldn't speak but T was able to call people on the phone and said "hello". T couldn't speak even when T was two and a half years old. They said that T should be speaking until that age under normal conditions. I had a golden bracelet, I sold it and took my child to a private clinic. They run lots of tests. They diagnosed my child with atypical autism at the end (TG, 29, HW, HS). "My baby was diagnosed with down syndrome during delivery in the 39th week. I cannot say I wasn't very sad, but I tried to conceal my sorrow. But what made me sad was the questions of "Will I be sufficient for my child?" And "What will happen to my child after my death?" Only these two questions worried me to a great extent. Subjects such as how to take care of my baby and how to educate didn't affect me a lot. I didn't reveal my emotions to my husband at all (ABV, 49, HW, SS). "Approximately 40 days after the birth of my baby, the seizures started. The doctors here referred us to the izmit province. The doctors in Izmit province said that my baby had seizures. We were admitted to the hospital as an inpatient for three months. Lots of treatments were administered, and the baby had MR tests. In short, everything happened after the fortieth day (AA, 39, HW, HS). "The pregnancy period was normal, we had a normal delivery. Everything was normal until the baby was six months old. B (the baby) couldn't hold his head. B was very inactive. We took the baby to the child neurology department in İzmit. The doctor said that the baby suffered from the cerebellar degeneration. After that diagnosis of the doctor, I cried a lot that day, I was so scared. I suddenly let myself go. But then I said to myself "I have to be strong" (BB, 37, HW, SS). "After the one-year vaccination, I observed some changes in my child. Because my other three children were normal" (DD, 46, HW, PS). "I didn't work and took care of my baby until K (the child) was one year old. K was one year old when I realized that K was different. K wasn't interested in toys I bought, K did not look at the toys. K didn't establish eye contact with me. But I act like nothing. Then one day my sister said "Sister, your baby doesn't establish eye contact with us... K doesn't react to the toys. Is there something wrong with your baby? I took some videos of your baby without your notice. I showed the videos to a friend of mine, who is a special education teacher in İstanbul. My friend said he couldn't tell exactly the problem. However, he said the baby might be autistic. My sister urged me to see a doctor. It was the first time I heard the word "autism" from my sister. Then my sister and husband took my baby to a doctor without my notice. The doctor diagnosed my baby with autism. They returned home and told me the situation in tears. We cried all together" (KD, 35, FW, SS). "My child was born, and there was a change. I took the child to the child neurology department of Marmara University in Istanbul. They investigated the development of the child. They administered the Denver test. This happened when my baby was between ten to eleven months old. They did the genetics tests and other similar tests. It wasn't down syndrome. My child was diagnosed with delayed cognitive development. I was upset, I cried all the time (SH, 28, HW, HS). I went to the doctor seven times for routine checks during my pregnancy. I went into hospital one or two days before the delivery. I learned that my baby had Down

Syndrome during delivery. I was lying in the delivery table when I heard it. The doctor said "This baby had down syndrome. You didn't know it?" I could not understand what was "down". "Will my baby die?" I remember asking.

I was so scared. They briefly explained that the baby was healthy but had down syndrome (YEK, 37, HW, PS). "When my maternity leave was over, I started to work again. It was after I went to work when everything started to happen. When I went to work, something change in my baby. My baby was nine months old at the time. It was like, something happened and a break from the world happened. I realized that something was wrong when YM (the baby) was ten months old. A decline happened in the child" (YMO, 28, HW, HS). "We learned about the condition when my child was eleven months old. I felt so bad. It is an unexplainable and different emotion. That moment, I asked myself "Why did this happen to me?". May God forgive me. I feel very sorry for those thoughts. I didn't rebel against God, but I thought "Why me?" (ZK, 40, HW, PS).

Findings about the first reactions of themselves and the people in their environment when they learned about the special condition of their children

According to the information obtained from the mothers in the sample of the study, especially the elder siblings (elder sisters and elder brothers) positively met their sibling with special needs, they didn't exclude the sibling and tried to help. In addition, the family elders accepted and adopted the child with special needs, despite not understanding the condition of the child. Parents of the special needs child accepted the condition of their child while at the same time experienced a shock. However, in the aftermath, they recovered from the shock and focused on treatment opportunities. "When my sister learned about the condition of her sibling, she was eight years old. Since then, both her and my son try to protect their sibling, they are always anxious" (MD, 31, HW, SS). "The siblings of my husband came to our house. They told me that they wouldn't leave me alone, they would give me moral and material support. And they did as they had told. They always gave me support. My in-laws always supported me. They even said "You deliver the baby, we will support you. Don't worry when we are with you". My parents never considered my baby as disabled. They prepared their house considering my child's needs. They still don't consider my child as disabled (ÖD, 36, HW, SS). "My child is still treated with great respect. My husband always feared that the child wouldn't be loved. He feared our child's exclusion in society and school. He feared that people wouldn't want our child in the school (AÇÜ, 27, HW, SS). "Not all of our relatives know about the condition of our child. Only my father-in-law and mother-in-law know. They accepted my child" (TG, 29, HW, HS). "Our relatives learned after the report came back. We said that there was a possibility. I didn't hide it from anyone. Some of our relatives didn't come to congratulate the birth of our baby. Because they didn't know what to say. When my son learned about the condition of his sibling he said: "This baby is the key to heaven for you". He was just seventeen years old" (ABV, 49, HW, SS). "Our family elders were very upset when they learned about the condition. But then they accepted it as normal" (AA, 39, HW, HS). "Everybody was confused, especially my family. They were upset. They asked, "What will you do, how will you take care of the baby?". Right now everything is fine. They accepted my child. They said "There is nothing to do. This is God's willing. God gave you this child" (BB, 37, HW, SS). "When I learned about the condition of my child, I cried. It was difficult for me to accept the child. My husband wasn't with me. I had difficulty in accepting the child. I cannot lie, I even attempted suicide. I was left alone in life. The psychiatrist I went gave me medication. I accepted the situation in time. There is currently progress, at least. Even the people in our circle see that I pulled myself back" (DD, 46, HW, PS). "I fought very hard to accept the difference in my child. I didn't go to the doctor because I didn't want my child to be stigmatized. My mother in law said "Your husband also spoke late. Your husband and your brother-in-law both spoke when they were nearly five years old. There is nothing wrong with your child" (KD, 35, FW, SS). "My husband didn't even react in any way. We said "God gave us the baby. Even we had known about the condition, we wouldn't have done anything". Our families took the situation normally. My family, relatives and neighbours supported us. I only cried when the doctor said: "Your baby has down syndrome" (YEK, 37, HW, PS). "I didn't want to associate my baby with any illness. We experienced various emotions. We felt sorrow. We felt stress. I cried a lot. What we will do if the baby has autism? What will happen in the future? These questions run through our minds. My husband still cannot accept it. He feels great sorrow but he doesn't realize" (YMO, 28, HW, HS).

Findings about their biggest supporter

According to the information obtained from the parents in the study sample, eleven of them showed their husbands as their biggest supporters while one of them said her children were her greatest supporters. "My husband gave me so much



support" (MD, 31, HW, SS). "My biggest supporter on this subject was my husband. He was always with me" (YEK, 37, HW, PS). "My husband and I sat on a park bench. We cried together. Then, he looked at me. He said, "Don't cry". I will be at your side for my whole life. If you think about it, we will have a very favourable and obedient child. Because the child will never harm us. We have to support our child all the time. We have to do kindness and I will not be a bad father. I promise you, I will be with you for my whole life. So we are the biggest supporters of our child. Never expect anything from my parents. I don't expect anything from your parents, either". (ÖD, 36, HW, SS). "I am grateful for my husband. He gives full support in anything. My husband never leaves our child, as well" (AÇÜ, 27, HW, SS). "My biggest supporter is undoubtedly my husband. He's always with me. We both have large families. But only my husband experience the same feelings with me. My elder sister feels sad, my elder brother tries to consolidate me. They offer financial support but what I need most is spirituality. My husband gives that spiritual support in the best way because he understands me. Because he experiences the same feelings with me "(TG, 29, HW, HS). "My husband was very supportive. We always doubted whether our child had down syndrome or not, because our child didn't look like a child with down syndrome. We didn't hurt each other on these issues. My husband is very religious, he never forced me and accepted the child very insightfully" (ABV, 49, HW, SS). "You get used to the situation in time. My husband gave so much support during this process" (AA, 39, HW, HS). "My husband gave me support. Sometimes, I suddenly fell into pessimism. I feel so sorry when the head of the baby feel to the side, when the baby cannot control the neck, or in similar situations. My husband said "Why you feel sad? This is our child. Whether our child can or cannot walk or talk, this is our child" (BB, 37, HW, SS). "My biggest supporters were my children. My daughters have accepted their sibling, thus we accepted our child as well" (DD, 46, HW, PS).

Findings about the Attitude of Social Circle and the experiences the mother had

According to the results of interviews conducted with the parents participating in the study, while nearly half of them gave negative answers, the other half of them gave positive answers. Some of the people in the social circles of participants supported and accepted the condition of children while some of them were confused, looked askance at the situation and found it strange. "I am not obsessive in that subject. In other words, I don't care. Sometimes I see faces looking at us strangely or like we are desperate" (MD, 31, HW, SS). "I felt social exclusion. I felt social exclusion from my neighbours and relatives. I sometimes felt exclusion from my father-in-law and mother-in-law. I don't know. I don't know if it was real or I felt it psychologically?". Such as if a neighbour came to our house, or if someone in the house had influenza, my mother-in-law said: "You can take the child downstairs, or else the child may catch the flu", I got her wrong. Doctors say the same thing. My child has a delicate condition. But when my mother-in-law said like that, I understood it like "Take your child downstairs, so nobody sees your child". But now I overcame this problem" (ÖD, 36, HW, SS). "They like my child very much, and my child also loves them" (AÇÜ, 27, HW, SS). "I haven't received any negative verbal reaction so far. Maybe people saw us differently but I don't care much about these types of situations" (ABV, 49, HW, SS). "I received positive support from the people in my environment. They said the child would get better. People didn't leave me alone. My friends, my family and my neighbours gave me so much support" (AA, 39, HW, HS). "I didn't feel anything negative for my child from the people in my environment. We walk in the streets in downtown. One day a woman in the downtown came and caress my daughter, and asked: "What does she suffer from?" How much you accept the condition of your child, this question reminds you of the reality. I felt sorry for a moment" (BB, 37, HW, SS). "Apart from this, I feel excluded from my social circles because of my child. We have great difficulty especially in parks, neighbourhood and shopping centres" (DD, 36, HW, PS). "People say "So strange, so gull, so pitiful". Now my child understands everything" (SH, 28, HW, HS). "All the people in our social circle loves our child very much. Our child is the most beautiful part of our home, our family. We didn't feel any exclusion from our social circle" (YEK, 37, HW, PS). "I lose my nerves when people give pitiful reactions when I say "My child cannot talk". I cannot imagine what will they say when I explain the whole situation (autism)" (YMO, 28, HW, HS). "I have not received any negative reactions. People love our child. We don't have large circles. But we go together with our cild when we go to weddings or similar social gatherings" (ZK, 40, HW, PS).

Findings about Whether They Received Psychological Support

Half of the parents participating in the study stated that they received psychological support after the delivery while remaining half stated that they didn't receive any support. "We couldn't receive support. We waited for our child to start school. If nothing goes wrong, we will take support as the whole family. My husband, my daughter, my son. We want to

consult for ourselves, for our special child, and our children" (MD, 31, HW, SS). "I went twice to the hospital in Bursa to see a psychiatrist. The psychiatrist there referred me to a psychologist here.

When I went to the psychologist, I explained my experiences with my husband, my mother-in-law, and my siblings with all the details. When I look back now, I see that so much weight was lifted off my shoulders. As the psychologist doesn't know me, I was able to explain my problems easily. I didn't get in bad with anybody. These sessions were actually beneficial for me" (ÖD, 36, HW, SS). "Yes I took medication but I did not want to be addicted to the pills. I used pills for one month then discontinue. I said, "Medicines will not work for this issue". But, unfortunately, I went to the doctor again a week ago "(TG, 29, HW, HS). "I didn't receive psychological support regarding the condition of my child" (ABV, 49, HW, SS). "I didn't receive psychological support at that time, I didn't feel the need. I had to stay strong and not collapse. I adhered to my husband and overcame this process with him" (AA, 39, HW, HS). "I thought about suicide, and then I went to the psychiatry department. Psychiatric support felt good. Watching videos about autism and starting the special education made it easier for me to accept" (DD, 46, HW, PS). "A that time my fainting seizures started. I went to the hospital. Doctors diagnosed me with the panic attack. I started to take medication" (KD, 35, FW, SS). "No, I didn't receive psychological support. We thought everything as God-given, so we didn't do anything" (YEK, 37, HW, PS).

Findings About the Future Concerns of Parents

Some of the participants in the sample mentioned their future concerns while some of them stated they didn't have any concern for the future. The future concerns of parents took form of social rights and contents such as financial aspects, speaking ability of their children, whether their children could go to school, whether their children could make friends, etc. "I only had one question: Will my child be able to talk? Are there children with this condition who cannot speak at all? I don't know. I wonder if my child can talk? I pray for my child's good health, but this is a concern for me. Will we be able to talk with each other?" (MD, 31, HW, SS). "No, I want to live the moment. I don't have any future concern as to what will happen to my child when something bad happens to me. I used to fear that my child would be sick if someone coughed in the same room with us" (ÖD, 36, HW, SS), "In fact, I have financial concerns. For example, school is very limited in Sakarya province. How will the families with no financial means afford the education" (AÇÜ, 27, HW, SS). "Of course. "Will my child be able to go to school?", "Will my child have friends?", "Will my child be able to adapt?". I fear that my child will be considered an idiot. I fear that people will treat my child as "T (the child) has autism, T will not understand whatever we say". I fear that T will not be able to get married when the right person comes. The future is what I fear most" (TG, 29, HW, HS). "After school started, my concerns about my child decreased. We felt relief after early education" (ABV, 49, HW, SS). "I have no future concerns for my child" (AA, 39, HW, HS). "I don't think about that question. I want to live in the moment. I try to think about the things that make me happy. Sometimes these questions suddenly come to my mind. I think about what will happen. Will my child be able to walk or talk in time? But when we do things together, I think about my child's smile while doing things. I try to live the days thinking about the good things my child does. When I don't do this, I become depressed, I cry and my head hurts. I feel bad and cannot take care of my child" (BB, 37, HW, SS). "I used to have concerns about the future but I felt relieved after watching TV serial "Mucize Doctor (Miracle Doctor)", depicting the life of a medical doctor with autism. My only concern is if my husband will take care of my child after my death. But at least my son will take care of his sibling" (DD, 46, HW, PS). "At first, I had intense anxiety. Now I still have concerns. Will my child will continue in the inclusive education? Will my child be able to talk? I still have concerns. But not as intense as it used to be. But I think I started to accept the situation" (KD, 35, FW, SS). "All rivers fall into the sea. I think that our child's only problem is talking. I think that when the child talks, we will communicate and overcome problems. We will share something" (SH, 28, HW, HS). "I have concerns for the future. I wonder what will happen to my child after my death. I have older children to take care of my child, but I am mother, I wonder what will happen after me" (YEK, 37, HW, PS). "Will my child be able to talk? Will Z (the child) be able to go to school? Will Z be able to learn something? Will Z be able to fend? What will Z do if I die? Who will take care of Z? These are my concerns" (ZK, 40,

Findings about the parents' knowledge of their legal rights

All of the parents participating in the study are aware of the legal rights of children. They all know their legal rights. "For instance, my child has a report stating "Severely Disabled". We can get a certain salary, we can get discounts for the bus fare, we can get free diapers, etc. We know that but didn't need until now. I did not want to get diapers for free. We have one



child, we can afford right now. But if I need in the future, I can apply for these free/discounted services. I don't oppose at all. But if there is no need, then I oppose benefiting from these services" (ÖD, 36, HW, SS).

"Yes, I know my rights. We just applied for the salary" (AÇÜ, 27, HW, SS). "I know our legal rights; our state always gives us strength" (ABV, 49, HW, SS).

"I know my legal rights and I benefit from them. I know about the discounted fares, discounted telephone services, etc." (AA, 39, HW, HS). "I am the legal guardian, and I know my legal rights. My legal rights include special education, social rights, guardian's fee. I have a salary through my father" (DD, 46, HW, PS). "We know my legal rights and we receive a salary. If "special needs" is written in the report, it is sufficient" (YEK, 37, HW, PS).

Findings about the Parents' Pieces of Advice to the Other Parents First Learning about the Special Condition of Their Children

The parents participating in the study especially recommended that children should be loved and paid attention, and their education should be definitely given importance. "I saw that peace in the family has great effect on the child. I was a cleaning freak. I even abandoned it. I wish I hadn't given mobile phone to my child till that age. Let me put it this way. M (the child) was always on the phone or tablet pc until M was 1.5-2 years old. I wish I hadn't given M these electronics. M watched TV a lot. Especially when we were inpatients in the hospital. Two or three vascular access changes were made during this process. M didn't eat, I couldn't make M eat the food. M only ate a little when I gave the child phone. I asked the nurses about the phone, and they saw no problem. I wish I did not. I could take care of my child by playing more" (MD, 31, HW, SS): "The parents should first love their children. They can even be seen as freaks by the outsiders, but in fact, they are very beautiful. They are dependent on their mothers no matter their condition or their minds. If we harm them then they will never develop in their lives. We should first be calm. We should ask "What does my child suffer from?". "What can I do best for my child?". Stand firm besides your child. The parents should accept and recognize their children. They shouldn't fear about getting the disability report or the education process. Because there are many disabled people in Turkey. We are not alone. Nothing is like what it used to be. We should take our children to the streets. You shouldn't lock them in the house. They cannot be locked" (ÖD, 36, HW, SS). "They should love their children very much. It is that simple. Because the children need love" (ACÜ, 27, HW, SS). I would not do anything. I left the child and always cleaned the house. I neglected my child because of cleaning. I was not such an extrovert person. I was an introvert. I wish I had been more extrovert. I wish I contacted people while weeping. I made a mistake. I took my child to the playground when my child was one year old. You should take your child to the playground even if she/he doesn't play. My father-in-law, sister-in-law, everybody said something. They said the child looked after that person or another person, and I believed them. I shouldn't have believed them. I shouldn't have believed hearsay information. I should have gone to an expert doctor. If I could go back, I would change a lot of things. But when I told the midwife and doctor that my child couldn't speak, they said: "you did everything". They never mentioned autism. All mothers should be informed. I get most angry on this issue. I wished doctors gave information about this subject. Because I went to the paediatrician. She said, "Nothing is wrong with your child". She gave no information to me. She didn't warn me against the symptoms. Midwives only do what they have to do, they sign and send you back home. I especially want to bring the vaccines to the agenda. I suspect the side effect of vaccines because my child became like this after one and a half year vaccine. If there is something like that, who should be held responsible? This is the major question in my mind" (TG, 29, HW, HS). "Parents get confused as to what to do when they have a child with special needs. Parents should be educated first. Families should first love their children so much. Because love can open all doors. The second point is the education process. Parents should research for education and support their child. Apart from these, the people in their circle are important, there should be people around them. Families shouldn't upset themselves in vain. They should love their children so much. People should behave families with disabled children with tolerance" (ABV, 49, HW, SS). "Mothers learning about the special condition of their children should stand strong and do whatever they can. When they are strong, everything becomes better in time. I did like that, I didn't let myself go. I considered this special condition as God-given. I have done whatever it takes and will continue to do so" (AA, 39, HW, HS). They should think positively. This will give them strength. My child will become good as long as I feel good" (BB, 37, HW, SS): "I had many regrets. I could have recognized the child's behaviours earlier. If I could have travelled to one year earlier, I wouldn't have vaccinated my child. I would search for the diseases I heard about. My advice to the parents learning about the autism of their children is that they should accept the condition. We should trust the teachers. We should search and give importance to special education. We should accept the situation. We should never think about suicide, etc." (DD, 46, HW, PS). "They should accept them normally. They should make

sure that the children get intensive training. They should love their children" (KD, 35, FW, SS). "They shouldn't neglect their children. They should go to the doctor.

They should send their children to rehabilitation, Earlier Childhood Education Center, Education Center for Autistic Children, etc. They should also work for the children in the house. They should take their children to the gatherings. They should talk to their children. They should communicate" (SH, 28, HW, HS).

"They shouldn't get upset because it is a God-given thing. They should hug them and give more attention to them" (YEK, 37, HW, PS). "Firstly, parents shouldn't worry in any way. This is a situation that can be improved with education, so parents should give importance to education. I wish I had taken the special need report at the very early stages. I wish I hadn't waited" (YMO, 28, HW, HS). "They should love their children. The children should be given special education. Parents should also try to educate their children at home" (ZK, 40, HW, PS).

DISCUSSION and CONCLUSION

This study investigated the first physiological, cognitive, emotional, behavioural and psychological reactions of mothers of children with special needs between the ages three to six, their husbands and families when they first learned about the special condition of their children, whether the mothers received social support from their spouses and families, whether they experienced social exclusion, whether they have future concerns about their children, whether they know their legal rights, whether they received psychological support in this process, and their suggestions to other parents learning about the special condition of their children.

Most of the mothers learned about the special needs of their child when the child was between the ages of 0 to three. The majority of mothers of children diagnosed with down syndrome or cognitive milestone learned about the special condition of their child during the delivery or in the first few months after delivery. Some of the mothers learned about the specific diagnosis about the special need within the first year. The mothers of children diagnosed with autism learned about this condition between the first and third ages of their children.

During the interviews conducted with mothers, the feelings, opinions and reactions (shock, denial, blame, rejection, etc.) they had or felt during the acceptance process were focused. It can be inferred from the statements of mothers that a mourning period started for them when they learned about the special needs of their children. As the family members face a problem that they cannot overcome, they react differently during the acceptance process. While the difficulties the families experience are similar, the resilience and coping methods they employed during this process can be different. Some families overcome this process more easily, take constructive steps both for their children and themselves, and try to organize their life by making plans while some families don't accept this situation and cannot overcome a long period of sorrow and mourning (Sarı, 2007).

Most of the mothers reported their first reactions as crying, inability to sleep, inability to eat, losing weight, thinking constantly about the situation, etc. Apart from anxiety, cognitive processes such as inattentiveness, forgetfulness, excessive dreaming as well as emotional reactions such as rage, crying for no apparent reason, inconsistent behaviours, violence and depression can be observed in families with special needs children (Aslan, 2010).



Most of the mothers participating in the study stated that the reactions of their husbands were calmer compared to their reactions. In addition, the husbands used supportive statements and accepted the children as they were. This, in turn, gave power and energy to the mothers. Most of the mothers participating in the study stated that they received the biggest support from their husband and they shared the problems of their children with their husbands. Various studies have found that the reaction of father towards having a disabled child directly affects the emotions of mother and can make the mother anxious and hopeless (Metin and San, 1992; Ceylan, 2004; Staub and Hunt, 1993; Yıldız, 2009; Eripek, 1996; Yıldırım Doğru and Aslan, 2008; Coşkun, 2013).

The majority of mothers participating in the study stated that both their families and their husbands' families exhibited accepting behaviours towards their children with special needs.

In Turkey, especially as a characteristic of eastern culture, the families with special needs children are given support by their families and relatives, they aren't left alone in terms of spiritual and financial needs. The whole family try to overcome difficulties together (Ciğerli et al., 2014: 78). While having a child with special needs cause a mourning period initially, it was observed that in such a situation, considered as a negative one, family bonds become stronger in some families due to the stress and anxiety. In addition, having a disabled child has been observed to have a positive effect on some marriages, strengthening the marital bonds (Kazak and Marvin, 1984; Sarısoy, 2000; Çetin, 2018).

The mothers participating in the study were found to describe their children with special needs as "bringing me and my husband together, our sharings increase, my child is the joy of our home, etc.". It was revealed that children with special needs didn't have a negative effect on the marriage of parents. Özekes et al. (1998) found that spouses in marriages evaluated each other based on the child, and there wasn't any negativity due to this situation in the families with mentally handicapped children and with autistic children. Şen (2014) found that spouses understanding each other and respecting the difficulties have more quickly accepted the situation and found solutions.

Some of the mothers participating in the study stated that they needed and received psychological support after learning about the special condition of their children, some of them received psychiatric support while some of them didn't feel the need to receive support. Vural Batik (2012) conducted an experimental study on the families with special needs children and found that the psychological support decreases the hopelessness levels and increased the optimism levels of mothers of children with the low level of mental disability. In other words, psychological support was found to be effective. Yukay Yüksel and Bostanci Eren (2007) implemented a psychological counselling program lasting for 10 weeks, having a pre-test and post-test pattern with control-group, to decrease the depression levels and increase the problem-solving skills of families with autistic children. As a result, a significant difference was observed in decreasing the depression levels and increasing the problem-solving skills of families.

Almost all of the mothers participating in the study expressed that they experienced intense anxiety about the future of their children starting from the first moment they learned about the special condition of their children. Most of the mothers interviewed were observed to be anxious about the social exclusion of their children, as well as about various subjects such as having their own family, continuing their education and their caretaker after the death of mothers. It was found that the anxiety levels of mothers decreased over time after accepting the special condition of their children. After accepting the children with special needs and organizing daily life in some way, future concerns constitute the basic anxiety. Parents wonder what will happen to their child, who is likely to live longer than themselves, without their support and protection, and fear that situation (Ciğerli et al. 2014).

It was found that almost all of the mothers participating in the study were informed about their legal rights due to the special needs of their children.

Almost all of the mothers suggested the other families with special needs children that the parents should love their children, they shouldn't get upset about the special condition of their children, they should start the special education early, they should find specialist teachers for their children, they should be involved in the education process and make intensive efforts in this direction. Mothers especially emphasized the importance of professional support during early childhood.

Suggestions

It is of great importance that families of children with special needs are given information and directed accordingly before, during and after the delivery by the specialists (doctors, nurses, physiotherapists, psychologists, social workers, other health care professionals, child development specialists, special needs teachers, etc.). It is possible to decrease their disappointment and intensive anxiety situation about the future with the information given by specialists. Long term psychological support should be provided to the families of children with special needs starting from the moment they learn about the special condition of their children (before, during or after the delivery). It is of great importance that parents accept the fact that their children with special needs have differences from the other healthy children. In addition, parents should understand that it is possible to help their children, but their children can't recover completely. The fact that the close relatives (grandparents, uncles, aunts, etc.) and social circles (friends, neighbours, seniors in the workplace, colleagues) are informed about the condition of the children with special needs and give social support to the parents of the child will facilitate the acceptance process of parents.

Different activities (such as public spots, social media information, hand brochure, etc.) should be conducted on a local and national level to raise awareness towards changing the negative perception of society about the children with special needs. It is significant that the schooling for special need children increases nationally so the children with special needs can benefit from the early childhood education departments (0-36 months old) and special education preschools (37-78 months). Improvements should be implemented for the special education rights (monthly 8 hours of course or monthly 8+4 hours of course) of children with special needs.

Parents of children with special needs should be encouraged to benefit from professional help, such as conscious psychological support services, coping skills programs, motivational interviewing applications, etc.

Considering that the communication between the parents of children with special needs with other parents facing the same challenges facilitates the acceptance process, public resources, non-governmental organizations and volunteers sensitive about this subject should be mobilized.



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