

Determining the Problems Experienced by Mothers of Babies with Special Needs

Визначення проблем матерів немовлят з особливими потребами

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ABSTRACT

Introduction. *Having a baby with special needs causes serious emotional problems in families. Mothers are greatly disappointed and go through a difficult process when they learn that their child has any disability during pregnancy, during childbirth, or later. The lack of systematic support services in Turkey regarding this situation makes the process even more difficult.*

Goal. *This study, it was aimed to determine the problems experienced by mothers who have babies with special needs.*

Methods of the Research. *The sample of the study consists of 15 mothers who have babies with special needs. The research is a qualitative study, and the research data*

were collected with a semi-structured interview form (8 questions). An information form consisting of 8 questions was used to obtain socio-demographic information about mothers.

The Results. As a result of the research, intense anxiety and stress states were found in the majority of mothers. In addition, it was determined that mothers after birth could not reach a source from which they could get regular and healthy information about deficiencies. It was determined that mothers could not reach a source from which they could get regular and healthy information about deficiencies after birth. Moreover, they stated that they felt lonely and helpless after the diagnosis and that they could not get enough support from their spouses and close friends (relatives and friends). The mothers also stated that another problem they experienced was the lack of a place where they could reach at any time and get the right information and support about the problems they experienced. While some mothers stated that the experience of parents with previously diagnosed children is better than that of experts.

Conclusions. In line with the data obtained from mothers, the following can be recommended to experts who will conduct research on this subject in the future and to people related to this subject: (a) families feel alone and helpless during the diagnosis of children with special needs. Having a free center that will enable families to receive systematic and regular support about this new issue can help reduce the level of anxiety of families; (b) organizing the right information resources about special needs by the government (online – face to face) and enabling families in need to access these resources easily after the first diagnosis can relieve families.

Key words: special needs, baby, mother.

Introduction

Families with children with special needs often experience social, economic, and psychological problems. When families first learn about the special needs of their children, they experience emotions such as great surprise, shock, intense sadness, and mourning. They cannot always tolerate this situation which they do not know and understand exactly what it is. Having a child with special needs brings a serious change in the life of families. While parents are excitedly waiting for a healthy child, they enter into a process full of financial and emotional difficulties when a child with special needs joins the family (Yüksel & Tanrıverdi, 2019; Aktürk, 2012; Ersoy & Çürük, 2009). With the birth of a child with special needs, parents experience complex emotions and do not know what to do, from whom and how to get help, where to apply, and most importantly, how to live with such a child (Çetrez İşcan & Malkoç, 2017; Çiftçi Tekinarslan, 2010; Metin, 2012). For this reason,

they get confused and try to use all kinds of methods/approaches in order to understand the problem and produce a solution. They often fall into the hands of frauds who try to abuse parents in distress. Parents try many unrealistic methods, paying huge financial costs, in the hope that their children will be like their normally developing peers. However, these negative experiences destroy both the hope and the will of the families to strive.

As a result of research conducted with families with children with special needs in Turkey, it is seen that families experience many problems. Prominent among them; are financial difficulties, being uncomfortable with the point of view of the society on disability, having difficulty in communicating with their environment, having a constant fear of injury/accident regarding the child, worrying about the future of the child, feeling guilty about the disability of their children, having difficulty in the treatment process and not being able to receive any financial and emotional support from their environment (Yüksel & Tanrıverdi, 2019; Ayyıldız et al., 2012; Karadağ, 2009; Kurt et al., 2008; Altuğ-Özsoy et al., 2006). In some cultures, the child is viewed as the personal success or failure of the parents. This situation is mostly perceived as the mother's responsibility in Turkey. If the child is healthy, the mother has done a good job. However, an unhealthy child may be perceived as an unsuccessful process and the mother may be blamed by her environment (relatives, friends, etc.). The father's reactions to having a disabled child also directly affect the mother's feelings and cause the mother to feel Worries and hopelessness (Yazıcı & Durmuşoğlu, 2017; Yıldırım Doğru & Arslan, 2008; Metin, 2012; Hu, 2020). Social norms in Turkey still consider mothers to be primarily responsible for their children's basic vital and developmental needs (Tezcan, 1993). For this reason, it has been demonstrated by many studies that the social support that families with children with special needs can receive from their environment is necessary and important especially for mothers (Yüksel & Tanrıverdi, 2019; Çiftçi Tekinarslan et al., 2018; Gören, 2015; Aktürk, 2012; Köksal & Kabasakal, 2012; Ersoy & Çürük, 2009; Yıldırım Doğru & Arslan, 2008). Studies generally include the problems of mothers who have children aged four and over. However, it has been observed that there are not enough studies in the literature on the problems and needs of the parents after the birth of the baby with special needs or immediately after the diagnosis. Therefore, in this

study, it is aimed to determine the needs of mothers who have babies with special needs.

Methods

Research Model. The research, which was conducted to determine the needs of mothers of children with special needs who applied to İzmir Province Research Hospitals and Guidance Research Centers for diagnosis, is a qualitative study conducted with a descriptive model.

Participants of the Research. The participants of the study consist of mothers with children with special needs who applied to Izmir Province Research Hospitals and Guidance Research Centers for diagnosis purposes. The sample group was determined by using the purposive sampling method among the mothers who accepted to participate in the study voluntarily. In this direction; Having a baby with special needs between 0–3 years old, that the child’s special needs have been diagnosed or in the process of being diagnosed within the last thirty-six months were taken into account as criteria. Fifteen volunteer mothers who met these conditions formed the research group. The demographic distribution of mothers is presented in Table 1.

Table 1
Demographic information distribution of mothers participating in the study

Mothers	1.	2.	3.	4	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.
Age	28	19	37	25	35	40	50	30	32	43	41	52	43	39	51
Education Level	U	H	H	H	U	H	H	U	U	H	H	H	U	U	H
Income Rate	H	L	M	M	L	L	L	M	M	M	M	M	L	H	L
Marital Status	M	M	M	M	S	M	M	S	S	M	M	M	S	S	M
Number of Children	1	1	1	3	2	4	3	2	1	1	2	2	3	1	2
Birth Order	1	1	1	3	2	4	2	1	1	1	1	1	3	1	2
Gender Of the Child	B	G	G	G	B	B	G	B	G	G	B	G	B	G	G
Types of Disability	M	A	D	M	D	M	D	A	A	D	D	A	D	M	M
Level of Disability	S %90	M %60	S %88	M %57	S %88	S %78	M %58	S %83	M %64	M %63	S %87	M %70	S %94	M %65	M %68

“Coding: U: University, H: High school; H: High, M: Moderate, L: Low; M: Married, S: Single; B: Boy, G: Girl; M: Mixed Disability, A: Autism, D: Down Syndrome; S: Severe, M: Mild”

Data Collection and Data Collection Tools

In order to determine the problems experienced by mothers with children with special needs; Semi-structured interview questions obtained by the researcher through the literature review and demographic information about mothers were used as data collection tools. After the semi-structured interview form developed to collect the research data was prepared, 6 faculty members working in the special education department were asked to examine the questions. After receiving feedback from the field experts, the questions were rearranged and the same 6 experts were asked for their opinions again. After receiving expert opinions, necessary arrangements were made, and in the final interview form; 8 demographic information questions (age, education level, income rate, marital status, number of children, birth order of the child with special needs, gender of the child, type and level of disability of the child) and 8 semi-structured questions were prepared. It was paid attention to ensure that the questions are clear, understandable, and simple, as well as questions that mothers can answer without getting bored and share their valuable experiences with us.

Interview Questions:

- When and how did you realize your child's special needs?
- What was your first reaction when you learned about your child's special needs?
- What did you experience after realizing your child's special needs situation? How was your attitude towards him/her?
- From the moment you felt or learned that your child has special needs, what kind of process did you follow for treatment?
- What were the approaches and reactions of your close circle (friends, family, relatives, etc.) when it was revealed that your child had special needs? How did these approaches and reactions affect you?
- What challenges do you face as a parent of a child with special needs?
- What are your plans for the future of your child with special needs?
- What would be your advice to parents of children with special needs?

Data Collection Process

In the study, semi-structured interviews were conducted face to face with the mothers who applied to the Research Hospitals and Guidance Research Centers in İzmir for diagnosis purposes. The interviews were carried out over a period of 40 to 90 minutes. During the interview, the questions were explained with examples so that the mothers could answer the questions more easily.

Analysis of Data

The data obtained in the study were analyzed using the descriptive analysis method. After the information obtained from the semi-structured interview form was read several times, the same and similar findings were grouped. While analyzing the data, the researcher used a coding such as “mother 1” without changing the expressions of the participants.

Results and Discussions

In this section, the statements of the participants regarding the themes targeted during the research process are included. These themes are recognizing special needs, their first reaction when they learn about special needs, the way followed in the treatment process, their attitudes towards their children with special needs, the reaction of relatives and friends, the difficulties experienced by mothers, their concerns about the future of their children with special needs, and suggestions for families with special needs children.

- **When and how did you realize your child’s special needs?**

According to the interviews, 14 of the mothers who participated in the study, to the question about when they noticed the disability of their children, stated that they noticed it in postpartum in the hospital, or in the health institutions they went to during the first 12 months of their developmental check-ups of their babies. However, a mother stated that she took her child to the doctor with the warning of her relative. The prominent comments of mothers on this subject are as follows.

.... *My child is born with Down syndrome. The doctor says it will always be like this but I pray. “Dear God give us the best. Heal my child as soon as possible... As long as she is good, I will give up everything”. I say. I gave up on her disability, it's enough for me that she can get rid of these seizures ...*

... We learned that the child had special needs when I am 7.5 months pregnant, but there was nothing that could be done, it was predestination. The doctors said that if she is born, she cannot walk, she cannot run, she will never be like their peers, and most importantly, they do not know her urine and stool ...

... Actually, the doctor said. But I was observing my child's behavior as if there were some things going wrong. Because my child's reactions were not like his peers. I was expecting such a result due to the health problems he had. I cried for days ...

... We went to the doctor for a routine checkup of my child. He was three years old but there was no speech. Sometimes he didn't even look us in the eye. Even though I felt some weirdness because it was the first child, I couldn't think of it. During the examination, the doctor said that this child is disabled. My husband and I both froze. Doctors can be so cruel ...

... My sister and I took the kids to the park. "A" never played with the other children, pretending they didn't exist. He was always a quiet child. Frankly, we were even happy that he wasn't causing any problems. He was constantly looking at the internet from the TV or the phone. My sister said, "Should you take "A" to a psychologist, it's not normal for him to be quiet like this". I was very angry, I thought that he was jealous of A because her own children were very mischievous. But unfortunately, she was right. "A" was autistic ...

Having a baby with special needs in the family environment means that all expectations of a typically developing (normal) child have come to an end. This means that families who have no experience of having a child with special needs will have to cope with different difficulties (Gören, 2015; Çetingöz et al., 2018). In this regard, experts should be aware of the difficult process that the family is going through and should use clear and understandable language when informing the family.

- **What was your first reaction when you learned about your child's special needs?**

For families who are expecting a typical developmental baby and dreaming and planning about it, having a baby with special needs causes serious disappointments. Many things can change in our lives with the participation of a baby in the family. For example; economic

conditions, social life, family relations, etc. While this is the case even with a normal baby, a special needs baby will require more time and financial expenditure. Parents get more tired when dealing with these problems. Uncertainty about the future also causes them to experience intense stress. According to the interviews conducted with the mothers participating in this study, the reactions of the mothers to the process they experienced when they learned about the disability are as follows.

... My child also opened his eyes to life as a disabled person. This is such a sad situation that even talking about it now makes people get emotional. Of course, like every mother, I would like to give birth to my child in good health. But this is ultimately kismet. I said "whatever God wants will happen" and accepted fate ...

... My husband didn't even come to me at the birth because he never wanted the baby to be born anyway. My parents were always with me ...

... It's like I went to pieces. Our daughter was not even one year old when we learned of her condition. My daughter could not hold her head upright, and could not sit without support. All her muscles were soft like jelly. The doctor said to start physical therapy immediately. She seemed to have improved a little at first, but the doctors said that there was a delay in her development as she got older. It took a long time to accept the problem. Of course, You accept over time ...

... It was like the world stopped when the doctor said your daughter was autistic. I could only say "What is autistic?" ...

... When we first learned, we were devastated. We went to pieces. We thought that such a situation only happened to us. We felt so alone and helpless ...

... We were crushed when we first found out. This was our first child. Our child has a disability. It's like my world has collapsed. I thought a lot that "What sin have we committed that this happened to us?" ...

... One morning my child suddenly lost consciousness, and we immediately took him to the hospital. However, because there is no cure for the disease, "He will be disabled", the doctors said. Learning this crush us ...

There are two important issues that families worry about when they have a child with special needs. The first of these are concerns like “What will happen now? What will I do?”. The second is how they will deal with the problem in addition to these concerns. Parents do not know whom to apply to solve the problem, what kind of process they will follow, and when to apply (Çağlar, 2000). When we look at the studies on this subject, it is seen that especially families who do not have any information about the special needs of the child, experience negative emotions such as shock, rebellion, constant intense sadness, mourning, hopelessness, grief-depression, etc. (Olsson & Hwang, 2003; Zan & Özgür, 2004; Ergün & Ertem, 2012; Avşaroğlu & Okutan, 2018; Çetingöz et al., 2018). The process of learning the situation of special needs is very confusing, uncertain, and difficult to understand for families. This process is met with different reactions by each parent. The process of parents accepting the situation and the reactions of each parent can be different. The important thing is to get over this process quickly and to use the rapid development period (0–6 years), which is important for the child, to good account for.

- **What did you experience after realizing your child's special needs situation? How was your attitude towards him/her?**

When families are expecting a baby, they desire to have a healthy child in their ideals. The child to be born has a special value in terms of completing the aspirations and aims of the family. For this reason, the birth of a child with special needs creates a trauma and shock effect in the family. Because having a disabled child means losing the ideal child. Families may tend to mourn the loss of their imaginary (ideal) child during their lifetime. Learning that the disability is an irreversible and permanent loss of function will increase the sadness of the families even more. The mothers who participated in the study stated that they experienced similar feelings.

... When I was pregnant, I learned that my baby would be disabled. It's Hydrocephalus. I was so sad, I was in despair. Doctors scared me a lot. They said, “This child is not born normal. She will have a head enlargement and vascular occlusion. She will need constant medical support...”. I felt like an alien was growing in my stomach. The first thing that comes to my mind is “What will happen after the baby is born? What kind of process awaits us?”. I always thought about these. But she deserves to live, too. I will provide her with any support she needs ...

... When he was born, I thought “Will I be able to give my child a good education?” at first. After all, he is my child, I love him so much ...

... If we weren't a religious family, we might be in very different psychology... I could leave my child... There are actually people who do this ...

... Like every family, we wanted to have a healthy child. But when I was pregnant, the doctors said that our child would be severely disabled and would probably not be aware of his surroundings at all, and would need constant treatment. I was devastated. Why me/my child? I said. My husband said to get an abortion. We felt so guilty ...

... I get very tired sometimes. It is very difficult alone. Actually, I am very angry at his disability, not at him. I feel hate. I feel devastated later and I regret it ...

... We learned at birth that our daughter has Down syndrome. When I saw her we thought this is not our child, there was a mess in the hospital. We thought saying that we can't take this child and thought about leaving her in the hospital ...

... Sometimes I wonder if I can be enough for him. He dies without me ...

... I get very angry especially when he doesn't act like other kids when we go out. But I'm too afraid to show it. Because people always look at weirdly/judgmental anyway. Like it's my fault ...

Although families experience a serious shock when they learn that their children have special needs, they get used to this situation over time. In this regard, in the study of Yıldırım Doğru and Arslan (2008) on the Worries levels of families; It is stated that families have hopes, expectations, and plans for the future, and families have to make serious changes in their plans with the birth of a child who does not have these expectations based on a healthy child. Studies on this subject show that the situation of special needs affects both parents. However, more responsibilities of mothers cause them to experience more worries (Yıldırım Sarı, 2007).

- **From the moment you felt or learned that your child has special needs, what kind of process did you follow for treatment?**

After learning that their children have special needs, families are expected to recover quickly and search for solutions in order to support their children's development. However, on account of the fact that having a child with special needs causes big changes in the roles of parents, their private lives, social circles, future plans, business life, family structure and functioning, financial issues, etc., this process does not always go as expected. This situation may cause parents to have difficulty directing their attention to their children and their special needs. While families are trying to cope with intense stress, they can also try all kinds of treatment methods in the hope that their children will recover. The mothers who participated in the study stated that they tried many different methods in the hope of their children's recovery;

... My relatives insisted. There was a shrine near where we lived. My relatives always said, "Let's take her even once" and they insisted. But I was constantly searching about what autism is on the internet or something. I researched so much that I became a doctor too. In the end, I understood, "Oh, this is not a disease that can be cured". ...

... Experts said that education is very important. Yes, it would be better if there was education, of course. But a voice inside of me was always saying, "I wonder if this kid was possessed by a genie?". Also, It can be bad energy or something like that. So I tried everything I heard. I had the Muslim clergyman write amulets and pray for her. I even visited a shrine. I think it had a positive effect. My daughter was very irritable and stubborn. Her anger subsided. I think it became better ...

... We visited many doctors, and paid a lot of money, but none of them could cure our child. Experts have already said that this is not a disease, it cannot be cured. We had hope. It's so hard ...

... My child was very angry, he was hitting and hurting himself and sometimes others. He often talked with himself. My relatives said, "The genie possessed this child's head. Take him to a Muslim clergyman, and have him pray for the child. It is not possible to take him to the doctor all the time". So I took him to the clergyman, I had amulets written. Unfortunately, nothing has changed ...

... At first, my son was in much worse condition. If God had not brought that doctor to us, my son would not be in this better condition now. Maybe he wouldn't talk at all, his situation would get worse, and he could regress instead of going further ...

With the birth of a new child in the family, it is seen that the expectations of the family members from each other and from life differ. This new situation requires many innovations and changes within the family. It is a very difficult process to get used to these innovations and changes. Diagnosing a child with special needs is a very traumatic experience for the family. Families react very differently to the fact that they have a child with special needs. These reactions may differ according to family structure, culture, education level, perspectives towards the child, and personality traits of the parents. For some families, this period can be overcome more easily and in a short time and provides an environment for constructive practices while for some families, it causes long-term grief and mourning, and it manifests as the inability to accept the child, exclusion or overprotective behaviors (Lafçı et al., 2014; Akgemlik, 2019). All these reactions also determine what kind of process will be followed for the treatment of the child.

- **What were the approaches and reactions of your close circle (friends, family, relatives, etc.) when it was revealed that your child had special needs? How did these approaches and reactions affect you?**

Families with a child with special needs have to cope with a role that they did not choose, while at the same time they have to struggle with a society that tends to accept what is normal (Ideal). This struggle is usually with the closest relatives, friends or neighbors. Although it is thought that families get the most support from these people in this process, the reality may be very different. The results show that the mothers participating in the study did not receive the social support they expected from their close circles in this process. In this regard, mothers stated the following.

... I no longer see many of my relatives and friends that I met before my child was born. Maybe they do it unconsciously, I don't know, but Their comparisons like, "Oh... look, my daughter is younger than your daughter... but she doesn't act that weird at all" is so offensive ...

... It's like eyes are always on us. When we go out, everyone is watching us as if they are watching a movie. We know they didn't actually do it to make us suffer...but it's so embarrassing ...

... My relatives are constantly questioning. Actually, they don't say it openly, but I understand from their looks that they blame me ...

... Comparisons upset us the most. Yes, our children are growing up, but they are still little in terms of mind and in their behavior; they are like little children accordingly... they do not do this on purpose ...

The reaction of each family member to the situation and the recovery process differs. Therefore, the support services to be provided should be planned accordingly. Studies on this subject indicate that the services for children with special needs are not limited to the services provided to the disabled child, that the family structure is a whole and that the problems of each individual in the family should be determined, and their needs should be determined and services should be planned in line with these needs (Gören, 2015). In addition, the presence of a child with special needs does not only affect the nuclear family (mother, father, and sibling). Especially, in environments based on traditional culture, like Turkey, extended family structures (grandmother, grandfather, and other relatives) are also involved in the process. For this reason, the support service to be provided should be offered to everyone involved in the process.

- **What challenges do you face as a parent of a child with special needs?**

Parents experience intense tension, anxiety, and stress because having a child with special needs brings along many problems. In addition, families experience complex emotions and difficult and stressful moments when they learn about their children's special needs, as they do not know exactly what to do and where to get information and support (Akgemlik, 2019). The most apparent difficulties of parents are; Lack of information/education/treatment support, new costs due to a child's disability, one of the parents having to leave the job due to the need for more care for the child with special needs, serious undesirable changes in lifestyle, changes in relations with family, friends and social environment. All these situations disrupt the psychology of families and prevent them from establishing healthy relationships with their babies.

The mothers who participated in the study on this subject stated the followings.

... As families of children with intellectual disability, autism, Down syndrome, and other disabilities, our biggest problem is environmental factors. We, as mothers, are psychologically exhausted in the first place by being excluded by people, being exposed to strange looks, that people staying away as if we have a contagious disease. We are not comfortable in the houses of our own families or neighbors. That's why we, as mothers, have to shut ourselves up at home and it makes us very tired ...

... When I see a normal child, I say to myself "I wish my child was normal, we could do a lot of things together". Unfortunately, my child cannot speak. Sometimes, I look at the children of my friends or relatives. They are younger than my son but better at many things ...

... I became very upset ... You look at them with envy. No matter what you do, some things are always missing in you. From time to time, You are asking "My God, why me?". Then you regret thinking like that. You say in your heart "God, forgive me, I didn't want to think like that" ... it's not his (my child's) fault after all ...

... Sometimes I have urgent things to do, but I can't leave my daughter to anyone and do these things. If she was a normal child, I could get support from all my relatives ...

... Most of all, when I go out to eat something or go to a cafe to drink coffee... I feel very embarrassed when I have to go to the grocery store. When I come home, I get very stressed. Then I regret and feel sorry ...

... If I'm going somewhere by bus, (we can't always take a taxi. Too expensive) my son yells when it's crowded. He cries. Everyone looks at us, some become very angry. I can't shut him up either; we're getting off the bus right away ...

This difficult process that mothers go through with their children can prevent the formation of a healthy bond between the child and the mother. In addition, the uncertainty about the disability experienced by the child causes mood disorders in parents. Considering the studies on this subject; Akandere et al. (2009) studied the life satisfaction and

hopelessness levels of mothers and fathers with mentally and physically disabled children and according to the results of this study, about the future the feelings, expectations, and hope scores of the parents aged 51 and over were found to be significantly higher than the parents in the other age group. In the study of Avşaroğlu and Gilik (2017); it was found that the hope, feelings about the future, and expectations scores of the older mothers were higher than the young mothers. It is thought that the reasons for this are that mothers take care of the child physically and mentally from birth, they spend more time with the child than the father, they look after the child tirelessly for years and the health problems that occur at an advanced age will make it difficult to care for the child, that parents are in despair because of the concern that they will not be able to meet the needs of child's care (Avşaroğlu & Gilik, 2017). In order to avoid these uncertainties that families have to live with, it is necessary to have a center where they can get healthy and accurate information from the moment their child's special needs are noticed.

- **What are your plans for the future of your child with special needs?**

When every parent decides to have a child, of course, they dream of a healthy child. In this dream, there are various expectations that start with birth and go to school, adolescence, youth, marriage, and starting a family. However, if the born child has special needs, all dreams may suddenly change, leaving their place to despair and worry. A child with special needs also means a child who is dependent on your care and support for his/her life. The answers of the mothers participating in the study to the question were in line with this fact. Some of the prominent answers are as follows;

... *How will my child do without me? I pray constantly. I pray "My God, take our lives together". It is so hard. I don't want anyone to experience this process ...*

... *You can't actually plan much. From time to time, You think questions like, "Is he going to die? When does he die? Before me or after I died?". You mostly thought "Who will take care of him if he dies after me?". You have these doubts and anxieties ...*

... *Like every parent of a child with special needs, we are constantly worried about what it will be like in the future. Who will take care of*

*him if something happens to us? We don't have any other children ...
I don't think the state's facilities are sufficient for these children ...*

Although families are constantly faced with problems, solutions are also limited. In a sense, the problems of the child with special needs are also the main problem of the family. This situation affects the whole family in many ways. Due to the situation they are in. A family with a child with special needs is faced with problems related to protecting their economic status and marital integrity, education of children, health problems, and the future of the child (Özgür, 1993; Ercan et al., 2019). In addition to all these problems, concerns about the future (what the disabled child will do after they die) can prevent families from dreaming of futures.

- **What would be your advice to parents of children with special needs?**

It can be said that the mothers participating in the study had a common idea in their answers on this issue. All 15 mothers stated that. They also stated that they felt very lonely and helpless because they did not receive enough support. The opinions on which the mothers agree on this issue are as follows.

... Public awareness should be roused and psychological support should be given to mothers. Fathers have a lot of work to do, but most of our spouses do not even accept their disabled children. For this reason, we request training seminars and support from experts in this field. In short, the thought of "What will happen to my child when I die" is our biggest fear. We need social regulations that will throw this thought out of our minds and at least give us some relief. The biggest obstacle/disability is lovelessness ...

... I am mostly sad about being left alone. After all, this situation is fate, it can happen to anyone. I wish there was a place where I could comfortably ask my questions. For example, if I want to ask a small question, I have to pay a lot of money to the doctor or the specialists. If you don't have money, everything is getting more difficult anyway ... they (Families of children with special needs) can reach out to experts on this issue or to families who have a similar problem ...

... As a mother, I wouldn't want to hear my child's disability from a doctor in the form of "this child is autistic...?". When I first heard

“autistic?” I thought about what it is. I was so confused. I scared ... I would love to have a place where I can get information about these conditions in the hospital where I gave birth or in a health institution ...

... Actually, I learned most of the information from another mother in the hospital. When I went to the hospital to get a report for my child... I was waiting in line in psychiatry. He had a son, just like mine. She told me what she went through, the same we went through ... God bless her ... Experts are the best, but it is better to talk to families with disabled children ...

Parents with children with special needs have intense worries for their children at every stage of their lives. Due to the roles in the family, mothers have more responsibilities regarding all the needs of the disabled child, and this causes mothers to be psychologically affected more than fathers. In addition, having a disabled child may cause mothers to not have enough free time to spare for themselves, to be unable to spend time on their hobbies, to have limited friendships, and to become busy people at home due to care of children all day long. All these reasons can cause mothers to run out of energy and experience natural isolation from society. This increases their anxiety and stress levels (Toros, 2002; Yıldırım Doğru & Arslan, 2008; Yazıcı & Durmuşoğlu, 2017; Akgemlik, 2019; Ercan et al., 2019). In order to prevent all these problems, the answers received from the mothers show us that they need the right support for the problems they are experiencing. It is concluded that an early intervention and counseling center where experts in different fields provide services is needed in order to achieve this.

Conclusions

This study, which was conducted to determine the problems experienced by mothers with children with special needs, was conducted through interviews with 15 mothers with babies with special needs. At the end of the study, intense worries and stress were found in most of the mothers. In addition, it was determined that mothers could not reach a source from which they could get regular and healthy information about deficiencies after birth. Moreover, they stated that they felt lonely and helpless after the diagnosis and that they could not get enough

support from their spouses and close friends (relatives and friends). The mothers also stated that another problem they experienced was the lack of a place where they could reach at any time and get the right information and support about the problems they experienced. While some mothers stated that the experience of parents with previously diagnosed children is better than that of experts. They also emphasized that specialist support is very costly. In line with the data obtained from mothers, the following can be recommended to experts who will conduct research on this subject in the future and to people related to this subject:

- Families feel alone and helpless during the diagnosis of children with special needs. Having a free center that will enable families to receive systematic and regular support about this new issue can help reduce the level of anxiety of families.
- Organizing the right information resources about special needs by the government (online – face to face) and enabling families in need to access these resources easily after the first diagnosis can relieve families.

Although there are many studies on the diagnosis processes of children with special needs and the difficult process that starts with diagnosis, there are not enough studies on the support provided to families. Concentrating on the provision and effects of support services by researchers who want to work in this field can contribute to reducing the problems.

ADHERENCE TO ETHICAL STANDARDS

Ethics Declarations. Participation in the research (for the sample group) was done on a voluntary basis. Participants were informed about the research and were asked to sign a voluntary consent form. In addition, ethical rules were taken into consideration at all stages of the research.

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Consent for publication. The authors approve of this submission and, conditional upon the decision made by the editorial board from the peer-review

process, consent to the publication of the current work. The work has not been submitted to other journals in consideration for publication.

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АНОТАЦІЯ

Вступ. Народження дитини з особливими потребами викликає серйозні емоційні проблеми в сім'ях. Матері сильно розчаровані і проходять складний процес, коли дізнаються, що їхня дитина має будь-яку інвалідність під час вагітності, під час пологів або пізніше. Відсутність системних служб підтримки в Туреччині щодо цієї ситуації робить процес ще складнішим.

Мета. Це дослідження було спрямоване на визначення проблем, які відчувають мами, які мають немовлят з особливими потребами.

Методи. Зразок дослідження складається з 15 матерів, які мають немовлят з особливими потребами. Дослідження є якісним дослідженням, а дані досліджень були зібрані з напівструктурованою формою інтерв'ю (8 питань). Інформаційна форма, що складається з 8 питань, використовувалася для отримання соціально-демографічної інформації про матерів.

Результати. Дослідження показало, що в більшості матерів були виявлені інтенсивні тривожні та стресові стани. Матері після народження не мають доступу до джерела, з якого вони могли б отримувати постійну та корисну інформацію про вади дитини. Вони почуваються самотніми й безпорадними після діагнозу і не можуть отримати достатньої підтримки від своїх чоловіків та близького оточення (родичів і друзів). При цьому деякі матері заявляли, що досвід батьків з раніше діагностованими дітьми кращий, ніж у фахівців.

Висновки. Проведене дослідження дало змогу розробити рекомендації для експертів, які будуть у майбутньому проводити дослідження з цієї теми, і людям, пов'язаним з досліджуваною проблемою, а саме: (а) сім'ї почуваються самотніми й безпорадними під час діагностики дітей з особливими потребами. Наявність безкоштовного Центру, який дозволить сім'ям отримувати систематичну й регулярну психолого-педагогічну підтримку може допомогти знизити рівень занепокоєння сімей; (б) організація Центрами та державними органами управління різних форм роботи з сім'ями, які виховують дітей з особливими потребами, розробка інформаційно-довідкових ресурсів про особливі потреби дітей і надання сім'ям, які потребують допомоги, легкого доступу до цих ресурсів після першого діагнозу – вагома допомога сім'ям, які виховують дітей з особливими потребами.

Ключові слова: особливі потреби, дитина, мати.

