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THE PROBLEMS OF THE FAMILIES WHO HAVE AUTISTIC CHILDREN: A QUALITATIVE RESEARCH

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ABSTRACT

Autism is defined as one of the neurodevelopmental disabilities which continue for life and affect social development, communication and behaviors of the individuals in a negative sense. Purpose of this study is to determine how parents with autistic children figure out the autism, what their reactions are and what the effect of the believe is to accept it, how they declare it to the people around them and how the reaction of people is, who and how they get support from and what the possible future difficulties and requirements are. The study was based on qualitative research method and interview form prepared based on the purpose by the researcher was used in the study. The study is based on case study which is a qualitative research method and uses an interview form that is prepared by the researcher according to the purpose of the study. Study group is composed of 15 mothers and 8 fathers selected by purposive sampling method among parents of children going to special education centers. Study results have been shown that, it was found that the parents first noticed the inadequacy of language development without noticing the autism. In addition, it was seen that the first reaction of the parents' children to get autism was also the intense sadness. There is another result which is that parents need to get information about an autism with the sadness they have experienced. Parents have expressed concern about the future of their children, depending on the strength of their children's self-expression. It has been determined that the society has negative attitudes towards autistic children and that parents would like to see the society to be more moderate towards autistic children. Results have been determined, it is important to establish empirical studies that will increase the awareness of other individuals about autism while showing the needs for supporting from autistic families. Study findings have been discussed with similar study findings included in the literature.

Key Words
Autism, Individual with Special Need, Family Opinion, Social Support, Explosion

OTİZMLİ ÇOCUĞU OLAN AİLELERİN YAŞADIĞI SORUNLAR: NİTELİKSEL BİR ARAŞTIRMA

ÖZ

Otizm, yaşam boyu devam eden ve bireyin sosyal gelişim, iletişim ve davranışlarını olumsuz yönde etkileyen nörogelişimsel bir bozukluklardan biri olarak tanımlanmaktadır. Bu araştırmanın amacı, otizmli çocuğa sahip anne-babaların otizmi fark etme şekillerini, verdikleri tepkileri, kabullenmeye yönelik inancın etkisini, çevreye nasıl aktardıkları ve çevreden nasıl bir tepkiyle karşılaştıklarını, kimlerden ve nasıl destek aldıklarını, geleceğe yönelik beklenilen olası zorluk ve gereksinimlerini belirlemektir. Araştırma, nitel araştırma yöntemlerinden durum çalışmasına dayandırılmış ve araştırmada amaca yönelik araştırmacı tarafından hazırlanan görüşme formu kullanılmıştır. Özel eğitim merkezine devam eden çocukların anne-babalarından amaçlı örnekleme yöntemi ile seçilmiş 15 anne ve 8 baba, çalışma grubunu oluşturmaktadır. Verilerin çözümlenmesinde içerik analizi kullanılmıştır. Araştırmanın sonuçları incelendiğinde otizmi fark etmede anne-babaların ilk olarak dil gelişimindeki yetersizliği fark ettiği bulunmuştur. Buna ek olarak anne-babaların çocuklarının otizm tanısı almasına yönelik verdikleri ilk tepkinin yoğun üzüntü olduğu görülmüştür. Yaşadıkları üzüntü ile birlikte bilgi alma ihtiyaçlarının olduğu da elde edilen bir başka sonuç olmuştur. Anne-babalar, çocuklarının kendini ifade etmede yaşadıkları güçlüğe bağlı olarak çocuklarının geleceğine dair kaygı duyduklarını belirtmişlerdir. Sosyal çevrenin sıklıkla otizmli çocuklara yönelik olumsuz tutum sergiledikleri ve anne-babaların çevrenin otizmli çocuklara yönelik daha ılımlı yaklaşmalarını istedikleri belirlenmiştir. Elde edilen sonuçlar, otizmli ailelerin destek ihtiyacını ortaya koyarken diğer bireylerin de otizme yönelik farkındalıklarını artıracak ampirik çalışmaların yapılmasının önemini ortaya koymaktadır. Araştırma bulguları alanyazında bulunan benzer çalışma bulguları ile tartışılmıştır.

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Introduction

Autism spectrum disorder is defined as a neurodevolopmental disabilities which emerges in the first three years of life and continues throughout the entire lifespan (Sicile-Kira, 2014; Korkmaz, 2005; Tortamış-Özkaya, 2013). It is explained as a neurodevelopmental disability which negatively affects the social interactions, communication and behaviours of the individual. Although different opinions are presented concerning the causes of autism for years, genetic findings have been gaining importance recently (APA, 2013). The most significant features observed in the autism can be explained as inability to interact socially, being different in language, communication and symbolic development and a limited number of attention and activity to pay attention (Darica et al., 2000; Ar, 2014). It is stated that children with autism are different in both qualities such like convenience, variety, creativity, complication, and quantity such like time and frequency involved in game activities of preschool period than their peers in the same age group who develop normally and who experience developmental delay (Rutherford, Young, Hepburn and Rogers, 2007). Plays for children with autism are reiterative, sensorial, isolated, tangible and far from imaginary events (Paterson & Arco, 2007). Early diagnosis has been increasingly given importance while autism has been becoming common day by day. Notwithstanding, families do not know what they will do when they face with the autism diagnosis and they feel stress and desperation due to their concerns about how they will comply with the change in their life (Dogru & Arslan, 2008; Ar, 2014).

Theoretical Background

Family with Autistic Child

Autism is defined as one of the developmental disorders which appears in the first months of life and continues for the life (Korkmaz, 2005). Family members bear some duties in many fields such like education, health for their children who develop differently and experience several difficulties accordingly (Darica et al., 2005). Parents with autistic children experience more problems and have more concerns than other disabled groups (Lee et al., 2007). Parents feel isolated and without support since they know less about autism and do not know how to tell other people around them about this situation (Woodgate, Ateah & Secco, 2008). Most parents state that they felt relaxed and started to struggle by seeking for information after the diagnosis of autism had been made (Gurel-Selimoglu, Ozdemir, Toret & Ozkubat, 2013). Parents with autistic children feel more stressed as they have more responsibilities than other disabled groups (Sencar, 2007). It is stated that some families seeking for social support received the support but other families could not (Sencar, 2007). It is indicated that a parent support is expected further (Tunali and Power, 2002). While parents with autistic children have specified certain people who provided them with social support, there are also several findings that nobody was in the first place in this regard and that they got social support from their partners (Sencar, 2007).

In the case that the parents of the child with special needs cannot identify and determine these needs in a timely manner and fulfil these needs properly, several irrecoverable problems (such as inability to raise the child with special needs in a suitable education setting, the family being deprived of the necessary psychological support etc.) which reduce quality of life can emerge in the future for both parents and children (who show normal development and who has some inabilities) (Varol, 2006; Ardic, 2012; Cavkaytar, 2013).

The studies conducted demonstrate that parents with children having special needs are in need of social support, social supports decrease the negative cases caused by stress levels (Dunn, Burbine, Bowers and Tantleff-Dunn, 2001) and make mothers accommodate to the process they experience (Weiss, 2002); but these needs are not met (Altug-Ozsoy, Ozkahraman and Calli, 2006; Ayyildiz, Sener, Kulakci and Veren, 2013; Karadag, 2009; Kurt et al., 2013). In the studies conducted, mothers have concerns about who would look after their children when they were absent (Ozsenol et al., 2003). The economic problems experienced increase the need for social support (Bromley, Hare, Davison and Emerson, 2004). Social support is an important factor to increase and develop functions of the family. Ozbay and Aydogan (2013) state that indomitableness levels of the families make contribution to their loyalty through the

social support and Kara (2008) states that moral support helps parents having children with special needs to deal with heavy duties. In addition, the state is primarily responsible for taking care of and raising every child. These people should be provided with institutional support through the policies to change perspective of society in a positive sense by means of legal regulations on financial support, education, etc. Institutional support is also important in terms of emotional and cognitive support as families such as getting information on special needs of their children, learning about methods to encourage developments of their children, not feeling alone, and being approved and accepted. Institutional support should be given to these people through legislations on such areas as financial support or education and policies aiming at changing the viewpoint of the society in a positive direction. Institutional support is also important in that the parents become knowledgeable about the special needs situations of children, learn methods which support the development of children, make them feel that they are not alone, and are accepted and approved, which are elements of emotional and cognitive support (Gurel-Selimoğlu, Ozdemir, Toret & Ozkubat, 2013).

The Process of Living with Autistic Children

It is known that parents, who have an important role in encouraging development of children with autism, experience some troubles from time to time in emotional, psychological and economical senses during the period to live with autism (Ozkubat, Ozdemir, Selimoglu & Toret, 2014; Avsaroglu & Gilik, 2017). Parents think especially about how their children dependency will affect their own lives in the future without their parents (Kaner, 2004; Ludlow, Skelly & Rohleder, 2012), and they are worried about futures of their children: what the functional levels of their children will be in the future, what will be done when they are in a case they cannot look after their children and what kind of services their children can benefit from when they become adults (Nealy, O'Hare, Powers and Swick, 2012). In a study conducted by Cassidy, McConkey, Truesdale, Kennedy and Slevin (2008) on the described concern for the future, 31% of the parents participated in the study stated that they think their children cannot live independently and they are worried about the care of their children without their parents, in a different study by (Ludlow et al., 2012) in which twenty parents participated, 12 of them stated that they have concerns for the future as their children have no independent life skills. It is understood that having a child with autism requires more responsibilities than having a child with normal development (Jarbrink, Fombonne and Knapp, 2003) and lives of the parents take a shape mostly around requirements of the child with autism (Hock, Timm and Ramisch, 2012). In this regard, parents stated that they spend most of their times, attentions and energies for their children with autism and therefore they have problems with their parents and their other children with normal development (Nealy et al., 2012). In addition to this problem, researchers emphasize that economical/financial needs of the children with autism in their developmental processes are almost three times more than other children with normal development (Nealy et al., 2012, Avsaroglu & Gilik, 2017). Since 33% of participants in the study by Cassidy et al., (2008) state that they could not get social, physiological and financial support they need, and parents left their workplaces where they worked actively in order to meet needs of their children (for example, care, education) and they pay regard to flexible working hours more than the salary in their choices of profession, it is indicated by this study that parents experience physiological and emotional difficulties. It is stated that parents describe this case by using the words "continuing, endless stress" (Ludlow et al., 2012). Special education has a holistic approach. Family involvement is particularly beneficial for children with autism with special education support. Accordingly, the difficulties of having an autistic child and the identification of parents' needs have significant role. Determining the parents' needs according their thoughts may help to determine the qualification of support to parents. This support is thought to increase the participation of parents in the child's development process. Towards the importance of this topic, the objective of this study is to examine the opinions of parents with autistic children as regards the process of diagnosing autism and thereafter.

Sub-problems

•What are the factors which made you notice the autism of your child?

•What are your opinions concerning the diagnosis process of your child?

•What are the challenges experienced after receiving autism diagnosis?

•What are your opinions concerning the future of your child?

•What are the expectations of parents concerning support?

Method

Research Model

It is defined as the research in which a descriptive process is followed to demonstrate the events in a realistic and integrated sense in a natural environment through the data obtained by qualitative data collection techniques such like qualitative research, observation and interview (Kose, 2013). In this research which employs case study, a qualitative research model, data were obtained through semi-structured interview technique and content analysis was used in the analysis of data.

Study Group

The study is qualitative and it has been conducted in Nicosia city, Turkish Republic of Northern Cyprus. List of children with autism has been obtained from Special Education Centers and Special Education Institutions and centers with autism programs in Nicosia city. In this study, purposeful sampling model has been used. The following characteristics are sought in the participants who would be included in the study:

1.The child having diagnosed with autism

2.The child receiving special education

3.Voluntarism to participate in the study

The parents of children with multiple disabilities, comorbidities and high functionalities were excluded from the study group even when they meet the above criteria. 30 parents in Nicosia city center were the targets for sampling but study was conducted with 23 families as 6 families could not have been reached and one family refused to interview.

Study group of the research is composed of 23 parents as 15 mothers and 8 fathers with autistic children. Study group has been selected for the purpose of study by the purposive sampling method (Table 1).

Table 1. Details on demographical variables of mothers-fathers participated in the study

Mothers	Age	Education level
M1	51	High school
M2	32	High school
M3	35	High school
M4	40	High school
M5	28	Secondary school
M6	34	Primary school
M7	29	Primary school
M8	40	High school
M9	27	Secondary school
M10	34	University
M11	36	High school

M12	37	Post graduate
M13	36	University
M14	27	University
M15	25	High school
Fathers	**Age**	**Education level**
F1	46	Post graduate
F2	46	University
F3	37	High school
F4	42	Secondary school
F5	34	High school
F6	30	High school
F7	32	University
F8	41	High school

Ethical Considerations

The data of the study were collected according to Helsinki principles. Permission was obtained from TRNC Ministry of National Education for the application. The sample of the research was obtained from the records of the institutions. In this direction, firstly verbal permission was obtained from the foundations. In this direction, firstly institutional permission was obtained. Then, permissions have been collected from the participants who agreed to participate in the study. The participants were asked to undersign informed consent forms without indicating any personal information before the interviews. We declare that the people whose opinions we asked did not suffer from any psychological and/or physical damage.

Data Collection Tools used in the Study

It was paid attention while preparing the interview form used in the study that questions are as clear and apparent as possible, allow interviewee to make a statement and give detailed answers in order to communicate more efficiently and productively with the interviewees and that the questions are not multidimensional so that an unintended load of question is not created on the interviewee. Besides, it was paid attention to prepare alternative questions and certain tips in case the individual does not understand any question (Kose, 2013). Interview form prepared by the researcher was presented to seven domain experts as three of them are experts in special education, two of them are in Turkish language, two of them are in measurement and evaluation. Moreover, it was presented to other three experts who conducted several studies by using interview method, and the required revisions and changes were made in the form upon the opinions and recommendations of nine experts. Pilot scheme gives an idea how well the interview form was prepared and if the used statements are suitable for the group interviewed (Kose, 2013). For this reason, the interview form has been revised in direction of the recommendations from experts was tested on three teacher candidates before using it as a data collection tool, and the interview form has been finalized according to the reactions and answers of the interviewees to the questions.

Interview form was structured according to the titles presented in the objective of the study. Accordingly, the first section includes a question on awareness process. The second section including reactions concerning diagnosis consists of two questions. The third section which follows includes 3 questions seeking to describe the problems experienced in the process. The fourth section consists of a single question on the opinions concerning future. The last one is a single question with three additional questions (social setting, family, state) with the purpose of determining the expectations, which is the fifth section of the study. The researcher used an interview form which was prepared so as to serve the research (Table 2).

Table 2. Semi-Structured Interview Questions

1.	When and how did you realize the difference in your child's development?
2.	What was your first reaction when the difference was diagnosed? What did you feel?
3.	What are your feelings to accept your child's status? Share it please?
4.	What are your personal problems in terms of your child's status?
5.	What are the problems on your child's status you experience with your social sphere?
6.	What are the financial problems due to your child's status?
7.	What are your concerns and opinions on your child's life in the future?
8.	It meets your child's needs;
	a.What are your expectations from Social Sphere?
	b.What are your expectations from your Family and Relatives?
	c.What are your expectations from the State?

In addition to the semi-structured interview form, demographic information form was also used. Gender, age, education level and the education level of the other parent were asked within the scope of the study.

Data Collection

Families were informed on the study and their verbal and written consents were taken. Interviews were conducted at houses and centers by getting an appointment when the families were available, and these interviews took nearly 35 minutes. It was recorded on the tape with consent of the family. Tape records were written at the same day. Interviews were completed in a 3-month (8 January - 11 April) period. Tape records were solved with the interviewer and expert and the details obtained were evaluated by theme analysis method.

Data Analysis

The data obtained has been analyzed by content analysis method. Categories have been created by making significant groups according to the answers for semi-structured questions, and contents of the answers. Data has been coded according to the categories. Coding has been regulated by the content and they are presented by direct citing in the findings section.

Some parents displayed multiple codes as a result of which the frequencies of determined categories were presented according to the codes of parents. Codings were organized according to the content and presented in "findings" section with direct citations. Coding was made with letters and numbers instead of names of participants in accordance with ethical principles.

Validity: after the data obtained from participants were written in detail, the manner with which conclusions were reached was explained in detail. While reaching the conclusions, the opinions of interviewed parents were directly presented for validation.

Reliability: The researchers refrained from directing the participants during interview. For the validity of the coding used in the study, 6 datum randomly selected from 23 papers were coded separately by the researchers and the consistency between two coders was calculated. Consistency was estimated as 80% in the calculations.

Results

This section of the paper deals with the opinions of parents of children with autism concerning autism experiences based on the analysis of the answers they gave to the questions in the interview form.

The opinions of parents concerning the time when and based on which features they noticed autism symptoms of their children. An examination of Table 2 shows that 2 mothers noticed autism symptoms when their baby was 3 years old, one mother and

one father noticed the symptoms when the child was 7 months old, one father and 4 mothers noticed the symptoms when the child was 16 months old, 4 mothers and 4 fathers noticed the symptoms when the child was 18 months old and 4 mothers and one father noticed the symptoms when the child was 2 years old. It can be said that parents more easily notice autism symptoms after their child is one-year-old. Significant limitations in language development and communication are among the diagnosis criteria of autism. Accordingly, parents must pay more attention to the speaking of their children and their communication with other people as of their age.

Table 3. The frequency of parents of noticing autism symptoms according to the age of the child

Age of the child	F	%
3 months old	2	8.70
7 months old	2	8.70
12 months old	5	21.74
16 months old	1	4.34
18 months old	8	34.78
24 months old	5	21.74

The first theme of the study is determined as collecting information concerning parents noticing autism. In this direction, parents were asked how they noticed autism. An examination of the answers provided brought three sub-themes to the forefront first of which was language development. A majority of participants stated that they noticed that their child could have a problem based on the awareness on language development (f=10). In addition, the difference in communication skills (f=8) and difference in actions/reactions (f=7), which are two other sub-themes, are determined as features that parents take into consideration in noticing the autism of their children.

M4 "I noticed at the age of 2. I understood from his being motionless."

M6 "development of my son after his brother was born when he was 1-year-old not speaking, not making eye contact, kinking at his hands and looking at a spinning car wheel. He did not look when I called him. He looked at the television carefully. He did not leave it."

F3 "He was like 1 or 1.5 years old. He began to fail to make the sounds that he used to make. He did not look when we called him."

M12 "2 years old. He does not make eye contact. He does not react to voices."

Two questions were asked in the theme of reactions given by parents in the diagnosing process of the child with autism. In this direction, two sub-themes were developed, namely first reactions and acceptance process. As for the first reactions, parents stated that they felt intense sorrow (f=17). It is also seen that there are participants who experienced the first stage of the mourning process, shock stage (f=2) and the last stage, acceptance stage (f=2). In addition, participants who stated that they felt guilt (f=4) is also witnessed. Another participant (f=1) mentioned physical complaints.

M8 "I was shocked. I could not think of anything at that moment. I was frozen."

M11 "Like every mother, I was very sad and I cried. You cannot know this situation without living it, you have to experience it."

F1 "I was so sad that I thought that I was crashed about my ears."

M12 "Our first reaction was sadness. We tried to understand. We accepted it in time."

F3 "I was crashed about my ears. I cried all the way long. I thought why it happened to me, what wrong had I done. I thought it was because of me."

M9 "I was losing my sleep when I thought about it at night. I used to cry all the time. I lost 6-7 kilos in that period. It is such a feeling that it cannot be described. I did not know what to do."

An examination of the answers given to the question "what did you feel about accepting the situation of your child?" shows that parents mostly find it difficult to accept but accepted in order to seek a cure (f=13). One participant accepted the situation earlier and produced a solution (f=1). In addition to the participants who stated that they were anxious about the future of their children (f=5), participants are observed who claim that they felt hopelessness (f=3). One participant stated that he could not accept the situation and sought psychological support (f=1).

F4 "This is a difficult situation to understand. In the beginning we had difficulty in accepting the situation. But we believe that it will get better with education."

M4 "I did not ask myself 'why did it happen like that?" I accepted, I did not exclude. I studied searching. I thanked God that it was not worse."

M8 "Why me... then I received psychological support."

M12 "Actually accepting was not difficult, the difficult thing was explaining it to the community."

F6 "The feeling I had when accepting the situation of my child was praying so that my child can stand on his own feet, does not live dependent on others and has a good career and improves himself."

The third theme of the study was organized as determination of the problems experienced by parents in the process. Accordingly, three sub-themes were created, namely personal, social and financial problems. First of all, the personal problems as regards the situation of the child were asked. It was reported that parents frequently experienced anxiety (f=11) and had difficulty about the reactions from the community (f=7). It has also been found out that some participants felt restrained in every area (f=5). One participant stated that he did not experience any difficulty (f=1).

M1 "He is very well at the moment; there is no difficulty for me. What matters is that he becomes self-sufficient."

M3 "I am experiencing all kinds of problems.

M8 "Reactions from the community, the way they look and weird questions."

F4 "Being restrained about everything."

F5 "Hopelessness, uneasiness, the fear of what will happen all the time."

M13 "The attitude of parents of other children at public school, them not wanting my special child in their class and not saying anything to their children who are mocking with my child by calling him "disabled" and your child is disabled and handicapped. He will go to school and I hated that he would not enjoy it."

M15 "I am having too many difficulties. I do not know how to deal with it. I am having sleeping disorders. I think that I cannot raise him on my own as he is strong and powerful, taller than me, I thought that I would ask for an assistant for taking care of him."

An examination of the answers given to the questions on problems caused by the community, two different opinions were identified as supportive/positive (f=2) and negative (f=21). The fact that community members are not knowledgeable about autism and feel discomfort although they learn autism emerges as a very difficult situation for parents. It is seen that there are participants (f=1) who state that they feel sorry about the negative attitude of the community. Another participant stated that he encountered both negative (f=1) and positive attitudes. One participant mentioned the limitations imposed with the effect of the community.

M4 "People around me are doing everything they can in order to help me. People are aware of autism."

F3 "People are looking out of pity, I notice that but they still try to understand and help."

M7 "I am deeply saddened by the fact that our community does not know autism, see autistics as disabled people, have prejudices, and have different viewpoints."

M9 "Being excluded, them being inconsiderate towards special kids."

M11 "Of course, we received different reactions as people did not know. Some of them understand the situation quickly and behave optimistically but some of them feel uneasy although they understand the situation."

M10 "We cannot go everywhere we want. People look with odd eyes. He avoids crowds and is disturbed by noise."

An examination of the answers given concerning financial problems shows that parents mostly have difficulties as regards the expenditures of special education (f=19) whereas it is observed that one participant stated that he did not have any financial problems. Some participants avoided answering this question (f=3). It was found out that the participants who stated that they suffered from financial problems received financial support from different resources.

F2 "The salary received by a person working at private sector is insufficient; as a result, we are experiencing all kinds of financial problems."

F3 "Fortunately my financial situation is good, for this reason we did not have any problems."

F7 "Living on is difficult without help, we cannot live on a single salary. We are trying to handle it with family support."

M8 "Education is too expensive; the family may not be able to cover it."

M12 "Medicine is expensive. Government covers its costs partially but there is some medicine that it does cover at all, and that can be a problem."

Another main theme indicated in the study was the opinions concerning future. When they are examined, it is determined that all participants feel anxiety about the future of their children (f=23). The content of the anxiety includes opinions as how the maintenance of the child will be assumed whereas one participant thought that his brother would take care of him (f=1).

F1 "The government does not have a system which will support the family and the child. He is under the responsibility of Ministry of Health until 3 years old, Ministry of Education between the ages of 4 and 18, and Ministry of Labour and Social Security after 18 years of age. There is no coordination between these three ministries. With a multidisciplinary method, health problems medicine treatment is a load on the family. The family has to receive additional classes and therapies. There is no family counselling. There is no family education. There is no system to embrace the child when he is left with no one.

F5 "I am worried but as he has a brother I am sure that he will not withhold his assistance in the future."

M12 "We have concerns. How and where he will be, what kind of life he will lead, will he be able to stand on his own feet without us, I want him to be successful in something."

The expectations of parents concerning support are examined in three sub-themes, namely social community, family-relatives and the government. An examination of the expectations from the community showed that all participants (f=23) expected the community to support autistic children with a positive viewpoint. Among these positive attitudes, being understanding (f=12), sensitiveness (f=7) and acquiescent behaviours (f=9) can be listed.

F5 "One should be more positive and constructive. Our children must be seen normal."

M5 "My expectation from social community is that they do not tease our children with special education needs, love them without questioning, and accept them. Their love and help they should approach more sensitively."

M13 "Tolerance, helpful, interest, love, understanding"

It is seen that among the answers given to the support expected from family/relatives, which is the second sub-theme, moral support (f=21) has the highest frequency. In

addition, some participants stated that they should stop giving the negative reactions they always give (f=3).

F2 "They should be a little bit more interested and tolerant than other children."

M5 "It is not enough if they do not criticize and interfere with"

M10 "Fortunately my family always supports me in that issue."

Finally, the parents were asked about the support they expected from the government. An examination of the answers given by the participants shows that all of them thought that government should give more support (f=23). An examination of the topics of the mentioned support shows that financial support is not sufficient and has to be increased (f=10). In addition, it is emphasized that support should be given for tools (f=6) and more special education institutions are needed (f=3). Some participants, on the other hand, indicated the necessity of increasing the number of social areas (f=5). Two participants stated that improvements were needed in hospitals (f=2).

F5 "Increase in financial support, more comfortable conditions at hospitals.

M6 "Increasing financial support and social areas."

M8 "Helping us in all areas, both financially and morally".

M10 "They should pay attention to our special children as they pay attention to their positions and provide more support and opportunity for their education."

M13 "Our expectation from the government is increasing special education centres and supervising special education centres (public ones) and increasing special education foundations. I want to have more neurologists at public hospitals. They are not sufficient. I demand that the contribution (salary) for his education is increased. It is not adequate."

Discussion and Conclusion

In the study, 8 parents, 2 parents, 2 parents, 1 parent, 5 parents and other 5 parents participated in the study have indicated that they realized developmental differences of their children when he/she was 1.5 years, 7 months, 3 months, 16 months and 1 year and 2 years old, respectively. While studies emphasize on the importance of early diagnosis, it is observed that applications increase between the age of 1.5 and 2. A study includes some findings concerning when families were asked when they had realized the differences for their children, 24% of the families had doubts about development when their children were 1, 5 years old, 24% of them suspected when their children were 2 years old and 17% of them realized a developmental difference when their children were 3 years old (Selimoglu, Ozdemir, Toret & Ozkubat, 2013).

Limitations experienced in the expressive development that is one of the diagnostic criteria for autism are one of the first signs which parents observe on their children. Parents participated in the study have indicated that they realized autism by different development of their children in communication. Children with autism, whose social interactions are weak, have difficulty in comment or share about their experiences in accordance with their ages (Johnson et al., 2007). As a result, parents begin to search for solutions to the problem depending on the development of their children who are different from their peers. Parallel to the statements of the participants, it is seen that symptoms of OSB in children with OSB (lack of eye contact, not looking when called, failure to establish verbal communication, social boundedness, behavioural problems etc.) generally emerge at the ages of 1.5 to 2; but they can be noticed by parents or health personnel (Sayan and Durat, 2007) before the age of four (Arslan, 2011; Bicak, 2009; Selimoglu et al., 2013).

In the study, parents indicated that they were deeply sorry when they learned about autism diagnosis. In keeping with the study, it is stated in different studies that happiness felt by the parents when they have a child gives way to shock and a deep sadness when they learn they have a child without a normal development (Koksal and Kabasakal, 2012). In a study by Selimoglu et al., (2013), 48% of the families indicated the first feeling was a deep sadness when they learned the diagnosis for their child was autism. Parents are more shocked especially when they learn their children who

seem normal have limitations to communicate (Boyd, 2002). In addition, it is known that factors such like uncertainty brought along the autism, awareness of autism, incidence for the society and severity and duration of the autism make difficult for the parents to accord and accept the diagnosis (Bloch and Weinstein, 2010). Families feel themselves too alone especially in psychological sense and they become so desperate due to the problems such like having no time for home, partner and other children as they bear all the responsibility and they feel they are isolated from the society (Selimoglu et al., 2013). It becomes easier for parents with autistic children to acknowledge the autism and comply with the situation they encounter when they get support from the immediate environment as well as the support from experts and institutions (Unluler, 2009). It is found that parents participated in the study get different reactions from the society. These reactions consist of positive attitudes as well as being sorry and backing up.

Social support is defined as emotional, physical, informative, material and financial supports which allow individuals to believe they are loved, paid attention cared about and to decrease negative results of any crisis, change in his life, make easier to comply with critical life events and protect his psychological health and which is provided by the social sphere (Unluler, 2009). It is indicated that there is a negative and unapparent relationship between autism and sense of social support (Tufan, 2006). It is demonstrated by the study findings that families with autistic children have higher levels of stress (Montes and Halterman, 2007). It is remarkable that level of the social support perceived by the parents in the experienced adaptation process plays an important role in sustaining the parents' health (Koksal and Kabasakal, 2012). It is emphasized that social support (s) will have functions to ensure their physical health and psychological health get better, and relieve them and make positive contributions to their health by giving the feeling that they are not alone, they are important and valuable by ensuring a morale of resistance for difficult situations (Baltas, 2000). The literature on the social support given to parents with children affected by any disability shows that parents of children with OSB mostly receive social support from their spouses, friends and relatives (Ozdemir, 2012; Twoy et al., 2007). There are several participants in the study who indicate that they did not get support from anybody, they were not supported enough and they perceive social support from both their partners and the society.

When parents were asked about difficulties for the future, they indicated they were extremely worried about concerning the dependencies of their children and who would look after their child if they died. Another difficulty determined is that children with autism cannot express themselves and have difficulties in expressing. A biased society and difficulties had in the governmental institutions responsible for children are added. Especially the parents who have to think about how the dependency of their children will affect their lives after their parent's decease (Ludlow, Skelly and Rohleder, 2012) can feel anxious about the future of their children, i.e. what their functionality level will be, what will be done when they become unable to take care of their children and what kind of services their children will benefit when they become adults (Cassidy et al., 2008). In another study, it was found out that 31% of the parents think that their children with autism cannot live independently and that they are worried about the care of their children after them (Cassidy et al, 2008). In another study which was attended by twenty parents, 12 stated that they suffered from future anxiety as their children lacked independent living skills (Ludlow, Skelly & Rohleder, 2012).

Primary need of both parents was considered as attention when they were asked about their requirements. One of the participants indicated that all needs such like financial, moral, time, attention are interconnected and they need all of them. It is emphasized that families are in need of getting support because of additional expenses which kids with special have compared to the kids with normal development and also difficulties had in trying to explain condition of the child to other people and dealing with negative attitudes of people in the society (Sagiroglu, 2006). 88% of the families with autism indicated they needed psychological support, 86% of indicated they needed to be informed on autism, 80% of indicated their children had educational needs (Selimoglu et al., 2013). For Bircan (2004), there are some problems in family functions and domestic relations and communication when

the individual joins the family is with special needs. It is expressed that some parents' professional lives are affected when a child with autism is born and joins the family. Financial income decreases as professional lives are affected and family has difficulties in this regard. There are several findings concerning another problem encountered when a child with autism joins the family is that social life and social relations of the families become limited and they are isolated from the social life. Parents with autistic children indicated that they could not get much support and they were alone in care and social support process. Parents have expressed the difficulties in social support process in selecting the proper institutions for their children. In this process, social service experts and guides and psychological counselors should give assistance to the families by using their consultancy and educational roles.

Autism diagnosis is defined as a neurodevelopmental disability which affects all family members for life beyond the child. It is found also in the study that difficulties encountered by the families are maintained by an extreme concern about the future. Since environmental support and information needed by the families would make easier to accommodate themselves to autism, it is very important that children begin special education at early period and their dependencies are minimized. It is considered that studies to conduct will make great contributions to the field with regards to the development of psychological support services for family that it is easy for parents to access. It has been suggested to apply the methods for providing parental psychological support and eliminating the losses in the direction of the obtained results. The level of autism has not been taken into consideration in the research conducted. The difficulties the child experiences and the difficulties parents will experience will also increase. In this direction, the addition of such variables as comorbid disorder, autism severity will make a big contribution to literature.

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