

**PERSPECTIVES OF TURKISH MOTHERS ON
HAVING A CHILD WITH DEVELOPMENTAL DISABILITIES**

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The purpose of the present study was to examine the perspectives of Turkish mothers of their children with developmental disabilities. A descriptive study was conducted via collecting data using semi-structured interviews. 39 mothers of children with developmental disabilities who were enrolled in a university unit. The data analysis has shown that mothers of children with developmental disabilities face many difficulties and changes in their daily family lives after the birth of their child with developmental disabilities. The results were discussed with the reference to other related studies.

Parents, in general, have the responsibility of preparing an appropriate environment of love, care, and meeting the needs of their children who follow a normal pattern of development. Parents' responsibilities rapidly multiply when their child has developmental disabilities. The responsibilities they face are many, among them: different teaching skills, counseling, behavior management, parenting their other children at home, maintaining appropriate communication between husband and wife, creating sustainable relationship with the school (Heward, 1996; Sucuoglu, 1997). At the same time, parents of children with developmental disabilities need to learn to accept the fact that their child is different from their typically developing peers, and to keep up with frequent trips to the hospital, doctor, physiotherapist, and the special education teacher (Kroth & Edge, 1997). Often the focus is solely on the child, and the parents' feelings might be forgotten (Garguilo & Graves, 1991).

Having a child with developmental disabilities causes a crisis in the home (Dyson, 1993). As Kroth and Edge (1997) mentioned, most of the parents show similar responses when they learn that they have a child with a disability. Other authors reported that parents have different responses depending on the religious, socio-economic, and educational levels of the parents, and the level of disability of their child (Blackhurst & Berdine, 1992; Norton, 1976). Whichever perspective one supports, one may conclude that having a child with developmental disability strongly affects family dynamics. Many families change their daily and social lives because of the child with disability (Hallahan & Kauffman, 1997). A research examining the problems of the parents who have children with disabilities during their daily lives pointed out changes in the daily routines and their social lives as their financial responsibilities increased (Donmez, Bayhan, & Artan, 2001).

Parental reaction to a disability is highly individualistic. Each parent responds in his/her own way (Gargiulo, 1985; Gargiulo & Graves, 1991). Different approaches related to the reactions of parents when they have a child with disability exist: psychodynamic approach, functionalist approach, psychosocial approach, and interactionist approach (Ferguson, 2002). The reactions of parents when they have the child with developmental disabilities are shock, denial, and grief. Following these first reactions, anger, bargaining and depression follow. Eventually, the parents should accept the facts, but some families never manage to reach this final point (Heward, 1996; Schulz, 1987).

Hallahan and Kaufman (1997) stated that many researchers who work on the parental adaptation process use the grief model. According to the grief model, the first stage consists of shock, denial and depression; the second stage consists of complexity, guilt, and anger; and the third stage consists of bargaining, acceptance, and adaptation (Gargiulo & Graves, 1991). The types of behavior shown by the parents differ depending on the characteristics of the parents. Despite the differences in the behaviors or the stages parents find themselves, most of the parents accept their child with developmental disabilities (Haveman & Berkum, 1997).

The first information given to the parents about their child's disability plays a very important role in the parental adaptation process in the future. Where, when and by whom the information was given, the content of the information effects negatively or positively the stages which the parents will experience (Seligman, 1991).

There are several research studies that examined the problems and needs of parents who have children with disabilities (Lai & Ishiyama, 2004; Lehr Essex, 2002; Sucuoglu, 1995; Sucuoglu, Kucuker, & Kanik, 1993). In all these studies, health and behavior problems related with the disability of the child, lack of social relations, financial problems of the families providing educational and related services for the child were the problems mentioned. On the other hand, there is still need for examining the relationship between the parental reactions and cultural and ethnic characteristics of parents of children with disabilities (Ferguson, 2002).

The purpose of the present study was to describe the perspective of parents after they have a child with developmental disabilities. Under this general purpose the following questions were tried to be answered: (1) How did they learn that their child had developmental disability? (2) How did their reactions changed from the day that they learned their child had developmental disability until today? (3) Which differences occurred in their family life from the day that they learned their child had developmental disability until today? (4) How did they learn that they could provide special education for their child? (5) Which differences occurred in their family life after their child with disability started to get special education? (6) What were their expectations about their child's future? (7) What were their expectations from the community, institutions, and government? and (8) What would they want to say to the community, other parents of children with disabilities, and special education teachers of their child?

Method

Participants

The participants of the study were 39 mothers of children enrolled in a university unit for children with developmental disabilities. These mothers were the volunteers out of 70 parents of the unit. The average age of mothers was 36 (range= 24-55). Slightly over half of the mothers finished primary school (54%), few of them finished elementary school (8%), some of them finished secondary school (26%), and some of them finished a college or university (12%). They had 1-3 children, but the majority had two. The average age of their children was 9 years. 41% of the children had mental retardation, 31% had autism, 23% had Down's

syndrome, and 5% had developmental disability plus another disability. The participants were mostly from a middle income level community.

Data Collectors

Seven students collected the data. One was a graduate student in the department of sociology, two of them were undergraduate students in sociology and the remaining four were undergraduate students in the special education department.

Before data collection began, an information seminar about semi-structured interviews was given to the data collectors. A simulation interview was conducted with the data collectors by one of the authors during the seminar. After the seminar was completed, each data collector conducted a pilot interview with a mother other than the participants of the study: The interviews were observed and feedback was provided by the authors to the data collectors immediately after they conducted the interviews. After the training procedure the data collectors started to conduct the interviews with the participants of the present study.

Settings

Before the interviews, each participant was asked where they would prefer to make the interviews, either at home or at the unit. All of the participants preferred to take the interviews at the unit while their child was having 1:1 or group education. The interviews were conducted in the seminar room of the unit. In the room there were 20 long seminar tables in a U position, and 50 chairs around them. There was also a computer, and a overhead projector in the room. During the interviews a tape recorder was used to record the dialogue between the mother and the data collector .

Procedure

The questions were prepared before the data collection was started and three researchers in the field of special education verified the questions prepared for the interview. At the end of this task 15 open-ended questions were included in the interview (Table 1). Although the questions were prepared in a sequence, the data collectors were told that they were free to change the sequence.

At the beginning of each interview the data collectors told the purpose of the study to the participants. Participants of the study were also told that this was a volunteer procedure, they were free to withdraw from the study whenever they wished, and also that they had the chance to refuse to answer any of the questions during the interview, the data would be used only as the research results and pseudonyms would be used instead of their real names.

The interviews lasted from 45 mins. to 1 hour 15 mins (average 1 hour). Each interview was transcribed verbatim by the data collectors and the researchers, and checked for accuracy by the researchers by listening to the audio tape and reading the transcripts.

Table 1
Interview Questions

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1. Can you please tell us about your family?
 2. How did you understand that there was a problem with your child?
 3. (a) How were you told that your child had developmental disabilities?
(b) when were you told that your child had developmental disabilities? and
(c) where were you told that your child had developmental disabilities?
 4. What were your feelings when you learned that your child had developmental disabilities?
 5. What are the changes in your feelings from the day that you learned that your child had developmental disabilities until today?
 6. Who had effects on these changes?
 7. How did your family life changed after you had the child with developmental disabilities?
 8. What kind of problems did you face after you had the child with developmental disabilities?
 9. For solving these problems:
 - (a) what did you do?,
 - (b) what did your husband do?, and
 - (c) what are you still doing?
 10. (a) When did you learn that your child could get special education?
(b) Where did you learn that your child could get special education?, and
(c) From who did you learn that your child could get special education?
 11. (a) Where did your child start to get special education?, and
(b) When did your child start to get special education?
 12. What kind of changes occurred after your child started to get special education in your family life?
 13. In the future, what are your expectations; (a) about your child's health, (b) about your child's education, and (c) from other people?
 14. What are your expectations from (a) the institutions providing special education, and (b) the government?
 15. What would you like to say or what are your recommendations for
 - (a) the other parents who have a child with developmental disabilities,
 - (b) the community, and
 - (c) the special education teachers related with your child?
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Data Analysis

Ten randomly selected interviews were read by the first and the second authors independently. Each researcher identified categories related to the answers to each question. Then they compared the titles and made a list of titles corresponding to the answers of participants of the ten interviews. The titles then, were placed in a checklist format and given photocopies for each participant and each researcher. The researchers independently marked the related title for each question of each participant. Then the researchers together compared the answers they marked and calculated the reliability of their analysis with the formula of *number of agreements divided by number of agreements plus number of disagreements multiplied by 100*. The mean reliability between two researchers was 91% (range= 75-100%).

Results

The purpose of the present study was to describe the perspectives of parents after they learned that they had a child with developmental disabilities. The results of the study were grouped according to the research questions which were mentioned under the general purpose. According to the research questions, eight headings emerged from the data gathered. While giving the results, the ones with less than five frequency (11%) were not reported in this manuscript. Moreover, interesting words mothers used were reported with the frequency data

below. During data analysis, each mother was given a code number. The numbers in parentheses below (e.g., m. 6) are the numbers given to the mothers as code numbers.

Learning about the child's disability

Learning about the disability gave a real shock to the parents. Parents talked about various issues related to this event. First of all, parents told about the time they realized that there were some problems with their child. Many of the parents mentioned that they realized that there was a problem with their child when there was a delay in learning to walk (16%); a delay in speaking (15%); when the child was born (15%); when he/she became ill and was taken to the doctor (11%). For example, a mother mentioned the difficulty in her child's learning to speak *there were difficulties in her speaking when she was 3-4 years old. She used to have a tantrum when she couldn't manage to tell whatever she wanted to* (m. 7). Another mother pointed that they learned that there was a problem with the baby before the birth, *I used to go for regular check ups to the doctor when I was pregnant, it was determined that there was a problem during the pregnancy* (m. 9). In general, the participants of the study realized there was some problem when their children had difficulties or delays in reaching developmental milestones.

Mothers were asked how it was told that their child had mental retardation/ developmental disability. 25% of the mothers told that doctors told them that he/she had other illnesses apart from mental retardation; 22% of the mothers were told that the child would be developing slower than his/her peers, for example one of the mothers mentioned this with the following words: *when we went to a different doctor when she was 11 months, he told us that she was acting like an eight months old baby* (m. 37); also 22% of the mothers were told that he/she would need to get special education, for example one of the mothers expressed this with the following words: *they told us that she would need to get special education when we were in the hospital for her regular check up* (m. 37); and 22% of the mothers were given information about the disability and provided resources related to the disability. For example one of the mothers said that they were given information about the disability of the child with the following words: *we were told that he would talk, walk and learn later than his peers, also that, we should be prepared for such a child* (m. 10), and another mother mentioned that they were given detailed information about the characteristics of children with Down's syndrome (m. 8). None of the mothers pointed that they were directly told that their child had mental retardation/developmental disability.

Mothers were also asked where and when they were told that their child had mental retardation/developmental disability. 76% of the mothers pointed that they were told in the hospital. Others were told in the rehabilitation center or school where their child got his/her educational services. Also 23% of the mothers were informed when their child was 2-4 years old; 19% of the mothers were informed when their child was 4-6 years old. On the other hand, 16% of the mothers were told that their child had mental retardation/developmental disability when he/she was born in the hospital.

Mother's reactions

When the mothers were asked what their reactions were when they first heard the diagnosis of their child, they mentioned that they became very sad (34%), were shocked (26%), for example one of the mothers used the following words in order to tell her reaction: *before telling the situation, the doctor gave me a book about the subject. I read it and learned about the disability however, when I heard it from the doctor I was demolished* (m. 15); did not believe (17%), as one of the mothers described her reactions: *we became very upset, we could not believe. I used to think that this kind of things would happen to other people but not to us* (m. 38).

When the mothers were asked if there were any changes in their reactions over time, they told that they had depression and stress (22%); complication (16%); and acceptance and adaptation (14%) from the day they were told about the diagnosis. One of the mothers talked

about her feelings: *when we first learned we became very sad, we did not have even a day without being upset. But after we started to take him here for special education, we began to realize the development and changes in his behaviors, hence, our reactions started to change. We started to have hopes about his future.* (m.37).

The Mothers mentioned that her parents (26%); husband (23%); parents of herself and her husband (14%); and educational institutions (14%) had effects on the changes of her reactions. They received moral support (21%); educational support (21%); and negative feedback (21%). One of the mothers stated: *we worked together with my husband as mother and father together. We still work on his speech, we always talk with him. My husband is a very strong support for me.* (m. 37).

Changes in family life after they learned that their child was disabled

Within this theme, mothers were asked about the changes they had in their family lives after they had the child with developmental disability. 30% of the mothers mentioned that they did not have any change in their family lives; but on the other hand 10% of the mothers pointed that they had limited the relationship with their friends and other social environment, and other 11% mentioned that the siblings were negatively effected by the child with developmental disability, : *my other two children's social lives have stopped. We can't go out for a walk, for a picnic. Until the day he starts to understand where to sit where to stop, we can't go anywhere with him. Therefore we can't go anywhere together as a family.* (m. 38).

Participants were also asked what kinds of problems they had after the birth of the child with developmental disability. Some of the mothers mentioned that they did not have a normal family life any more (20%), *we are totally devoted to him. Whatever we do is only for him now.* (m. 36); others pointed that they did not have any problems (20%); some of them mentioned that they had financial problems (16%); and some of them expressed that they had to go to hospital frequently (11%).

When the mothers were asked what they did for solving the problems emerged after the birth of the child with developmental disabilities, some of them mentioned that they looked for ways of medical treatment (33%), for example one of the mothers used the following words in order to tell her thoughts about the subject: *we are totally interested in his health. We are always busy with the doctors and hospitals related with his health problems.* (m. 8); looked for school and rehabilitation centers (30%); and tried to teach some things at home by themselves (25%).

Mothers were also asked what their husbands did for solving the problems mentioned before. More than half of the mothers mentioned that, their husband helped them with problem solving (51%); and some of them expressed that since the fathers did not accept the child's disability he did not do anything at all (12%), *my husband didn't accept the child at all, therefore I am always between them.* (m. 25).

Some of the mothers mentioned that they were trying to do whatever they can at home (28%); trying to meet the needs of their child related to school (27%); trying to take the child to parks and other social environments (16%); and trying to solve health problems (13%). *We take him to the hospital when he is ill, we bring him here for getting special education, and also we take him to social environments to learn something from neighbourhood.* (m. 31).

Providing special education

Mothers were asked how and when they learned about providing special education to their child with developmental disability. Some mothers mentioned that they learned about special education when their child was 1-3 years old (40%); some of them expressed when the child started to attend preschool education (23%); and some others mentioned when the child

started primary school education (17%). Most of the mothers learned about special education from the pediatrician (57%); some others learned from their friends and relatives (13%); and some others learned from teachers (13%).

Another question asked to the participants was where and when their child started to take special education. Most of the mothers mentioned that they started to take special education from the university unit (60%); and some others pointed a rehabilitation center (30%). Some of the mothers expressed that it has been one year that their child started to take special education (41%); some of them mentioned for two years (26%); and some others for four years (18%).

Changes in family life after special education

Mothers were asked what kind of changes occurred in their family life after their child started to take special education. Nearly half of the mothers (47%) mentioned that they become happy when they see the progress in their child; and some of them (19%) mentioned that they felt relieved after their child started to take education. The serious changes in our child made us very relieved. It is a great support, moral support and happiness for us. (m. 38).

Expectations about the child's future

Mothers were asked what their expectations were about their child's future. The answers differed. Some of the mothers (29%) mentioned that they expected him/her to meet his/her own needs by him/herself; some of the mothers (22%) said that they expected him/her to progress by the education; and some of the mothers (13%) expected their child to go to a regular primary school in the future. *I would want him to stand on his own feet, to eat and drink independently, sleep and go to toilet independently.* (m. 38).

When mothers were asked what they expected from other people in the future about their child with disability. Some of the mothers (34%) expected nothing from other people; whereas the others (17%) expected siblings of the child with disabilities to be more responsible from his/her brother/sister. Some others (17%) expected other people be more conscious about people with disabilities and act as so. For example, one of the mothers told her feelings about this subject with the following words: *I am not expecting anything from any one directly. I just want him to know what is harmful, what is harmless for him when we pass away and he is left alone.* (m. 13).

Mothers were asked what were their expectations from the institutions providing service to children with disabilities. Their answers varied. 22% of the mothers expected individualized education for each child with disability; 22% expected effective teaching techniques to be used in the institutions with their children; 17% of them mentioned that they expected consultancy service from the institutions for the parents of children with disabilities; and 11% of the mothers expected continuity in education for children with disabilities.

Mothers were also asked what their expectations were from the government. Some of them (24%) mentioned that they expected increase in the financial help for education of their child and regular payment by the government; some of them (22%) pointed that they expected the government to protect and patronize the children with disabilities; some other (17%) expressed that they expected the school for children with disabilities to be widespread all around the country; and some of them (12%) expected the government to open new vocational centers for their children. *We want the schools become widespread all around the country and the number of schools to be increased in our city.* (m. 37), and another mother with the following words: *we want work sites for them* (m. 13).

Recommendations of the mothers

Mothers were asked what their recommendations were for the other parents who have children with disabilities. Some of the mothers (31%) recommended parents to support their

children's education with all their resources; some of them (21%) suggested them to be patient, devoted and indulgent; some of them (19%) recommended them to accept their children as they are; and some others (17%) offered them to work hard for taking their children to the highest point possible. *I recommend the other families to apply for the special education courses as early as possible, and to be patient, devoted, and indulgent.* (m. 37).

Mothers were also asked what their recommendations were for the community about the individuals with disabilities. Some of the mothers (66%) recommended the community to accept individuals with disabilities as they are, not to compare them with normally developing peers; and some others (13%) suggested them to be more conscious of individuals with disabilities.

Discussion

The purpose of the present study was to examine the perspectives of mothers of children with developmental disabilities. The results of the study showed that parents had different experiences with their children with disabilities.

According to the results of the present study, parents of children with developmental disabilities make changes in their family lives such as reducing their social lives. Research on this subject supports this finding, and mothers recommended that parents of children with developmental disabilities should be encouraged for taking a lifelong family role with providing sufficient support services (Essex, 2002).

In the present study one of the points mothers mentioned was that fathers did not accept their children with developmental disabilities, therefore they did not do anything for solving the problems faced by the mother. Essex (2002) also mentioned the lack of acceptance of the children with disabilities by their fathers and therefore being apart from the relationship between the mother and child. Also that fathers did not accept these children if they also had behavior problems. Hence, it can be recommended to the institutions providing special education to children with developmental disabilities that, they can provide information and an adaptive course for the fathers' of their students about the disability their child have, the characteristics and needs of the children and also the importance of their emotional support for the mother and the child .

Examining the results, 22% of the mothers mentioned that they had depression and stress since the day they learned that their child was developmentally disabled. Various researchers also pointed out that parenting a child with disability can produce high levels of stress and a sense of imbalance in the family system (Boyd, 2002; Ferguson, 2002; Garguilo & Graves, 1991). Hence, it can again be recommended to the institutions providing special education to the children with special needs that they can provide psychological support to the parents of their students, at least at the beginning of the education of their children. It can also be recommended to the city hospitals' psychology services to make follow-up studies in order to find the parents of children with developmental disabilities and provide support to them as much as they need.

In the present study, 34% of the mothers mentioned that they did not expect anything from anybody in the future related with their children with developmental disabilities. Boyd (2002) supported this finding and added that lack of social support caused high level of stress in the parents of children with disabilities.

11% of the mothers mentioned that the siblings of children with developmental disabilities were negatively affected by their siblings. Boyd (2002) also supported this finding with saying that mothers of children with developmental disabilities reported more family problems (i.e., sibling problems, time demands) than parents with normally developing children.

Mothers interviewed mentioned different expectations related with the future of the children with developmental disability. Dyson (1993) also pointed to the increased parental stress relating to the age of the child and parental pessimism about the child's future. So, it can be said that this is a problem that parents should overcome with the help of the institutions providing special education to their children.

Conclusion and Recommendations

The reactions of mothers' when they learn that their child was having a disability seems to be similar. Since they feel shock and depression at the beginning, they start to accept and adapt their child with special needs. The acceptance level is usually seen after the child starts to take special education. During this period, mothers can be affected by various variables: size of the family, acceptance in the family, relationships between the family members, supports provided, cultural factors, and values of the family and community. The participant mothers of the present study had the following characteristics: (a) had families with two children, (b) usually finished primary or secondary school, (c) had middle level income, (d) still married, (e) usually housewives. When these characteristics were combined with the variables presented above, the results of the study were affected by this combination of factors.

As a result of this study, it can be recommended to future researchers that they can conduct a study with not only mothers but mothers and fathers together. Also it can be recommended to conduct a study with parents of children with different types of disability, not only developmental disabilities.

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