

The Life Experiences Of Turkish Mothers Who Have Children With An Autism Spectrum Disorder

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ABSTRACT

This phenomenological study explored the experiences of 11 mothers who have children with an autism spectrum disorder (ASD) in Turkey. Content analysis of data from interviews emerged three themes. They include response to ASD diagnosis, living with ASD, and future perceptions. The findings indicated that the participating Turkish mothers showed negative responses after the diagnosis; potential factors could be influential on these responses; the mothers use coping strategies. Also, mothers shared their future needs. These findings, which are hoped to contribute to the limited research literature on the life experiences of mothers, are discussed within the context of cultural elements in this study. The results discussed in terms of implications for future research and practices

Keywords: Autism spectrum disorders, mothers, phenomenology, qualitative research

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Families having a child with a disability try to cope with negative emotions and challenges (Dillenburger, Keenan, Doherty, Byrne, & Gallaghen, 2010; Meirsschaut, Roeyers, & Warreyn, 2010). Compared to other disability groups, challenges unique to autism spectrum disorder (ASD) may make life more stressful for the families (American Psychiatric Association, 2013; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). After children are diagnosed with ASD, their parents experience negative emotions. Raising a child with ASD causes limitations in the family's daily, social, and work life. The parents spend most of their time with their child diagnosed with ASD; in other words, it causes life of the whole family to turn around ASD (Cavkaytar, Batu, & Beklan Çetin, 2008; Desai, Divan, Wertz, & Patel, 2012; Güleç-Aslan, Cihan, & Altın, 2014; Woodgate, Ateah, & Secco, 2008). Despite these difficulties, research findings also indicate that living with an individual with ASD strengthens marriages, makes family members patient and have a stronger spiritual life, and parents are happy for dealing with their children in spite of all the challenges (Chang & McConkey, 2008).

The adjustment to life with ASD may be more difficult for mothers, who play an important role in the family. Main responsibility for housework and child care is laid on the shoulders of mothers though there are cultural differences and they usually work outside the house in almost every culture. This responsibility is bigger in societies where "traditional parenting role definitions" continue to be predominant (e.g. Turkey, China). In such societies, the main role of a mother in the family is to deal with house and child, and successfully perform the works related to child in accordance with the expectations of the society. In Turkey, there is even a proverb on this subject with a common use: "men make houses, women make homes". This proverb summarizes the roles laid on mothers by implying that main responsibility for performing domestic works and child care belongs to the woman, and the happiness of the

man and the family depends on the woman of the house. Fathers take on less responsibility for children, focus on issues apart from house and children, and thus may show fewer emotional responses when there are challenging situations associated with children. Therefore, the psychological well-beings of mothers, who deal with the works and problems caused by coping with a child diagnosed with ASD in addition to the responsibilities they are expected to fulfill in their normal lives, may deteriorate more (Bilgin & Kucuk, 2010; Dale, Jahoda, & Knott, 2006; Ersoy, 2009; Sileo & Prater, 2012). Research indicates that there are potential variables influential on mothers' responses to ASD and on their mental health. The core symptoms of ASD, regulatory problems, behavior problems of children, and child-related variables may cause mothers to have more negative emotions (Bilgin & Kucuk, 2010; Carter, Martinez-Pedraza & Gray, 2009). In addition, the age and developmental stages of child are potential variables influential on maternal well-being. Mothers are psychologically affected more negatively when the disorder is diagnosed first. As a result, they have higher levels of stress. A fall occurs in the stress level of the mother when her child starts to receive a proper education. The mental health of mothers may deteriorate again when their children reach adolescence and adulthood because of problems unique to these periods (Davis & Carter, 2008; DeMeyer, 1979). However, research findings are not clear in this matter. There are different findings which suggest that mothers with an older child use more effective coping strategies and thus have a better maternal health in the course of time in comparison to mothers with a younger child (Fitzgerald, Birkbeck, & Matthews, 2002); both the mothers of toddlers and the mothers of adolescents and adults have significant distress (Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008); and the parents of toddlers have a high level stress (Davis & Carter, 2008).

Various family-related variables such as mother's having a positive health, mother's having an optimistic personality, positive perspective (e.g. thinking that this situation will make a positive contribution to one's life) and marital adjustment make mothers have a better psychological state (Gupta & Singhal, 2004; Weiss, Robinson, Fung, Tint, Chalmers, & Lunskey, 2013).

Research suggests that these variables do not have a direct influence on the psychological well-beings of mothers, but their influences are moderated by coping strategies. In other words, the emotional states of mothers depend on coping strategies (Dunn et al., 2001). These strategies are basically problem-focused, emotion-focused, and religious coping strategies (Dunn et al., 2001; Lazarus & Folkman, 1984; Manning, Wainwright, & Benneth, 2011). Problem-focused coping strategies involve efforts to identify the problem that leads to stress, find a solution, or change the source of stress. Among these strategies are active coping that includes efforts to reduce the effects of the situation leading to stress, positive reinterpretation that involves redefining the event causing a problem from a positive perspective, and making solution-oriented decisions by acquiring knowledge to facilitate problem-solving. Emotion-focused coping strategies aim to reduce or manage the feelings of distress. Denying the existence of the situation that causes stress, focusing on the stressor and ventilating feelings, behavioral disengagement (stopping making an effort to solve the problem), escape-avoidance (e.g. using drugs), and distancing (acting as if nothing unusual happened) are frequently employed emotion-focused coping strategies. Research findings show that higher levels of problem-focused coping strategies (especially positive reinterpretation) and lower levels of emotion-focused coping strategies (especially disengagement) are associated with the positive well-beings of the mothers of children with ASD. Increasing the use of problem-focused strategies and decreasing the use of emotion-focused strategies reduce mothers' stress and positively

affect their psychological functions (Carter et al., 2009; Tunali & Power, 2002). Religious coping strategies, which involve religious beliefs used for explaining the situation experienced and religious practices (e.g. praying), may help people confronting with stressful events (e.g. ASD) to cope with the situation causing stress. People using these strategies may have a more positive perception of stressful situations and begin efforts to find solutions for them by getting support from their religious beliefs and practices. By this means, they can cope with the negative situation and have a lower distress. Positive religious strategies used by mothers with a child with a disability such as regarding the disability of child as a gift of God, considering it an opportunity for spiritual development, and focusing on religious activities are associated with better psychological function. However, negative coping strategies such as feeling anger with God, believing that God does not like him, and thinking that one is punished by God because of his past mistakes are associated with greater negative emotions (Hall, 2012; Manning et al., 2011; Tarakeshwar & Pargament, 2001).

Coping strategies and the effects of a specific strategy may vary by certain variables. It is reported in literature that mothers of individuals with ASD who are in adolescence period use emotion-focused strategies more. It is stated that this situation may result from the fact that mothers feel to have less control over their children because of the changes occurring in them in adolescence period (e.g. child becoming physically stronger). This is because; individuals frequently use emotion-focused strategies when they have a lower control over stressful situations (Smith, et al., 2008; Folkman, 1984). It is stressed that the adjustment of the father and siblings, social supports are very important for the mother's well-being (Hall, 2012; Seligman & Darling, 2007). Furthermore, it is reported that optimistic people have a more supportive social circle, use more effective coping strategies, and have a more positive psychological well-being in comparison to pessimistic people (Brissette, Scheier, & Carver, 2002). It is stressed in literature that new research findings about coping strategies may be guiding for planning and increasing the effectiveness of services to be provided for mothers (Mancil, Boyd, & Bedesen, 2009).

Another important concept associated with adjustment and coping is attributions theory. Attributions theory focuses on explaining the reason why a specific event or result has emerged. Individuals make various "causal attributions" about the cause of unexpected stressful events (e.g. ASD) or to search for explanation (Weiner, 1985, 2000; Whittaker, 2002). Questions like "why my child?" which mothers ask when they learn that they have a child with ASD are about searching for a meaning and thus attributions theory (Dale et al., 2006). All causal attributions comprise locus of causality, causal stability, and causal controllability. In locus of causality, the event is attributed to external or internal causes. In causal stability, attribution is made to whether or not the cause can or cannot change in the course of time. In causal controllability, attribution is made to whether or not an individual has a control over changing the cause (Whittaker, 2002). Causal attributions have a function of protecting individuals from stressful events and making them adjust more easily. However, that is not valid for all attributions. External attributions are related to better adjustment and effective coping strategies, whereas internal attributions are related to worse adjustment and negative coping strategies. Moreover, when the negative situation is regarded as an uncontrollable situation that will continue also in the future, negative emotions and coping and adjustment difficulties emerge. However, when the negative situation is considered changeable and controllable if an effort is made for it, individuals have a positive psychological well-being (Dale et al., 2006; Wong & Weiner, 1981). However, there are a limited number of research which indicate that the adjustment and coping difficulties of mothers having a child with ASD may be associated with causal attributions. These research findings show that some mothers

make attributions to themselves and blame themselves while some others make attributions to external sources and blame external sources for the event. They also show that attributions to external sources (e.g. God's will) are associated with better adjustment, but self-blame attributions are associated with worse adjustment. Also, it is reported that depressive symptoms are higher among mothers who feel high responsibility and blame for the behaviors of their child. Research suggests that new studies are needed on this subject (Chavira, Lopez, Blacher, & Shapiro, 2000; Mickelson, Wroble, & Helgeson, 1999).

It is stated that there are not cultural differences between the first emotional responses of families to disability diagnosis (Blatcher & McIntyre, 2006; Hallahan & Kaufmann, 2009). However, it is reported in some studies that cultural differences affect life experiences and emotions after diagnosis. Though literature on the relationship between ASD and culture is limited, it is known that the ASD experiences of mothers may change culture to culture. (Bilgin & Küçük, 2010; Chang & McConkey, 2008; Mandell & Novak, 2005). For example, mothers are expected to take more responsibility within family and society for bringing up children and are considered responsible for the behaviors of children due to traditional role perceptions in some countries (e.g. Taiwan, China, Turkey), which causes mothers to experience more negative emotions and have a difficulty in coping with them (Cavkaytar, 2010; Daley & Sigman, 2002; McCabe, 2008; Yapıcı, 2010). Moreover, more problems are confronted about services to be received by children and parents especially in advanced ages in some countries, and thus psychological healths of mothers are disturbed (Bilgin & Kucuk, 2010; Chang & McConkey, 2008; Dunn et al., 2001). For instance, especially the lack of services for children in advanced ages in Taiwan leads to intense worry and pessimism among parents in regard to who or which institution will look after their children in the future (Chang & McConkey, 2008). In China, the problems about diagnosis and education cause families to confront problems (McCabe, 2008). Though promising developments in ASD services in Turkey, families still cannot receive adequate services. Especially those families who have a child in adolescence period or adulthood period confront problems. A lot of families cannot receive adequate service for their children's problems during adolescence, vocational education, and the care of their children when parents grow old. That causes mothers have a negative psychological well-being (Bilgin & Kucuk, 2010; Cavkaytar et al., 2008; Üstüner Top, 2009). Additionally, religious beliefs and the perceptions of the society regarding the disability may influence the experiences of families regarding the disability (Mandell & Novak, 2005). For instance, a lot of Buddhists believe that people who go through difficult experiences (like ASD) will be rewarded after death (Chang & McConkey, 2008; Holroyd, 2003). Disability is perceived as a tragedy in India. The expectations of parents and the society regarding individuals with a disability are quite negative and unrealistic, and it is thought that what these individuals need is only help and sympathy. Also, according to the "theory of karma", which is invoked to explain life events like occurrence of disability, there is a negative belief that this situation is a punishment for past karmas. These perceptions have a negative influence on the psychology and social acceptance of families (Gupta & Singhal, 2004). Turkey is a country where majority of the population is Muslim belongs to Islam. In Islam, it is believed that difficult events like ASD are a exam for life after death and that God will reward those who do not rebel but act patiently in the face of these kinds of situations and give thanks to God for them, open the doors of the heaven to them, and make disabled children angels. In this sense, religious coping strategies are predominant in dealing with difficult situations in Turkey because of the Islamic belief there (Kara, 2008).

Consequently, literature suggests that mothers with a child diagnosed with ASD experience negative emotions. If mothers are strengthened through services to adjust to ASD, they can participate their children's education more actively and effectively (Phelps, Hodgson, McCammon, & Lamson, 2009; Meirsschaut et al., 2010). In this respect, research, especially the qualitative research, findings concerning what it is like to be a mother of a child with ASD, their real life stories and emotions may make significant contributions to planning the services. Nevertheless, research on families with ASD has focused basically on diagnosis and interventions so far. Though there has been an increase in qualitative research focusing on the experiences of mothers, there is still a need for new research (Hall, 2012; Woodgate et al., 2008). Moreover, most of the studies focusing on the life experiences of mothers have been carried out in the USA, Australia, and other western countries. Therefore, there are limited number of findings about the life experiences of mothers living in other countries, especially those living in Turkey (Bilgin & Kucuk, 2010; McCabe, 2008). Therefore, the present study aims to make a qualitative examination of the life experiences of Turkish mothers having a child diagnosed with ASD both at and after the diagnosis in order to make a cultural contribution to the literature on this subject. Furthermore, this research will provide information for the planning of "family-oriented" services based on the needs of families. Besides, this study will provide a perspective for research based on different cultures or ethnic groups. The research questions are as follows: (a) what are the responses of mothers to ASD diagnosis?; (b) what are the effects of ASD on the lives of mothers?; (c) what are the coping mechanisms of mothers?; (d) what are the future perceptions of mothers?

METHOD

This qualitative study has been conducted utilizing a phenomenological approach (Creswell, 2014; Smith & Osborn, 2004).

Setting and participants

The study included a nonrandom sample of 11 Turkish mothers with children who were diagnosed with ASD. All of the families lived in a small city. The age range of the participant mothers is 30 to 48, and the average age is 39 year. Nine mothers are housewives, one mother is lawyer and one mother is chef. The children of all the mothers have got education at the Education Center for Individuals with Autism (ECIA). ECIA is the public school which only children with ASD attend.

The children (nine males; two female) ranged in age from 8 years to 15 years, and the average age is 11 year at the time of the interview, with the children's age of initial diagnosis ranging from 18 to 60 month, and the average month is 28 month. As described by mothers, six of the children have regulatory problems and various problem behaviors. Four of the children display various obsessive behaviors. Nine children cannot speak, and two children can verbally communicate at a one-word level.

Research sample was determined in accordance with the purposeful sampling strategy and the standards of qualitative research (Creswell, 2014, Patton, 1990). The mothers of 50 students receiving education at ECIA, which is the only school attended by students diagnosed with ASD in city, were verbally informed by teachers and the researcher. Then 11 families who wanted to participate in the study were included in the research process. participants were informed written about research and research process by the researcher They and researcher were signed a contract about with the research ethics. Official and ethical permission for the study was taken from the national education directorate, the ECIA administration and the university scientific research board.

Data Collection

Semi-structured interviews were conducted with mothers and narratives identified by the notation of M(other) with accompanying participant number. Interview questions were prepared by researcher with reference to extensive literature review about the experience of mothers with children with ASD (for example, Desai, et al., 2012) and the 20 years teaching experiences of the researcher. The semi-structured interview included questions relating to the emotions of mothers, their experiences regarding raising a child with ASD, their ways of coping with the challenges they experience, and their perspectives on the future. Some examples for these questions are following: How did you feel when you first heard the ASD diagnosis? Please tell me how you and your family have been affected by having a child with ASD?, How do you cope with the challenges?.The mothers also completed a short demographic form.

The interview form was finalized based on the approvals of two faculty members working in ASD field.

All interviews were conducted at ECIA. Each interview lasted 1 to 1.5 hour. All interviews were audiotaped. At the end of the interviews, the families were asked whether or not they wanted to make any correction on the answers they had given. The names of the participants are kept confidential.

DATA ANALYSIS

The data were analyzed via content analysis. All interviews were typed into a Microsoft word file. Interview transcripts were examined repeatedly for initial categories. After initial categories were created, this categories were reviewed by one colleague who is familiar with qualitative research and ASD. After her feedback about initial categories, coding categories refined. Categories were reviewed for preliminary themes by the researcher and themes refined via peer debriefing process. For this process, another researcher who is also familiar with qualitative research and ASD field examine preliminary themes and categories. This researcher confirmed the consistencies between preliminary themes and categories. Afterwards, the researcher divided the transcripts into themes. The transcripts divided into themes were given to the researcher whose opinion was received in regard to the preliminary themes. The researcher gave feedback about consistencies between themes and data. Both researchers discussed about similarities and differences of their perspectives about themes and data until agreement had been reached. Finally, all themes have been organized and reported (Creswell, 2014).

In this study, some strategies were used to establish trustworthiness (Brantlinger, Jimenez, Klingner, Pugach ve Richardson, 2005): Investigator triangulations; member checking; peer debriefing; researcher reflexivity; behaving according to ethical principles; particularizability.

RESULTS

In the following section, the findings are discussed under the themes of response to ASD diagnosis, living with ASD, and future perceptions.

Response to ASD Diagnosis

The mothers' responses to the diagnosis are presented in Table 1. All mothers stated that they experienced negative emotions such as anxiety, worry, and sadness after their child was

diagnosed with ASD. Some of these mothers (n=8) stated that they went to a doctor upon noticing differences in the development of their child (e.g. their child did not speak), but they had a big shock when they learned the diagnosis and its characteristics as they had had no knowledge of ASD beforehand. Some mothers (n=3) stated that they had predicted before they went to a doctor that the differences in their child resulted from ASD. In other words, they stated that “they had already made the diagnosis” and thus they were not shocked when they learned the diagnosis.

I had already been suspicious of autism. I had read a book about autism. The psychiatrist made autism diagnosis. We weren't shocked, but we were very sad (M10).

The mothers made mention of some variables that affected their responses after the diagnosis (Table 2). All mothers stated that what made them most anxious and stressed after the diagnosis was that they did not have adequate knowledge of “ASD and what they had to do for it”. In addition, all mothers stated, “lack of an exact medical treatment for ASD” was influential on their experience of negative emotions. Two mothers stated that they were confused by the incorrect information about ASD provided by the doctors, which also caused them to experience negative emotions more intensely.

Table 1. The mothers' responses

N	Response to diagnosis	Sample statements
11	Negative emotions	<p>I can say that when I heard of autism for the first time, the whole world came crashing around me. I thought of how I could live in this world (M6). An absolute despair (M7). I just wanted to cry. It's something really sad for a mother (M9). I used to be a smiling and talkative girl in the past. However, now I get angry with everything. I'm not satisfied with my current state, but I can't put up with anything. It's as if my screws were loose and had to be tightened(M7). I was absolutely weary of life for a year. I can say that I was ready to sacrifice my husband and my other child. Only that child and I. We didn't go out at all. I had fallen into depression (M11).</p>
7	Shock	<p>We were shocked. The doctor said 'autism'. What is 'autism'? I had never heard of it before. They explained it. It was a big shock (M4).</p>

Table 2. The factors influential on the mothers' responses

N	The factors influential on the mothers' responses	Sample statements
10	Knowledge of ASD	This is a world in which I don't know what to do. I'm very desperate (M7). I'm anxious. What will happen? Where will my child receive education? (M10). I've never heard of autism. I even didn't think that it was a disorder. I just thought that my child had caught flu and would recover soon. I was very sad after I learned the reality (M2).
10	Lack of medical cure for ASD	It's something indefinite. In other words, it's like a dark well. It doesn't have an ending. You can't see the future. It doesn't have an ending and recovery (M1). Despair! Because you know that it doesn't have any medical treatment. It's a bottomless well without any exit. It's currently a disorder which can't be treated by any means. As it doesn't have any medical cure, it's a bottomless well. It's completely dark and full of despair (M10).
2	Incorrect information	I hadn't known autism. The doctor said that it's a psychological disorder. He didn't know it, either. He said that it's a social disorder. Upon hearing that, I felt somewhat relieved. I thought that it could be overcome as there was no damage in the brain. Then I went to a special education center where I saw other disabled children. I felt very relieved thinking that my child was well. A couple of weeks later, I decided to search it. What was it? What wasn't it? I was very bad when I learned what it was (M1). The doctor told us that our child didn't have any problem and sent us home. We felt relieved. To be honest, I had a big shock when my child was diagnosed with it (M2).

Living with ASD

The mothers stated that ASD brought various challenges and made certain contributions to their lives. The findings show that the mothers use various strategies to cope with this challenging situation.

All mothers (n=11) stated that after their child had been diagnosed with ASD, their life changed and they started to live a challenging life full of problems. Table 3 presents the problems confronted by the mothers and sample statements concerning these problems. The mothers who have lived negative emotions and problems as of the diagnosis process stated that they have been trying to cope with this new and challenging situation in various ways. While some mothers (n=4) stated that it did not take long for them to acknowledge the new situation after their child was diagnosed with the disorder; they overcame the shock in one year; and they started to feel better psychologically in the course of time though they experienced negative emotions from time to time. The children of these mothers have regulatory problems, behavioral problems, and symptom severity. These mothers stated that they try to know ASD better and solve it by acquiring knowledge about the problem, which makes it easier for them to acknowledge the situation. In addition, one of these four mothers stated that her husband has not been affected by this process much; he has supported her; and the support provided by him has played an important part in her coping with the negative emotions. This mother expressed the support provided by her husband and her own family as another factor facilitating the adjustment process as follows:

The process of acknowledging the situation was long for us. My husband, my own family, and the family of my husband have supported me. I overcame the shock rapidly. Some families have broken into pieces. It is just the contrary for us. This situation has strengthened our family life. I've obtained information about autism. The fact that I work has made a great contribution to me in this process. I went to work and returned from it on foot for two years. I walked six

kilometers in the mornings and six kilometers in the evenings. During my walks, I asked the questions in my mind to myself and answered them by myself in order to clear my mind. The brother my child with autism has never been jealous of him. He's had a very mature. He has just said, 'What can we do, mum? He's just a blessing sent by God to us (M2).

Another mother among the above-mentioned four mothers stressed that she has been supported by her husband, her own family, and her friends, but the family of her husband have not given her any support.

After the doctors told me the diagnosis, I started to read a book. I started to search it. My husband has supported me. The family of my husband haven't supported me. While he was younger, I couldn't make him eat and drink. My mother-in-law just says, 'You can't look after your child. You can't feed him'. When our child was diagnosed with autism, she just told, 'You go to doctor in vain. Some children start to walk and speak late. There's no such thing as they say (M5).

The other two mothers, stated that neither their husband nor the family of their husband have been supporting them and stressed the contribution of their own efforts and the support provided by their own family and their friends. For example, mother 3 stated that her child is eight years old; he was diagnosed with the disorder when he was just 30 months old; but the father acknowledged the state of his child only two years ago. In addition, she stated that her psychology has been negatively affected by that the family of her husband with whom she lives in the same house always accuse her and that the other child of hers is affected negatively. This mother also stated that after she had realized that negative emotions and thoughts would bring no benefit, she acknowledged that she had to look after and bring up her child, and she has concentrated on making an effort to have her child receive good education and advance in his life rather than paying attention to the negative responses of people around her, which has also strengthened her and made it easier for her to deal with the situation.

Moreover, these four mothers stated that their religious beliefs play an important role in their acknowledging and coping with the situation. They stated that they believe that ASD is something sent by God and thus they must keep living by acknowledging it and giving thanks to God for the current situation and that makes them stronger.

This is an award granted by God. I sometimes say, 'Is he testing us?' Maybe, if he were a normal child, I would experience more problems. He could have been ill-humored child. That's just an exam. I render my thanks to God for the current state of ours. At least, he isn't confined to bed as he can walk. He has healthy hands and arms. You can't do anything against what comes from God (M3).

These four mothers also made mention of some positive contributions of ASD to their life. For example, mother 2 expressed the contribution of ASD to her life as follows:
ASD has contributed to me. My child has taught me to be patient. He's also provided me with tolerance. I've lost, but I've also won a lot (M2).

Mother 5 stated that her most important gain was that she started to deal with other aspects of life than housework after her child was diagnosed with the disorder.

The findings show that the other seven mothers (mother 1, mother 4, mother 6, mother 7, mother 9, mother 10, mother 11) started to cope with problems one year after the diagnosis.

Three of these mothers stated that they coped with the situation by receiving support from experts. Mother 4 stated that her child was not diagnosed until he was five years old as they had not seen a doctor until then as her husband had rejected that their child had something different. She stated that besides the shock she had had because of the diagnosis, she had had a strong feeling of guilt in her husband and herself for their child not starting early education. She stated that she had fallen into depression because of that and the intensity of the regulatory problems her child had. She also stated that her emotional personality had had an influence on her depression and had overcome the period of depression by receiving psychological support and medication for approximately two years. Mother 10 stated that she had undergone psychological treatment and taken medicine for a while, but she is not on medicine currently. Mother 11 made mention of the support she received as follows: *"I'd fallen into depression, but then I coped with it by receiving psychological support."* Mother 6 stated that she does not receive support from experts, but the tranquilizers she uses make it easier for her to cope with this situation. She talked as follows:

I couldn't sleep, but I didn't go to a psychiatrist or anything like that. My mother-in-law gave me a low-dose tranquilizer. Thanks to it, I recovered to a considerable degree. When I'm very distressed, I get it. My brain recovers itself when I sleep during the night (M6).

Six of these seven mothers stated that the support they receive from people around them helps them cope with the situation. Four mothers (mother 4, mother 7, mother 10, mother 11) stressed the importance of the support provided by their husband; three mothers (mother 4, mother 6, mother 9) stressed the importance of the support provided by other children of theirs; three mothers (mother 6, mother 10, mother 11) stressed the importance of the support provided by their husband and their own family; one mother (mother 9) stressed the importance of the support provided by her own family; and three mothers (mother 4, mother 10, mother 11) stressed the importance of the support provided by their friends and by other mothers in the school of their child. Some sample statements of these mothers are as follows:

My husband and other children's mothers support me. This school we have been going to for one year is like a therapy for me. I've many friends. We can understand each other (M4).

My husband, my family, and the family of my husband try to help by doing their best if there's anything to do. How do I cope with it? Going to school and meeting families do me good (M10).

Mother 4 stressed that searching ASD, increasing her knowledge on this subject, and the progress she has observed in her child through education have made a great contribution to her coping. Five of these seven mothers stated that the most important factor influential on their coping with the situation is their religious beliefs (Table 4). Also, five of seven mothers stated that ASD has made positive contributions to their life and they try to cope with the situation by concentrating on these positive aspects (Table 4).

Table 3. The problems confronted by the mothers

N	The problems confronted by the mothers	Sample statements
7	Regulatory problems (eating and sleep problems)	<p>It was very difficult. He didn't sleep during the night at all. I remember swinging my child on my legs until 6 o'clock in the morning and leaving home at 7 o'clock to go to work for one year. Just think! He had eating and sleep problems. He was just like a skeleton. We couldn't make him eat anything. My only wish was him not to die of hunger (M2).</p> <p>Everything was a problem. Eating, sleeping. He's a non-sleeping child. He just sits in his room during the night until the morning. I could sacrifice my life for him to have a spoon of soup (M7).</p>
4	Behavioral problems and symptom severity	<p>We wake up in the morning and see that everything has been torn, spilled, and cut. He's awake until the morning and, oh God, messes up everywhere just like a thief. Even water was poured onto our computer once (M7).</p> <p>The most challenging thing is that he's hyperactive and full of action. This is because, he always messes up everywhere. We are afraid of him falling. He climbs up to the highest points. I get tired, too tired (M9).</p>
10	Restriction of the personal and social life	<p>We've started to adjust our life to our child. I really miss freedom. It's like an open prison. Social life comes to an end or is minimized. I always have to teach him something (M1).</p> <p>The most challenging part is that mothers are restricted. Dependence on others is really a big problem (M3).</p> <p>Our life has been limited in terms of freedom. We can't go on a holiday. I miss my old life. We can't eat out. He stands up and shouts so everybody turns to us and stares at us. My husband says, 'Let them stare', but I don't feel comfortable in such a case. I feel as if I was disturbing people. They're scared of him (M7).</p> <p>Our life has become autism. Especially my life. If a member of the family has autism, all family members are affected by it. However, I think it's the mother who is affected most because the father continues his normal life including his working life. Mothers have more responsibility. You shape your life based on his desires and order. That's a real problem (M10).</p> <p>I haven't looked after my little child at all. He's grown up with his grandmother. We've ignored him. A professor told me to make a sibling. We made a sibling, but it was just a selfishness. He's growing up with his grandmother. We can't see him. It's very difficult. He acts jealously. He says that we always deal with his brother. That's our biggest problem (M7).</p>
3	The siblings affected negatively	

- 3 Difficulty in explaining ASD to other people
- The most challenging aspect of raising a child with autism is to explain or fail to explain it to people. That's something awful. People don't know it. We can't explain it. For example, they say that my child hears and will speak one day. They think that all problems will come to an end when he starts speaking (M1).
- We're tired and bored of the questions asked. Is there any development in his education?, Is there any treatment of this disorder? I want no one to ask me anything in this matter. They don't ask in bad faith, but I'm tired of replying and explaining. I'm tired of their looks. After a while, I just start to be tired of everything (M6).
- It's had a negative influence on our family life. I've been disturbed by that my husband hasn't talked to or shared with me. It's been a problem that he doesn't give any response to me when I give him information about ASD. Our relatives from the family of my husband such as my father-in-law and my mother-in-law and my husband always accuse me of everything by saying things like 'This problem came out because he fell or he hit somewhere'. I call them ignorant as they don't know and don't want to learn. They've had a very big negative psychological effect on me as I live in the same house as them (M3).
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3 The negative attitudes of the husband and other family members (e.g. the husband and/or other family elders not providing support, the accusatory words of the mother-in-law)

Table 4. Sample statements of religious beliefs and ASD's positive contributions of mothers who started to cope with problems one year after the diagnosis.

Sample statements about religious beliefs	Sample statements about ASD's positive contributions
How do I cope with it? Surely, meds and other things are effective to a certain degree. I just seek refuge in God and pray (M4).	I'm a very impatient and aggressive person. It's taught me to be patient. For example, small things he does such as looking at my eyes for just two seconds make me very happy. His smiling is so important for me. I've learnt to be happy for small things (M4).
We don't enjoy the world and the life, but God exams us in this way. You don't enjoy this world not to be loser in the other world, but you still want God to protect you from a worse situation. I pray so as not to fall into worse situations. We believe that it comes from God (M6).	The relationship between the husband and the wife becomes stronger. That may be something about personality. That is, if a person sees the glass half empty, you can't make him see the glass half full no matter what you do. I've learnt to render more thanks to God for every moment we live. For example, I had a normal child after my disabled child. Maybe, I couldn't have been such a self-sacrificing, productive, and good mother if I had not experienced this problem. As I experience the difficult aspects of dealing with a child with autism, I understand the easiness of raising a normal child. I give thanks to God for the life and for the breath I take (M10).
Once, I just thought of throwing myself from the balcony. I've a strong belief and spirituality. I want and try to be patient. Sometimes, I have difficulty in coping with it. Then I beg God to give me strength. I query myself considering what I experience. Then I realize that it has come from God. He has given it to me. He is the trust of God to me. I have to live with it. I pray for God to give me strength (M7).	I've learnt to struggle. In the past, I didn't struggle against life much. With my child, I've learnt to struggle and endeavor and realized that I have to teach (M1).
I think that even though we have difficulty in this world, God will provide us with good deeds in the other world in return for these difficulties. I adopt this perspective in my life. These problems are our angels. They are our after-life angels (M9).	I've learned to be patient and grateful. I didn't use to give thanks to God in the past. My spirituality has become stronger. In the past, we had a very ordinary life. In the past, we didn't have any target. We just ate, drank, and slept. Now, I bring up a person and endeavor for him. I'm happy for this endeavor. I learn a lot from teachers. It's much better than gossiping during a five o'clock tea. I read books about autism. I have a e planned life. I'm very happy.
It has also a religious aspect. I regard it as a gift of God. If you consider it a penalty, you can't make any progress. You should always look at the bright side. You should regard it as a trust to you. I perceive it in this way. Belief is very important in this matter. It's something coming from God (M10).	I was afraid of driving in the past. I've learned to drive because it was very difficult on buses (M11).

Future perceptions

The findings indicate that none of the mothers knows how to cope with the problems and needs that they may encounter when their child reaches adolescence and/or adulthood and thus all mothers have intense anxiety and worry about the future. The mothers mentioned the uncertainties in the following matters as the issues that worry them most: (a) how they will control their child when he is physically developed; (b) how they will cope with the problems unique to adolescence; (c) the life of their child in the future because of the limitedness of

services in Turkey; (d) who will look after their child when they grow old or die. The mothers also made mention of their dreams for the future. The dream of all mothers was their child to receive education in an institution where he receives a higher quality education; he is engaged in other activities (e.g. sports) besides education; and he undergoes the components of vocational training. In addition, the mothers stated that they want the qualified educators, social and financial support to be provided to themselves, and safe institutions where their child can stay to be opened. Moreover, the dream of four mothers is to have a detached house with a garden where they and their children can live more comfortably. Two mothers stated that they want a miracle to take place and their child to recover completely. The statements of these two mothers are as follows Some sample statements of mother’s future perceptions are presented Table 5.

Table 5. Sample statements of mother’s future perceptions

Sample statements of mother’s needs and problems	Sample statements of mother’s dreams
<p>I want my child to be in a safe place after we go away. That’s such a sorrowful situation. Some people say, ‘take my life and give it to my child so that he doesn’t die before me’. That’s not true for us. We want him to go away with us or before us. That’s the worst and most difficult part of it, but 99% of the mothers with a child with autism or disability think the same. They worry about what will happen after them. That’s the worst thing (M1).</p>	<p>All of my dreams for the future are about autism. As it’s a disease which currently doesn’t have any exact treatment, I want this disease to be treatable (M10).</p>
<p>I’m growing old. He’s now eight years old. I’ll be almost sixty years old ten years later. I don’t know how strong I’ll be and in what kind of a situation I’ll be. He’ll be a stronger man. How I’ll control him. My husband is also growing old. That’s my only concern. I want him to be provided with continuing education. I don’t want any other thing. We want to have educated teachers. All teachers working here are from other fields. They mostly learn from us (M9).</p>	<p>I wish a treatment were invented for it out of nowhere, just like a magic wand. I sometimes think of it when I go to bed at night. I hope a treatment to be found. I always dream of an instant treatment for it at night. It’s a psychological challenge for me that it has no treatment and no solution. I wish he would become a normal child thanks to a treatment in the future. I wish he would tell me, ‘Mother! I’m awake. Good morning!’ when I wake up in the morning (M6).</p>
<p>It was easier when he was younger. He’s becoming physically stronger. My strength isn’t enough. I’ve difficulty in physical terms and I can’t imagine the future. I’m very afraid of adolescence. That’s my only problem for now (M11).</p>	<p>The following dream of a mother about her husband is quite interesting and tragicomic: I’ve also a dream for my husband. You know, phones are formatted. I wish my husband could also be formatted. In this way, his attitudes could change, and he could be a sweet-tempered man. It would be a great change for me if he asked me, ‘What can we do together?’. It would even be enough if he said, ‘You spend more time with the child. So you should tell what we should do (M3).</p>

DISCUSSION

This study explored the life experiences of mothers with a child with autism in Turkey. The findings have been presented under the themes of response to ASD diagnosis, living with ASD, and future perceptions.

Consistently with the similar research results in literature (e.g. Desai et al., 2012; Dunn et al., 2001), the first finding under the theme of response to ASD diagnosis indicates that the Turkish mothers participating in this study experienced negative emotions to ASD diagnosis. This finding is consistent with the research results in literature which suggest that the first emotional responses of mothers do not vary by culture (Blatcher & McIntyre, 2006; Koydemir & Tosun, 2009). In other words, mothers from different cultures experience similar negative emotions to diagnosis. Thus, as it will be discussed in detail in the following paragraphs, cultural elements may influence mothers' responses, and efforts to adjust to life with ASD after the diagnosis rather than their first emotional responses immediately after the diagnosis (Bilgin & Küçük, 2010; Chang & McConkey, 2008).

Another finding under the theme of response to ASD diagnosis is that some variables are influential on the post-diagnosis responses of mothers. One of these variables is the knowledge levels of mothers about ASD and the content of the information given to them by experts. This finding may be explained within the context of cultural differences. Providing families with informative services regarding ASD and living with ASD during and after the diagnosis can make it easier for family members to cope with this situation and enable them to have a positive psychological well-being (e.g. Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010). In addition, the fact that inadequate and/or wrong information is given to families by experts makes it difficult for mothers to cope with ASD, which is quite a challenging situation, and disrupts their mental health in some cultures. This finding also highlights the importance of awareness-raising efforts, which play an important part in increasing the knowledge of individuals in the society (Chang and McConkey, 2008; Dunn et al., 2001). Though there have been positive developments in ASD-services in Turkey, such services and awareness-raising efforts for families are still not adequate (Bilgin & Kucuk, 2010; Koydemir and Tosun, 2009). Therefore, it is thought that the Turkish mothers participating in the present study didn't receive adequate information service and thus confronted difficulties and experienced negative emotions. This finding is not surprising given the fact that the mean age of the children of the mothers participating in the study was 11 and all children, except for one child diagnosed at the age of five, were diagnosed when they were 18 to 36 months old (i.e. the children were diagnosed in the period when services in the field of ASD were more inadequate in Turkey). Another variable influential on the emotional state of the participating mothers following the diagnosis was seen to be lack of an exact medical treatment for ASD. This finding may be discussed within the context of attributions theory. As pointed in literature (e.g. Dale et al., 2006; Whittaker, 2002), the perception of the mothers about the continuity of the situation leading to stress may have resulted in the emergence of negative emotions. This finding implies that the mothers may expect a "medical cure for ASD" that will "change their child completely and immediately" rather than a development through educational support. In addition, this finding suggests that the mothers participating in this study don't know that children diagnosed with ASD can achieve significant developments if they are provided with quality education (Scheuermann, Webber, Boutot, & Goodwin, 2003); the education their child has received so far has not yielded significant developments; or these mothers expect too much from the education received by their child. It is also possible that these mothers need to receive psychological support in order to change these perspectives and emotions of theirs.

The findings of the present study under the theme of living with ASD indicate that all of the mothers participating in the study live a challenging life. This finding is consistent with the results of other studies suggesting that mothers experience problems and their emotional health is disrupted after the ASD diagnosis (e.g. Desai et al., 2012; Koydemir & Tosun, 2009). Though the literature on ASD-culture relationship is limited, the experiences and the intensity of the emotional responses of mothers raising a child with ASD may vary by culture. The fact that a lot of responsibilities are laid on mothers for child rearing in some countries where traditional mothers' roles and fathers' roles are still adopted (e.g. Taiwan, China, Turkey) may disrupt mothers' psychological well-beings and cause them to have difficulty in coping with the situation (Daley & Sigman, 2002; McCabe, 2008). The traditional and cultural expectations from the mothers participating in this study as well as the responsibility for and challenges of looking after a child diagnosed with ASD may have caused these mothers to experience negative emotions. Furthermore, mothers living in the countries where supports are not adequate for adjustment to the life with ASD experience negative emotions more intensely (Chang and McConkey, 2008). The intensity of the negative emotions experienced by mothers participating in this study may have resulted from the inadequacy of the services in Turkey (Bilgin & Kucuk, 2010; Cavkaytar et al., 2008; Üstüner Top, 2009). Additionally, the fact that still a big importance is attached to having a son to assure the continuance of ancestry in cultural terms in Turkey (Cavkaytar, 2010; Yapıcı, 2010) may have had a negative effect on the psychological well-beings of the mothers most of whom have a male child (n=9).

The findings of this study also indicate that the participating mothers started to cope with this challenging situation in different ways as of the diagnosis process. Four mothers who started to adjust to this situation within one year following the diagnosis try to cope with the situation by using problem-focused coping strategies. In other words, these mothers make an effort to acquire knowledge and skills that will enable them to solve the problems they confront. Moreover, these mothers have a tendency to redefine negative events from a positive perspective within the scope of positive reinterpretation. These findings are supported by some researchers who report that mothers using strategies of this sort start to adjust to the challenging situation and have a more positive maternal well-being in the course of time (Carter et al., 2009; Tunali & Power, 2002). It is remarkable that these four mothers are under the influence of child-related variables such as regulatory problems, challenging behaviors of children, and high symptom severity that are stated to be likely to cause mothers to experience more negative emotions (e.g. Sileo & Prater, 2012; Smith et al., 2008). Despite these variables, the fact that the mothers started to attempt to adjust within one year following the diagnosis and had a more positive psychological well-being implies that problem-focused coping strategies may be an effective strategy for coping with challenging situations. The mothers also stressed the importance of the intense support they receive from the people around them in coping with ASD. This finding is consistent with the literature which suggest that the coping strategy used and the influence of such strategy depend on certain variables (e.g. social support) (e.g. Brissette et al., 2002; Dunn et al., 2001). The mothers also made mention of the contribution of positive religious coping strategies. Within the scope of relevant literature (e.g. Tarakeshwar & Pargament, 2001), it can be said that the positive religious coping strategies used by the mothers participating in the present study for coping with the challenging situation reduced their emotional distress and enabled them to cope with stress more effectively. In addition, the fact that the mothers attribute the negative situation to an external source (attributions to the fate/God's will) within the framework of attributions theory may have enabled, as indicated in several studies (Mickelson et al., 1999), them to cope with this situation better. Given the

literature on the influence of the religious beliefs and of the culture/society one lives in on one's experiences and emotions (Chang and McConkey, 2008; Mandell and Novak, 2005), this finding is not surprising for Turkey where majority of the population are Muslim. This is because; in the Islamic faith, challenging situations like ASD are considered a test for afterlife. It is believed that when a person has a patient attitude towards these challenges and renders thanks to God for the current situation, God will reward him and open the doors of the heaven to them and make disabled children angels in the heaven (Kara, 2008).

Other seven participating mothers started to make an effort to adjust to and cope with the situation one year after the diagnosis. While one mother made mention of acquiring knowledge about ASD as a problem-focused coping strategy, five mothers focused on religious coping strategies. The mothers in this group, just like the mothers in the other group, stressed the importance of supports which are stated to be likely to influence these strategies. In this regard, as stressed in the previous paragraph, the strategies used by these mothers and various variables likely to influence these strategies may have played a part in the adjustment and coping efforts of the mothers. The marked difference between the statements of the mothers who made an effort to adjust before one year passed and those of the mothers who made an effort to adjust after one year passed indicate that those mothers who started to adjust before one year passed mainly used knowledge acquisition as a problem-focused strategy. In this sense, this finding is consistent with the research in literature suggesting that problem-focused coping strategies are important for coping with challenging life events such as ASD (e.g. Smith, et al., 2008). Only one of the mothers who made such effort after one year passed mentioned knowledge acquisition as a problem-focused coping strategy. The fact that she failed to make an effort to adjust within one year after the diagnosis though she used the above-mentioned strategy may be attributed to the fact that she was shocked when her child was diagnosed late (at the age of five); she considered herself and her husband responsible for their child not starting early education; and she fell into depression as a result of the strong feeling of guilt.

All of the mothers participating in the study also made mention of the positive contributions of ASD to their life. It can be said that the positive perspectives of the mothers on the situation enabled them to have a more positive psychological well-being. Similar studies also stress that positive perspective is a factor that makes mothers psychologically good and enables them to cope with the situation more easily (e.g. Gupta & Singhal, 2004; Manning et al., 2011).

The findings under the theme of future perceptions indicate that all of the mothers are anxious, and worried about the future. The mothers expressed the causes of these emotions as follows: the possible problems that may be confronted by their child in adolescence and adulthood and lack of knowledge about how to solve these problems; limitedness of the institutions that can provide services; and uncertainty about what will happen to their child when they grow old and become incapable of looking after their child or when they die. This finding implies that the age and stages of a child is variable likely to influence the emotional state of a mother. Mothers both try to adjust to developmental stages and attempt to cope with the challenges related to ASD coming out in such developmental stages. The psychological functions of mothers may be disrupted in this process (Davis & Carter, 2008; DeMeyer, 1979). When this finding is addressed from a cultural perspective, it is realized that mothers may have a more desperate future perception in those countries where services provided to adolescents and adults with ASD and their families are limited and where families with a child diagnosed with ASD "become isolated" (Chang & McConkey, 2008; Üstüner Top, 2009). As a matter of fact, the fact that the services provided to adolescents and adults diagnosed with ASD and their families are still inadequate in Turkey may have caused worry about the future. From the perspective

of attributions theory, the mothers may think that they have low personal control over ASD and they cannot change ASD by their own efforts, which may cause them to have negative emotions for the future. As a matter of fact, it is reported in literature that negative emotions emerge when we think that challenging life events such as ASD are uncontrollable and will continue also in the future (Dale et al., 2006; Wong & Weiner, 1981). From a cultural perspective, the fact that children, especially sons are expected to look after and financially and spiritually support their parents when they grow old in Turkey (Cavkaytar, 2010; Yapıcı, 2010) may have caused the mothers, most of whom had a son (n=9), to have these emotions.

LIMITATIONS AND CONCLUSIONS

To conclude, the findings of this study show that the participating Turkish mothers displayed certain negative responses after the diagnosis; there are various variables that may have been influential on these responses; and the mothers use several different strategies to cope with the challenges brought by ASD. It is thought that the present study will contribute to limited qualitative research literature on the life experiences of mothers with a child with ASD. The findings indicate that cultural factors may be influential on the emotions experienced by the participants in the ASD adventure. Given the limitedness of the studies conducted in different cultures and especially in non-western cultures, it can be said that this study contributes to the literature on this subject from a cultural perspective by looking at the ASD worlds of the participating Turkish mothers. The findings may guide experts for family-oriented services. On the other hand, this study, just like other studies, has certain limitations. This research is limited to 11 mothers with children whose mean age is 11. They are mothers living in a specific region of Turkey. Thus, there is no information about other mothers who are not covered in this study. The data were collected through interview. This study was planned as a preliminary investigation that would contribute to the limited literature on Turkish families and be a model to new studies with its findings. In this regard, it is important that future studies be carried through observations allowing more in-depth information. Despite these limitations, this study is very important in the sense that its findings are consistent with the results of similar studies conducted with Turkish mothers and contribute to the limited literature on Turkish mothers (Bilgin & Küçük, 2010; Koydemir & Tosun, 2009).

Based on the findings and limitations of this study, the following recommendations are put forward for practice: (a) supports should be provided by experts and institutions (e.g. educational and spiritual resources) that will make it easier for mothers to cope with negative situations; (b) efforts should be made to improve the cooperation between mothers and experts; (c) the government should take certain measures to minimize the economic difficulties experienced by families; (d) mothers should support one another to solve their problems.

Recommendations for future studies are as follows: (a) comprehensive qualitative and quantitative research should be carried out by using different data collection methods and on large sample to explore the experiences of families; (b) research should be conducted to examine the experiences of fathers and other family members; (c) research should be carried out on coping strategies and attributions; (d) family lives in different cultures should be explored to make intercultural comparisons.

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