

Social Isolation and Relationship in the Family of Children with Autism Spectrum Disorders

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ABSTRACT

In this study, the constructs of isolation problem are discussed within the context of autism spectrum disorders (ASD), particularly in terms of how children on the autism spectrum may experience this problem in different social conditions. Difficulty establishing relationships may be reason of loneliness in these children, meanwhile the experience of loneliness may also be affected by diversity of them, as cognitive function, self-perception, social awareness, and ability to understand emotional states. The loneliness and diversity of the children can be main cause for their isolation by others. To explore these concepts, we present findings from the extant literature, study materials regarding how the family of children with ASD live various situations.

ASD is a difficult condition to understand even for families who experience this condition firsthand. As individuals in society encounter a different situation that they do not know, children's different behaviors may cause them to be afraid, hesitant and angry. For this reason, families should go shopping, eat out and participate in many activities in society with their children, both to educate their children about appropriate behavior in social environments and to change the society's attitudes towards different individuals, in a way to educate the society about different individuals (Siff Excorn, 2005).; Wall, 2010).

The potential negative impacts of isolation by other children and adults, also family factor is discussed. The study concludes with suggestions for prevention and intervention to facilitate social relationships and thereby reduce the potential for development of isolation and other negative outcomes.

Keywords: autism spectrum disorders, isolation, loneliness, social relationships

LITERATURE REVIEW

Having a child is a change that changes family dynamics and brings new responsibilities to the mother and father. This change affects the lives of not only parents but also all family members, including siblings and close relatives. Having a child with a disability is a situation that affects all family members. However, this situation creates much more responsibility and more stress on the family compared to having a typically developing child (Hallahan and Kauffman, 2003; Hardman, Drew and Egan, 2005; Turnbull, Turnbull, Erwin and Soodak, 2006). Families who have a child with a disability intensely feel emotions such as shock, disappointment, sadness, fear, anger, numbness, uncertainty and feeling stuck immediately after the diagnosis. Even though these feelings are accepted, they are felt again from time to time throughout the

child's life. (Hardman, Drew, & Egan, 2005). Because disability is not a temporary situation and difficulties continue throughout life. These difficulties also increase the level of family stress (Hallahan and Kauffman, 2003). The effect of ASD on family stress, starting from the awareness process, what families experience in different processes, and how having a child with ASD affects family relationships are discussed to present intervention program.

It is known that having a child with ASD is a situation that increases the family's stress level (Doyle, and Doyle, 2004; Estes et al., 2013; Osborne and Reed, 2010; Walsh, Mulder, and Tudor, 2013). In fact, studies show that having a child with ASD causes more stress compared to families of children with other developmental disabilities and families of normal children (Estes et al., 2013; Hayes & Watson, 2013; Herring, Gray, Taff, Tonge, Sweeney and Einfeld, 2006; Marcus, Kunce, & Schopler, 2005; White, McMorris, Weiss, & Lumsky, 2012). It is stated that the reason for this is that families of children with ASD face more intense stress factors. Marcus, Kunce, and Schopler (2005) explained the most important of these stress factors and stated that families should be supported primarily in these areas.

The first of these stress factors is that the diagnosis process is complicated, the family is not given sufficient information after the diagnosis, and therefore the families do not know what to do. While in some deficiencies, the diagnosis can be made in a short time with certain tests and examinations at birth or even before birth, in ASD, due to the uncertainty of the causes, this process becomes longer, more uncertain, more complicated and becomes a both materially and morally exhausting process for families. Sometimes, years pass

between families noticing signs of autism in their children and the diagnosis being made. Although families are relieved when their children are diagnosed, as they reach a clear conclusion about what the difference in their child is, the failure of experts to adequately inform the family about ASD and provide the necessary guidance after the diagnosis leads families to greater uncertainty.

Delay in diagnosis is shown as a situation that prevents early intervention and increases the stress of the family (Ailing Moh and Magiati, 2012). When the diagnosis is confirmed as a result of the evaluations, the reactions of the families may vary. Some may be relieved because they can find an explanation for their child's condition (Attield and Morgan, 2007), some may feel great sadness, and some may become angry at the experts who made the diagnosis (Gallo, 2010; Ives and Munro, 2002; O'Brien and Daggett, 2006). In the above-mentioned research, families mentioned that they experienced feelings such as shock, sadness and uncertainty when their children were first diagnosed, 64% told them about ASD, 68% about what kind of process awaited them, and 36% stated that no information was given about health and education opportunities. However, even after the educational diagnosis process was completed, 68% of the families stated that they were not given any information from the RAMs. In this process, it was observed that the most needed needs of families were psychological support (88%), followed by informational (86%), educational (80%) and financial (74%) needs (Selimoğlu, Özdemir, Töret, Özkubat, 2012).

Another area that families are concerned about is their children's deficiencies in social communication. Although parents try to communicate with their children both

verbally and emotionally, their children with ASD do not react as they expect. In addition, they cannot demonstrate the expected communication initiation skills. This situation both worries families and increases their stress because they do not know how to communicate. At the same time, families expect a response for the love they show, and when they do not receive a response for the love they show, the stress of the mother and father increases.

Another reason that increases families' stress is that children's possible problem behaviors in society are seen as a cause for embarrassment for the family. Families feel obliged to restrict their children's activities outside the home in their daily lives due to these behaviors. When children throw tantrums outside, they think that the people they encounter outside will judge them as mothers or fathers who cannot control their children, causing them to be unable to perform even daily tasks such as grocery shopping. Such concerns cause families to feel lonely and excluded.

A child's education is not limited to school and school activities. It is important for the child to take part in activities in social life in order to socialize and prepare for an independent life (Bondy and Frost, 2008). Families with children with ASD often choose to isolate their children and themselves from society due to reasons such as behavioral problems, tantrums, and negative reactions of individuals in society (O'Brien and Daggett, 2006; Wall, 2010). For example, if going shopping, a family member or caregiver stays at home with the child with ASD, and the individual with ASD stays away from shopping environments throughout his or her life. This causes the child with ASD to never learn how to behave in society. In this case, teaching appropriate prerequisite skills

becomes mandatory to facilitate the participation of individuals with ASD in social life. For this reason, it is important for families to have the necessary equipment to contribute to the education of their children on how to teach appropriate skills to be displayed in social environments and how to manage inappropriate behaviors (Tekinİftar and Kutlu, 2012). The fact that families of children with ASD prefer not to participate in social activities with their children causes other individuals in the society to encounter these individuals very rarely, and when they do, they cannot understand their behavior.

The authors mentioned that the children's mental health problem, and conditions related to this problem influence the parent's relationship, too. Constantly focusing on the child with ASD and trying to meet his needs tires the family physically and psychologically. This fatigue can also negatively affect the communication of spouses.

It has been observed that mothers of children with ASD have higher levels of depression compared to mothers of children with developmental delays. This situation also reduces the level of satisfaction in the marital relationship (Brobst, Clopton, & Hendrick, 2009; Weitlauf, Vehorn, Taylor, & Warren, 2014). While the stress experienced by fathers is more related to the social acceptance of the child, the stress of mothers is more related to the behaviors shown due to the ASD diagnosis.

In order to reduce marital stress, spouses need to support each other (Kersh Hedvat, Hauser-Cram, & Warfield, 2006).

Although it may be difficult for family elders to understand the causes of ASD, a study of 2,600 grandparents in the United States reported that 1/3 of the grandparents were the first to become aware of the child's ASD symptoms, and when some elders

expressed this awareness, the parent of the child with ASD told them They stated that they were angry (IAN, 2010). In addition, when diagnosed, adults care not only for their grandchildren but also for their own children.

They also stated that they were concerned about the situation (IAN, 2010; Kirby and Sanders, 2012). According to IAN (2010), 85% of the adults who participated in the research reported that they were very worried about their children, and 90% reported that ASD made their relationships with their children closer. 34% of the participants stated that they took an active role in the care of their grandchildren, and 18% stated that they took their grandchildren to school or doctor appointments at least once a week. Additionally, adults stated that if the child with ASD has a sibling, they take responsibility for this sibling, provide financial support to their children, and support their children and grandchildren by sacrificing their own needs when necessary (IAN, 2010).

Studies conducted with siblings of individuals with ASD show divergent results. It has been reported that individuals with a sibling with ASD experience more depression, attention problems, and feelings of loneliness compared to individuals with a normal sibling (Erden & Akçakın, 2001; Tsao, Davenport, & Schmiede, 2012). However, it is reported that individuals who have knowledge about ASD and whose parents have positive attitudes have a more positive attitude (Tsao, Davenport, & Schmiede, 2012).

In his literature review on siblings, Beyer (2009) reported that some studies showed that individuals with siblings with ASD were positively affected by this situation, that they spent time with their siblings, had

fun, and even experienced more closeness and less conflict than individuals with other typically developing siblings. In addition, some studies have reported that siblings have less positive attitudes towards their sibling with ASD and share less positive experiences.

Beyer (2009) and Tsao, Davenport, and Schmiede (2012) stated that in order to improve the sibling relationships between the individual with ASD and the normally developing individual, teaching the normally developing individual games that he can play with his sibling, which requires both social interaction and social communication skills and physical skills. They state that playing games can contribute to the development of motor skills. They emphasized that in order to develop these relationships, it is necessary for the normally developing sibling to develop effective coping skills (Beyer, 2009). First of all, siblings should be allowed to talk about this issue, ask questions, and share their feelings. Among the emotions experienced may be feelings such as anger, jealousy, guilt, shame and anxiety about the future for having such a sibling.

The child may hesitate to share these feelings about his sibling within the family (Att field & Morgan, 2007; Morrell & Palmer, 2006; Stampoltzisa, Defingoub, Antonopoulouc, Kouavad, & Polychronopouloub, 2014).

To sum up, it can be emphasized that ASD affects family relationships. While ASD can strengthen marital relationships, it also appears as a condition that leads to divorce. Responsibility for the child with ASD usually lies with the mother. Even though fathers provide external support, they do not prefer not to take too much responsibility for the child. Additionally, they do not share their feelings as much as mothers do. For

this reason, these unshared emotions that accumulate over time can lead to disagreements. In order for the marriage relationship to continue healthy, spouses need to share their feelings with each other and spare time for themselves apart from their children. If they are experiencing problems and cannot solve these problems on their own, it is important that they receive psychological support. Siblings also experience different emotions such as anger, shame, jealousy, and guilt because they have a sibling with ASD. Siblings should first be informed about ASD. At the same time, if they cannot cope with these emotions, it would be beneficial for them to receive psychological support. Although giving responsibility to siblings is a behavior that involves them in the process and prevents them from feeling excluded, it is necessary to keep the ratio of responsibility balanced. It is important not to cause them psychological exhaustion by giving them responsibilities that require them to sacrifice their own lives.

As always, family elders can be the people who can provide the greatest support to parents. However, due to the generation gap, it may be difficult for them to understand ASD. Therefore, they also need to be informed. They may have reservations about supporting the family because they do not know how to approach the child. Firstly They can support their parents by sharing their other responsibilities at home. Over time, as they spend more time with the child and get used to the situation, they will be able to provide support regarding the child. If family elders volunteer to provide support, parents should see this as an opportunity to rest for themselves. Because, as mentioned before, the healthier the parents are, the more beneficial they will be for the development of their children.

CONCLUSION AND RECOMMENDATION:

- One of the most important stages regarding diagnosis is the interview in which the evaluation results will be announced to the family. Families are advised that on the day they will meet with experts on this subject, the mother or father should not go to the meeting alone (O'Brien and Daggett, 2006; Wall, 2010). If the mother and father attend this meeting together, it will enable the spouses to obtain the information about the diagnosis together, to support each other, and therefore to get through this process more easily (O'Brien and Daggett, 2006; Wall, 2010). If parents are raising their children alone, attending the interview with a relative will be useful both for support and to compare the information given later (O'Brien & Daggett, 2006).
- Additionally, families are more satisfied with the diagnostic process when they are allowed to ask questions during the diagnosis phase, when their questions are answered, when useful information is provided, and when experts display an empathetic attitude. In a study, immediately after the diagnosis, families were informed about early intervention programs, language and speech therapies, and explanations were made about the problems the child might present, and this information was found very important and useful by the families (Ailing Moh and Magiati, 2012). It is estimated that families who have good relationships with diagnosing specialists may cooperate more with specialists in the future (Ailing Moh and Magiati, 2012).
- After the child is diagnosed, families experience feelings such as guilt,

sadness, denial, depression and anger (Ives & Munro, 2002; Leventhal-Belfer, & Coe, 2004; Morgan, 2009; Williams & Wright, 2004). Research conducted in Turkey also shows that mothers' trait anxiety levels are high, and as their experiences with their children's disabilities increase, their anxiety increases (Dogru and Aslan, 2008) and their life satisfaction decreases (Balkanlı, 2008, Gülaldı, 2010). In addition, one of the biggest concerns of families is what will happen to their children in the future, especially when they are not alive (Bıçak, 2009; Ives and Munro, 2002; Morgan, 2009; Randall and Parker, 1999). The only way to reduce this anxiety is for the family to do their best to provide the child with the education he needs and to become a self-sufficient individual (Morgan, 2009). The family may need to receive psychological support to cope with the emotions experienced after their child is diagnosed.

- There are very limited studies in our country on the impact of ASD on marital relationships. ASD negatively affects the marital relationship. The way to reduce this negative impact is to understand this issue better. Due to our cultural characteristics, there is a need for research on ASD and parent's relationships.
- There is a need for research on the effect of ASD on siblings. In particular, determining the needs of siblings and taking initiatives to provide the necessary support will ensure that the individual with ASD and their siblings grow up in healthier relationships.
- Families prefer to stay at home due to their children's behavioral problems or the reactions of society. In order for the

child to gain independence and for the society to be educated, understood and accustomed to it, different children, such as children with ASD, need to be seen frequently in society. Therefore, it is important for families to participate in activities such as shopping, dining, and sports TOGETHER with their children with ASD.

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