EXPERIENCES AND KNOWLEDGE OF TURKISH SIBLINGS REGARDING AUTISM SPECTRUM DISORDER

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MASTER'S THESIS
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FINAL APPROVAL FOR THESIS

This thesis titled “**Experiences and Knowledge of Turkish Siblings Regarding Autism Spectrum Disorder**” has been prepared and submitted by **Areej AWWAD** in partial fulfillment of the requirements in “Anadolu University Directive on Graduate Education and Examination” for the Degree of Master of Social Science in Applied Behavior Analysis Department has been examined and approved on the date of____________________.

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ABSTRACT

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Anadolu University, Graduate School of Social Sciences, August 2020
Supervisor: Prof. Dr. Elif TEKİN İFTAR

The present study aims to describe the experience of Turkish siblings (n = 7) with typical development aged between 8-18 years-old about having a brother or a sister with autism spectrum disorder. Moreover, their knowledge about autism spectrum disorder was also examined in the study. This hopefully will contribute to improving the quality of services granting to families with a child with autism spectrum disorder the Turkish society and shed light on an equally important aspect of the effect of autism spectrum disorder on the family in comprehensive vision and on siblings in particular from their point of view.

A descriptive method was used in this qualitative study. Data were collected by the researchers conducted semi-structured interviews with the siblings. The questionnaire includes 20 open-ended questions. Content validity of the questionnaire was ensured by asking the opinions of experts (n = 3?). Prior to interviews with participants, the researcher conducted to a pilot study to test the interview process and the feseability of the questionnaire. Knowledge Of Autism Questionnaire (KAQ) developed by Ross and Cuskelly (2006) was used to evaluate participants’ knowledge on autism. Seven participants from six families from the city of Eskişehir were recruited in a snowball sampling (Hays & Singh, 2012).

The researcher audio-taped the the interview with each participant and then transcribed them. Data were analyzed descriptively and manually in the order: data immersion, coding, and themes identification. Four major themes; *Understanding of autism spectrum disorder, Relationships, and Interactions between the siblings, Emotional dealings, and Value of siblinghood* were grouped out of the data. Containing 10 subthemes, were emerged from the essences of the participants' lived experiences.

Results indicated that the older siblings of children with autism that have diagnosed for more than five years have a better insight into autism, thus, their understandings regarding autism rely on their personal conclusions formed depends on their experiences with their diagnosed sibling, moreover, this understanding gets more advanced with age. Although, some of these understandings are unreliable and do not reflect a clear awareness about autism, thus, they still find it difficult to explain autism to other people around them.

By focusing on qualitative methodology within obtaining a deeper understanding of the sibling relationship directly from the siblings' own perspective, this study contributes to an understanding of mental health professionals, clinicians, and paramedical workers toward children who have a sibling with autism spectrum disorder 's implicating. Suggestions of potential interventions, including at the first place siblings' education about the autism as early as possible, preventing implications that can evoke confusing thoughts, in the purpose of optimizing the strengths of the sibling relationship to reach effective dealing among this population, considering their specific needs in a cultural context that suits them. This study intended also to families for their education considering what the siblings may live and feel, as well as for research involving families when one of their children is diagnosed with autism spectrum disorder.

Keywords: Autism spectrum disorders, Sibling relationship, Knowledge about autism, Turkish society, Semi-structured interview, Descriptive analysis.

ÖZET

TÜRK KARDEŞLERİN OTİZM SPEKTRUM BOZUKLUĞU OLAN KARDEŞLERİNE İLİŞKİN DENEYİMLERİ VE BİLGİLERİ

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Bu araştırmanın amacı, 8-18 yaşları arasındaki tipik gelişim gösteren Türkiye’de yaşayan yedi kardeşin, Otizm Spektrum Bozukluğu (OSB) tanısı olan kardeşleriyle olan deneyimleri ve otizme ilişkin bilgi düzeylerini ortaya koymaktır. Araştırmadan elde edilen bulguların Türkiye’de OSB'li çocuğu olan ailelere verilen hizmetlerin kalitesinin iyileştirilmesine katkıda bulunması hedeflenmektedir.

Araştırmada nitel yöntem kullanılmıştır. Veriler araştırmacı tarafından gerçekleştirilen yarı-yapılandırılmış görüşmeler aracılığıyla toplanmıştır. Bu amaçla 20 açık uçlu sorudan oluşan görüşme formu kullanılmıştır. Sorular araştırmacılar tarafından hazırlanmış ve ardından uzman (n = 3?) görüşü alınmıştır. Çalışma öncesinde araştırmacı görüşme tekniği hakkında deneyim kazanmak ve ölçü aracının uygunluğunu sınamak üzere bir pilot çalışma yapmıştır. Ross ve Cuskelly (2006) tarafından geliştirilen Otizm Bilgisi Anketi (Knowledge Of Autism Questionnaire- KAQ) katılımcıların otizm hakkındaki bilgilerini değerlendirmek için kullanmıştır. Eskişehir'deki altı aileden yedi katılımcı kartopu örnekleme ile (Hays & Singh, 2012) belirlenmiştir.

Araştırmacı tüm katılımcılarla yaptığı görüşmeleri ses kaydına almış ve ardından dökümlerini yapmıştır. Veriler betimsel ve manüel olarak şu sırayla analiz edilmiştir; veri kaydetme, kodlama ve temaların tanımlaması işlemleri. Sonuçların dört ana temada toplandığı görülmüştür: *OSB'yi anlama*, *Kardeşler arasındaki ilişkiler ve etkileşimler*, *Duygusal işleme* ve *Kardeşliğin değeri*. Bunları da içeren 10 alt tema, katılımcıların yaşadıkları deneyimlerin özlerinden ortaya çıkmıştır.

Bulgular beş yıldan uzun bir süredir otizm teşhisi olan çocukların kardeşlerinin otizm hakkında daha iyi bir kavrayışa sahip olduklarını; yaşları büyüdükçe otizmi daha iyi anladıklarını göstermektedir. Kardeşlerin otizmi anlamaları kardeşleriyle olan deneyimlerine bağlıdır. Fakat, bazen kardeşlerin otizme ilişkin anlayışlarının güvenilir olmadığı, otizm hakkında net bir farkındalık edinemedikleri, otizmi çevrelerindeki diğer kişilere açıklayabilmekte zorlandıkları da görülmüştür.

Otizm spektrum bozukluğu olan çocukların kardeşleriyle yürütülen bu çalışmada nitel yollardan veri toplandığı için onların bakış açılarını yansıtan bulgulara dayalı olarak akıl sağlığı alanında çalışan uzmanların, uygulamacıların ve sağlık görevlilerinin uygun müdahaleler oluşturmalarına katkı getirildiği düşünülmektedir. Öncelikle kardeşlere otizm spektrum bozukluğu hakkında en erken dönemde bilgi verilerek onların otizmi doğru tanımalarına destek olunabilir. Bu durum hem kardeşler arasındaki ilişkinin güçlenmesi açısından hem de toplumsal açıdan otizmin anlaşılması açısından katkı sağlayabilir. Bu çalışmanın bulguları aynı zamanda ailelere otizm spektrum bozukluğu olan çocukların kardeşlerinin neler yaşadıkları ve hissettikleri konusunda bilgi sunmaktadır.

Anahtar Kelimeler: Otizm spektrum bozukluğu, Kardeş ilişkisi, Otizm hakkında bilgi, Türk toplumu, Yarı yapılandırılmış görüşme, Betimsel analiz.

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Finally, to the Turkish society, this thesis is dedicated to each family who has a child with the diagnosis of autism spectrum disorder, you do a great job. To the people of the city of Eskişehir in particular, the magnificent city that hosted me for the best three years during my master's degree, this was not be accomplished without the braveness of the families who took part in this study.

STATEMENT OF COMPLIANCE WITH ETHICAL PRINCIPLES AND RULES

I hereby truthfully declare that this thesis is an original work prepared by me; that I have behaved in accordance with the scientific ethical principles and rules throughout the stages of preparation, data collection, analysis, and presentation of my work; that I have cited the sources of all the data and information that could be obtained within the scope of this study, and included these sources in the references section; and that this study has been scanned for plagiarism with "scientific plagiarism detection program" used by Anadolu University, and that "it does not have any plagiarism" whatsoever. I also declare that, if a case contrary to my declaration is detected in my work at any time, I hereby express my consent to all the ethical and legal consequences that are involved.

Areej AWWAD
August 2020

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8. CURRICULUM VITAE

CHAPTER I

1. INTRODUCTION AND RATIONALE FOR THE THESIS

Families of children with autism spectrum disorder may face major and ongoing challenges, often accompanied by stress and emotional difficulties that may affect the family composition as a unit in several ways (Gray, 2002; Schall, 2000; Sivberg, 2002). Family incubation is profoundly important to the developmental, emotional, and cognitive growth of a child (Sameroff, 1990). In her role, "family" is expected to provide support and containment for each child in the family (Lukie et al., 2014).

In the field of autism, an abundance of studies has addressed essential aspects of the disorder and its impacts on the affected children and as well on their parents. Thus, the focus generally is given to these two factors (the child with autism and his parents). However, toward other family members (siblings) little studies conducted to examine the impact may autism have on them.

Recently, researchers began to investigate the implications of autism for non-effected siblings, however, the existing research on the experience of siblings of individuals with autism is relatively little, most of these studies are quantitative studies, which do not analyze the effect in-depth, or that relied on indirect methods in information acquisition by parents, not directly through the siblings and is also limited to European-American families (Sage & Jegatheesan, 2010).

With seven participants aged between 8-18 years old, I have tried in this study to document the experiences of brothers and sisters who have siblings with autism. In the belief that each member of the family has a different perspective that the parents may not fully understand, a direct method was used through semi-structured interviews guided by a qualitative framework. Considering a person's cultural background which has an important effect on how people interact with each other, behaviors, perceptions, education, and social values (Horton & Hunt, 1980).

The current research is confined to Turkish families in Turkish society in order to describe the experiences of typically developing siblings about having a sibling with autism, from their own perspective. Other aspects examined in this study were siblings' knowledge of autism and their needs (if any) from their point of view. This hopefully will contribute towards improving the quality of services received by families with a child with autism in the Turkish society and shed light on an equally important aspect of the effects of autism on the family in a comprehensive vision.

Clinicians, paramedical workers, and other mental health providers who work with families of a child with autism will benefit from the exploration of the sibling’s contributions as being an integral part of the family. Exposing their experiences and taking into consideration their needs can clarify the holistic image of the family system. This consideration may suggest a way that takes into account all members of the family to recruit them to more effectively cope with autism as a family.

1.1. Autism Spectrum Disorder

Autism spectrum disorder is a lifelong childhood-onset neurodevelopmental disorder characterized by persistent deficits in social communication and interaction across multiple contexts and by restricted, repetitive patterns of behavior, interests, or activities (American Psychiatric Association, 2013). To date, the exact cause/causes of autism spectrum disorder are unknown, but there is an agreement that there is a genetic component to the autism spectrum disorder manifestation. However, the genetic component of autism spectrum disorder is predominantly unlocked by certain environmental factors leading to the development of the disorder (Elsabbagh et al., 2012; Hallmayer et al., 2011).

Since there is a lack of biological tests or specific biological markers, autism spectrum disorder is diagnosed based on observations and behavioral descriptions (Abrahams & Geschwind, 2008). Initial signs and symptoms are usually evident early in the developmental period; However, social deficits and patterns of behavior may not be noticed until a child is unable to meet social, educational, occupational, or other important life demands. According to the characteristics of the individual and his environment, functional impairment's stage becomes obvious (American Psychiatric Association, 2013). While individuals with autism have certain core symptoms, 70% of individuals with autism can have at least one comorbid disorder (Simonoff et al., 2008).

When using the term "spectrum" in defining the autism disorder, it means that the degree of autism is expressed in different severities: mild, moderate, or severe autism (American Psychiatric Association, 2013). Individuals with autism do not resemble each other, there is a great deal of variation in the way autistic symptoms manifest and affect each person uniquely. According to that, in the fifth edition of Diagnostic and Statistical

Manual of Mental Disorders (DSM-5) three "functional levels" were defined based on the amount of "support" an individual requires to function, by classification to level 1, level 2, or level 3 which may make it easier to better diagnose and provide the services and intervention tailored to each case. These three levels reflect the individuals' ability to communicate, adapt to new situations, expand beyond restricted interests, and manage daily life. Individuals at level 1 are "Requiring Support", while those at level three are "Requiring Very Substantial Support" (Masi et al., 2017).

Autism may emerge in every society, regardless of race, ethnic origin, geographical area, and socio-economic structure, however, cultural and socioeconomic factors may affect awareness and diagnosis age (Elsabbagh et al., 2012). Individuals with autism spectrum disorder are expected to have lifelong symptoms and impairments and there is currently no cure (American Psychiatric Association, 2013). Which makes it an ongoing syndrome, thus adjustment, and adaptive lifestyle is an important aspect which must be considered.

1.1.1. Diagnosis and characteristics

Until 2013, according to the Diagnostic and Statistical Manual (DSM-IV), autism was defined as a disorder including five distinct diagnoses: Asperger syndrome which reflected the "high functioning autism", an autistic disorder which considered "severe autism", PDD-NOS diagnosis was given to individuals who had some but not all of the symptoms of autism (either mild or severe symptoms). Additionally, two rare genetic disorders, Rett and Fragile X syndrome, were also considered to be part of the autism spectrum.

However, according to the most recent update of the 5th Diagnostic and Statistical Manual (DSM-V) (American Psychiatric Association, 2013), autism defined as a single "spectrum disorder" and refined diagnostic criteria that appear at early developmental ages, describing symptoms in the areas of social communication, behavior, flexibility, and sensory sensitivity.

Based on DSM-V, the first criterion describes the disruption of social communication and social interaction in different contexts and continuously. These deficits may be expressed in three aspects:

- Lack of social-emotional reciprocity: inadequate dialogue skills, lack of sharing of feelings, limited expression of feelings. The third severity degree is expressed in the absence of initiative or response to social interaction.
- Lack of social non-verbal communication: poverty in social gestures, eye contact, and body language defects, difficulty in deciphering nonverbal communication of others. The third severity degree is expressed in the total lack of nonverbal communication and facial expression.
- Lack of development, preservation, and understanding of social relations: difficulty in adapting behavior to social context, difficulty in the imaginative game, and creating friendships. The third severity degree is expressed in isolation and lack of interest in peers.

The second criterion describes the limited and repetitive patterns of behavior and interest; These patterns are expressed in two of the following four aspects:

- Stereotypical or repetitive movements expressed in motor movements, objects, or speech: echoing, waving hands, turning around, arranging objects in a row, rolling objects, etc.
- Inflexible adherence to routines, insistence on the same, routine patterns of verbal or nonverbal behavior (Examples: insistence on a regular route to kindergarten, rigid patterns of thinking, rigid patterns of eating, etc.).
- Narrow and fixated interests and deviations in intensity and focus: non-functional gameplay, over-preoccupation with the details of something rather than the general picture, obsessive about something, and dealing with it repetitively.
- Hyper- or hypo-reactivity to sensory inputs, or an unusual matter in the sensory aspects of the environment: such as attraction to lights and movement, sensitivity to noise and textures, apathy to pain, touching, or smelling objects (American Psychiatric Association, 2013).

1.1.2. Prevalence

Autism Spectrum Disorder described as one of the fastest-growing medical concerns in the United States, is currently estimated to affect 1 in 68 school-aged children (Baio, 2012). Statistics show that autism prevalence rates have increased by 10 to 17 percent annually over the past few years;14.7 diagnose per 1,000 children in 2010 (Baio, 2012), compared with 2008 among 11.3 children (Baio, 2012) and 6.7 diagnoses in 2000 (Baio, 2012).

Other studies conducted in England, revealed a 1% prevalence among children in regular and special education schools diagnosed with autism spectrum disorder (Baron-Cohen et al., 2009; Waterhouse, 2008). Autism is diagnosed four times more often among boys than girls, it is estimated that 1 in 42 boys and 1 in 189 girls are diagnosed with autism (American Psychiatric Association, 2013). In Turkey, the prevalence of children with autism spectrum disorder is estimated to be 12/10,000 (Namal et al., 2009).

The increase in the frequency of diagnosis is partially explained by increased awareness in the field, both by the public and professionals and by the fact that over the years, the criteria for diagnosis have been updated and recently diagnostics can be performed earlier, as well as environmental influences (Presmanes Hill et al., 2007).

These data make the existence of a child with autism in the family, school, neighborhood, or in any other human environments more common. This triggers a red lamp on studying and indicating aspects regarding the existence of a child with autism and supplying a suitable service that meets the needs.

1.1.3. Impact of autism spectrum disorder on families

Having a member with autism in the family has a huge impact on the ways a family function (Corcoran & Walsh, 2009). Studies have indicated poor family cohesion among families affected by autism spectrum disorder than the general population (Gau et al., 2012; Higgins et al., 2005). Because of the unique nature of autism, its impact is not limited only to the individual’s functioning, however, all subsystems of the family (marital, parental, sibling and extended family) may be affected (Meadan et al., 2010; P., 2009), in multi-effect aspects: financially, emotionally, practically, and educationally on the family as well. These impacts need to be considered since they can influence the effectiveness of interventions, as well as indicate what services that family needs to obtain.

Financially, compared with having a typically developing child, as reported, spending money may be debilitating when having a child with autism spectrum disorder; These costs cover the bills for medical treatments, appointments, prescriptions, special school, and therapies (Boyle et al., 2018). Financial burdens are often exacerbated when the parent is forced to leave the job to stay full time for the child with autism spectrum disorder (Baio, 2012).

Additionally, researchers have reported that parents of children with autism spectrum disorder are at a higher risk of experiencing stress, poor psychological outcomes and health problems (De Andrés-García et al., 2012; Hastings & Brown, 2002; Seltzer et al., 2010; Woodman et al., 2016). This, in turn, affects the whole family, starting from the child with autism spectrum disorder, parents as a couple, and including the siblings. Besides, since autism spectrum disorder is mainly characterized by impairments in communication, emotional understanding, and behavioral characteristics, researchers suggested that individuals with autism spectrum disorder would be expected to face difficulties in their sibling relationships (Orsmond & Seltzer, 2007).

Before reviewing studies that examined the presence of a child with autism in the family and the impact it can have, we will understand the sibling relationship, its contribution, its mutual effect, and its value, particularly in the Turkish society.

1.2. Sibling Relationships

1.2.1. Typical sibling relationship and its impact on individuals

Psychologists Stephen Bank and Michael Kahn were the first who investigated the sibling relationship deeply, they described it as the "first peer relationship" that we experience and the longest relationship in our lives. Although this relationship may change over time, it is a permanent one, and one of great emotional significance. A study conducted in sixteen countries found a universal pattern that the closest emotional bonds were with mother, second with siblings, and third with father (Georgas et al., 2001). The nature of sibling interaction is arbitrary rather than determined by parental wishes or other external conditions (Stewart & Kushner, 2001). Strong sibling bond can be loving and warm, but it also can be negative and tension-filled and provide a source of either joy or pain (Bank & Kahn, 1982). Among typically developing siblings, positive behavior of sibling relationship focuses on helping, supporting, sharing and turn-taking in play, teaching, and caregiving, provision of advice and warmth, while sibling conflict behaviors include verbal (tease, argue), relational (social exclusion, undermining) and physical aggression (Coldwell et al., 2008).

In addition to the contributing of siblings' bond in self-satisfaction and providing a sense of security, siblings' relationship is a significant context for gaining and learning some skills like social skills, including the ability to understand others' minds and considering the other's feelings, emotion regulation, and empathy (Bornstein et al., 2003; Brody, 1998; Stormshak et al., 1996; S. Tucker et al., 1999; Youngblade & Dunn, 1995). Positive sibling relationships among children create a lifelong support system for the siblings involved, and it is associated with multiple benefits related to social, emotional, and health development throughout childhood and adolescence. Benefits include higher peer competencies (Kim et al., 2007), prosocial behaviors (Brody et al., 2003; Whiteman, Mchale, & Crouter, 2007; Whiteman, Mchale, Crouter, et al., 2007), academic engagement and individual achievement (Bouchey & Shoulberg, 2010; Wheeler, 2012), regulation of emotional health (Cassidy et al., 2008), empathy (C. J. Tucker et al., 1999), high level of self-regulation (Padilla-Walker et al., 2010) and better adjustment (Noller, 2005; Pike et al., 2005). Positive sibling relationships also contribute to deterring depression and other adversities (R. D. Conger & Conger, 2002; Kim et al., 2007; Widmer & Weiss, 2000). Additionally, in cases of poor contact with parents, having a strong sibling relationship may help to balance the void (Kitzmann et al., 2002). In the context, different parental dealing with children by varying amounts of attention, responsiveness' level to child's requests, discipline, intrusiveness, and control; may make a sibling relationship less amiable and more conflictual, unless the children do not see it as unfair (Kowal & Kramer, 1997).

Besides the direct effects, sibling support could also lessen the impacts of painful life events; As stated by Pérez & Verdugo (2008), the quality of family life is closely related to the life quality of each member in it. In a study by (Gass et al., 2007), after distressing life events, children with supportive siblings were reported to experience fewer depressive symptoms than those in unsupportive sibling relationships.

In parallel, conflicted siblings' relationship is likely related to anti-socialization, externalizing problem behavior, and involvement in criminal activities (Aguilar et al., 2001; Natsuaki et al., 2009). Several studies also found a clear relationship between sibling conflict and behaviors that reflect emotional problems of internalization (Kim et al., 2007; Pike et al., 1996; Stocker, 1994; Vogt Yuan, 2009). A study conducted by (Howe et al., 1998) showed that children who experience conflicts with their siblings are less likely to discuss their own and others' feelings, therefore, they may have difficulty expressing empathy and consideration for others (Stocker et al., 2002). Besides, several studies point out increasing depressive symptoms over time among siblings who are in a very conflictual sibling relationship (Brody, 1998; Richmond et al., 2005).

1.2.2. Sibling relationships across the lifespan

1.2.2.1. Early childhood.

The change in the attention given to a child when a sibling is born often produces at least temporary behavioral problems for the older child, including difficulties with toileting, withdrawal, aggressiveness, dependency, and anxiety (Cicirelli, 1995). However, in general, most children adjust well and pass this transient discomfort, mainly with the crucial role of the parents. Typically, between the ages of three and four years, children starting to show playing skills, which make them increasingly desirable companions for childhood play, as a result, the older child begins to pick interest in his young sibling as a playmate (Dunn, 1992). Sibling relationship begins to take shape often when older siblings act as behavioral models, play's head, taking a leadership role, as well as providing a security source for the young ones, while the second-born siblings are more likely to learn, imitate and be a follower (Cicirelli, 1995; Klein et al., 2002).

In early childhood, siblings spend time together and share valued relationships including parents' relationships, relatives, neighbors, and other common human contexts. This excessive contact would also increase the level of rivalry among siblings and create a multitude of conflicts (DeHart, 1999).

During this period, sibling's relationship is characterized mainly by three major characteristics: First, emotional loading which is defined by strong, uninhibited, positive, negative, and sometimes ambivalent feelings. Second, intimacy: when siblings spend more time together, they get to know each other well. Third, individual differences among the interaction between siblings. These factors are reflected in the need for emotional containment and instrumental support for one another, as well as in parent's role and intervention to solve conflicts considering the perspective of each one of the children (Deater-deckard et al., 2002).

The natural differences arising from the difference in ages among siblings may be reflected in the different responses toward family experiences by each one of the children. For example, younger children have the advantage of learning from their older siblings, while the eldest child did not have this opportunity, which sometimes leads to the precocious development of the second- borns in certain areas (Perner et al., 1994).

1.2.2.2. Middle childhood and adolescence

During middle childhood, there is an important change in how the sibling gets along. This is a time when the interaction between children becomes more equal and balanced when the younger sibling reaches eleven or twelve years of age, the older sibling does less nurturing, creating a more balanced relationship between the children. Besides, there is also a shift in dominance, with the younger child achieving a more equal footing with the older by about twelve years of age, this greater equity in caretaking and power may benefit both children. The younger child reaches an age of increased independence, and the older child is no more responsible for looking after the younger and may have more freedom to pursue adolescent goals (Buhrmester, 1992). During early and middle childhood and preadolescence, parents and siblings are the most important sources of emotional support and sharing for the children in the family.

During adolescence, increasing an individual's autonomy and emotional separateness from the family is reflected in a growing distance among the siblings (Perner et al., 1994), thus, this period is characterized by a poor level of affection and intimacy between the siblings (Buhrmester, 1992).

Sibling relationship undergoes continuous changes during the different periods of development. While siblings are close to each other during childhood, feel intense feelings, either positively or negatively; Early adolescence is characterized by a growing interest in the peer world, in later stages of adolescence, they spend more time with peers and less with siblings, but even so, they can be a source of security and taking advice from each other (Scharf et al., 2005).

1.2.2.3. Adulthood

Siblings are often at different phases on the pathway to adulthood, sometimes they may be ‘‘in sync’’ with one another, and at other times, ‘‘out of sync’’.

A prime period of sibling relationships' change occurs in late adolescence and early adulthood (K. J. Conger & Little, 2010). According to identity development research, the period between 18 to 25 years old is considered the individual self-exploration period, in which the individual deals with three main tasks: taking self-responsibility, making decisions independently, and formatting independence financial source (Arnett, 2004).

Emerging adults reported that they spend a little time with their siblings, or they simply choose to have little contact because they do not get along well with their siblings

(Stacker & Lanthier, 1997). Which in result leads to lower levels of conflict with their siblings than adolescents, displayed by less antagonism, quarreling, competition, and less conflict-related to power (R. B. Stewart et al., 2001). (Whyte, 2001) found that sibling social support (as measured by proximity, contact, giving, and receiving help) declines in early adulthood. However, proximity and contact stabilized in middle adulthood and sibling exchanges of giving and receiving help rise slightly after age 70.

It should be mentioned that, when the relationship is warm and supportive, siblings may experience a sense of loss as the older sibling moves into adult roles (leaving home, completing education, being employed, getting married, and childbearing). In contrast, adolescents with highly conflictual sibling relationships may feel relief that a source of daily discomfort is gone. Given the primacy of siblings to wellbeing throughout life (Akhtar & Kramer, 1999; Barden et al., 1989; Bengtson et al., 2006; McGoldrick, 2011; Merrell, 1995; Sutton-Smith & Rosenberg, 1970; Toman PhD, 1992; Waldman & Adler, 1979), in dealing with special needs children, clinicians, family scholars and development psychologists should give importance to this context and not overlook it.

1.2.3. Factors impacting sibling relationships

Research has identified many factors that affect the sense of being ‘‘in sync’’ among siblings throughout the life course, for instance, changes in power and equality within the relationship (Shortt & Gottman, 1997), the maturity of individual siblings (S. H. Stewart & Kushner, 2001), changes (either more or less) in daily interaction patterns (Cicirelli, 1996; Whyte, 2001), and ethnic and cultural influences (Riedmann & White, 1996; Suggs, 1989). In addition, structural variables, such as sibling age, gender composition, birth order, and family characteristics affect relationship properties like satisfaction, support, or competition (Bass & Riggio, 2006; Connidis & Barnett, 2018; Sullaway & Dunbar, 1996; C. J. Tucker et al., 2001). Culture is a powerful context that shapes societal and familial values, including siblings' interactions (Diana T. Slaughter-Defoe, 1995). Even considering someone to be a sibling varies ethnically and culturally (Bengtson et al., 2005; Mcguire & Shanahan, 2010; Riedmann & White, 1996).

A process called "access" is one of the elements of the emotional bond between children, strong sibling bonds with high access, is most likely to occur when children are of the same gender, close in age, and have many shared activities (Bank & Kahn, 1982). Family size also appeared to have an impact on sibling relationships. Typically developing children from families with many children had more feelings of self-doubt and psycho-emotional difficulties compared to typically developing children from families with two children (Stampoltzis et al., 2014a). Baham (Baham, 2009) also found a positive correlation between siblings' conflict at home and increased behavioral problems. Higher levels of internalizing problems in a child may predict poorer sibling relationships with less warmth and more conflict. Moreover, (Fiedler et al., 2006) reported that culture, traditions, interests, and environmental contexts all influence sibling relationships.

1.2.4. Sibling relationships in Turkish culture

Traditionally, the Turkish society is a society which is structured around collectivism, where the individual's value is subordinate to the values, goals, and success of the group (Göregenli, 1997; Uskul et al., 2004). Collectivists value loyalty rather than an individual's autonomy since interdependence between people is a key mechanism of the society, great importance is placed on preserving relationships (Erdogan & Liden, 2006). Additionally, there is a strong hierarchical ordering of Turkish families' members, especially regarding gender and generations (Sunar & Fişek, 2005). Younger siblings never call an older sibling by name, but rather by respectful terms (Abı/Abla) that are used for elder brothers or sisters (Selin, 2014). Children are socialized early into social norms according to this patriarchal environment and are controlled firmly by parents and close relatives. They are expected to be obedient and respectful toward their elders (Aycicegi-Dinn & Kagitcibasi, 2010).

In sum, a traditional Turkish family is generally characterized by their attitude of faithfulness to one another, sensitivity to the needs of each other, respect, and valuing family success far more than their own (Sunar & Fişek, 2005). Thus, the sibling relationship has an essential value in Turkish culture; preserving it, is part of maintaining family cohesion and unity.

In describing the Turkish family structure and functioning, it has been reported that the expressive role of the siblings involves giving emotional support to grandparents and siblings, keeping the family united, maintaining a pleasant environment, conveying traditional and religion to younger siblings, and preserving family relations. The instrumental roles involve doing housework, shopping, taking siblings to school, contributing financially, helping parents with their work, and babysitting siblings (Bekman & Aksu-Koç, 2009).

1.3. Sibling Relationships when Having a Brother or Sister with a Disability

When living with a young person with a disability, the effects on siblings may be different than if they lived with a typically developing young person (Dervishaliaj & Murati, 2014).

When one sibling has a developmental disorder, the aspect of the family system is out of whack, the typical relationships may not develop, in such cases, common rules about sharing parental attention and the concept of “if you are nice to him, he will be nice to you” may or may not apply. In case of having a child with special needs in one family, it is likely that most of the attention, time and engaging be dedicated to him, remaining a little of parents' energies, time and attention for the rest of the children in the family (Aytekin, 2016), in parallel, the child with typical development may be expected by the parents to lead the interaction and act maturely and responsibly even when such behavior is inappropriate for his or her age (Knott et al., 1995; Stoneman et al., 1991). The pressure exerted on the sibling as the "ideal child" who is tasked with compensating the "gap" of the disabled child in achieving and succeeding, many times prevents the parents from seeing the sibling as an individual with his personal needs, immersing in their expectations and the image they created for themselves.

Evidence suggests that when competencies of children with disabilities get lower, it is harder for them to maintain an interaction with their siblings, as a result, this creates a gap in siblings' skills' level which children find difficult to skip (Stoneman, 2001).

Sibling with typical development may experience feelings of anger, frustration, and rejection due to the impairment in the family's ability to become socially involved, and lots of sacrifices required of all family members. They also may feel compelled to help watching over their disabled sibling, keep him or her occupied and not burden their parents with more difficulties (Kaminsky & Dewey, 2002; Vollmer et al., 1999).

Studies have also shown a significant role for culture and religious beliefs in understanding the disability and dealing with it among the family members, on issues such as child-rearing and education, practices of socialization, roles and responsibility granting to family members such as siblings (Sage & Jegatheesan, 2010).

1.3.1. Siblings and autism spectrum disorder

An increase in autism spectrum disorder diagnosis means an increase in the number of typically developing siblings, who experience the impact of autism in their life (Meyer et al., 2011). Some researchers have discussed the quality of the sibling relationship concerning autism (Roeyers & Mycke, 1995). Having a sibling with an autism spectrum disorder could often add challenges to siblings that can affect a sibling both positively and negatively (Sicile-Kira, 2014a).

Past research has supported the positive influences of the sibling relationship, such as increased cooperation, nurturance, sensitivity, compassion and empathy (Dellve et al., 2000; Ferraioli et al., 2012; Guzman, 2009; Kiburz, 1994; Macks & Reeve, 2007; Pilowsky et al., 2004; Shivers & Plavnick, 2015), despite few positive interactions among the siblings (Kaminsky & Dewey, 2001). Chantal Sicile-Kira claimed that siblings of autism spectrum disorder children develop maturity, sense of responsibility and loyalty more than their peers, they learn the importance of supporting those around them, so they take pride in their siblings' accomplishments, they tend to show increased patience, more tolerant to differences in people and show acceptance and empathy toward others with special needs (Sicile-Kira, 2014a). A sibling can play a vital role in the life of a child with autism in developing social interaction skills, a child with autism can benefit from playing with siblings, which can provide appropriate play behaviors and modeling (Harris & Glasberg, 2012). Depending on siblings' reports, some studies have reported that compared to normally developing siblings' groups, siblings of a child with autism showed less competition and conflicts it was interpreted as a result of a lack of participation and spending time together (Kaminsky & Dewey, 2001).

However, siblings can suffer from being a member of a family with a child with autism spectrum disorder, as autism inherent with atypical social interaction styles and impairment in non-verbal behaviors, which may affect the development of sibling and peer relationships (Howard et al., 2006). It is hard to maintain a sibling relationship with a sibling who does not show interest in sharing or being a playmate. Some siblings, after several attempts, stop trying to interact with the one with autism spectrum disorder, thus, research has revealed that siblings of adults with autism spectrum disorder had less contact with their brother or sister and were less likely to be involved in the adult care of their sibling (Orsmond & Seltzer, 2007). Not only do they have a sibling who is hard to understand, is not social and who has a limited interest; but they may also have to deal with some bizarre behaviors by their sibling with autism, such as stereotypical movements and even manage certain behaviors, such as temper tantrums, self-injury, and aggression (Gray & Holden, 1992; Guzman, 2009).

Some other challenges siblings may face include relationships with their parents, they can feel the stress their parents are under and may be affected by it. Many siblings feel resentment towards the extra attention the child with autism gets, some feel guilt over their own good health. They may also feel overburdened and saddled with what they perceive as parental expectations for them to be high achievers, many of them feel anxious about how to deal and interact with their sibling with autism (Sicile-Kira, 2014a). Often there is a feeling of resentment toward having to take on extra household chores, coupled with restrictions in participating in social activities (Allgood, 2010). Siblings who are younger than the child with autism may be at higher adjustment difficulties risk (Hastings, 2003). In addition, findings from many studies among siblings of individuals with autism have indicated their concerns and worries about the future of their siblings with autism (Damiani, 2013).

Based on the research literature, there seems to be more negative than positive impacts exhibited in having a sibling with autism spectrum disorder when compared to having a sibling with Down Syndrome (DS), developmental disability (DD), Mental Retardation (MR) or no disability at all (Bågenholm & Gillberg, 1991; Greenberg et al., 2006; Hodapp & Urbano, 2007; Knott et al., 1995; Mascha & Boucher, 2006; Rivers & Stoneman, 2003; Ross & Cuskelly, 2006). Negative impacts of having a child with autism spectrum disorder on the adjustment of the siblings include alienation, aggression, loneliness, bitterness, low levels of prosocial behavior, externalizing problems and increased internalizing and peer difficulties (Fisman et al., 1996; Gold, 1993; Hastings, 2003, 2003; Ross & Cuskelly, 2006; Smalley et al., 1995; Verté et al., 2003). Additionally, siblings of individuals with autism spectrum disorder reported greater feelings of embarrassment than siblings of individuals with no disability (Mascha & Boucher, 2006). Other studies found no differences when comparing siblings of a child with autism comparing to siblings of typically developing individuals (Kaminsky & Dewey, 2002; Mates, 1990; Pilowsky et al., 2004).

Overall studies seem to indicate that the sibling relationship is a complex and diverse one, some siblings can be affected in a variety of domains to varying degrees, both positively and negatively (“The Views and Experiences of Disabled Children and

Their Siblings: A Positive Outlook," 2005). Understanding the siblings of a family with a member with autism helps professionals to understand the dynamics of the family and this particular dyad.

1.4. Rationale of The Study

Since great importance has been attached to sibling relations and its mutual influence on every individual in every family, the unclear vision of the literature, the lack of studies about siblings of children with autism in the Turkish society, and taking into account the increase of autism prevalence in the world as well as Turkey, more research is needed to fully understand the impact of having a sibling with autism spectrum disorder and to address the existing inconsistencies in the literature. The impacts of these aspects which may affect the quality of life of the siblings, the children with autism, parents, and the family as a whole, should be noted and indicated in order to provide a suitable intervention.

Taking in key recommendations from most researchers, who stressed the importance of considering one's cultural background, as it may also impact how individuals interact and perceive individuals with disabilities. Having the foundational background of the system in which the child exists lays the groundwork for exploring the specific experiences of sibling relationships. This study was conducted under the context of Turkish culture.

The present study aimed to describe the impact of a child with autism spectrum disorder among siblings from Turkish families in Turkey through self-reporting, to describe the knowledge that siblings of children with autism have on autism, and to indicate their adaptation ways with an emphasis on the social effect.

1.5. Research Questions

Using a qualitative research design, the following questions were attempted to be answered:

1. What are the experiences and feelings of typically developing siblings of children with autism spectrum disorder among Turkish families in Turkey?
2. What knowledge does the sibling of a child with autism spectrum disorder in Turkey know about autism spectrum disorder?

1.6. Significance of The Study

From the literary, little is known about the siblings of children with autism in Turkey (Aksoy & Yıldırım, 2008; Kahraman & Karadayı, 2015; Yavuz, 2014), prior to our research very few researches have been published in the English language about this category in Turkey. This study describes the experiences of siblings of children with autism aged between 8-18 years and exhibits a typical development, from the perspective through self-reporting, examines their knowledge on autism, and their needs (if found) in the Turkish society precisely, which didn't get enough spotlight before.

Through this study I'm trying to clarify the existing situation of typically developing siblings of children with autism in the Turkish society realistically and directly, their experiences and what they live in everyday life from their own perspective, the challenges they may deal with, and maybe the positive sides of having an a sibling with autism, their awareness and knowledge on autism and their needs, taking into account the cultural context.

Findings from this study can also be used by clinicians, paramedical workers in the various fields and educators, as well as parents and family members in dealing with an autism case.

These findings can reflect the quality of life of the siblings and the family as a whole by sharing their life experiences; specify their needs, review the knowledge they have; and accordingly suggesting and offering appropriate interventions to help them cope more effectively, provide them with information and knowledge necessary to achieve a fair and comfortable lifestyle and recruit them as autism' awareness agents.

CHAPTER II

2. LITERATURE REVIEW

2.1. Reviewing Sibling Experiences About Having a Sibling with Autism Spectrum Disorder

In a study conducted in India among 12 typically developing Indian siblings between nine and sixteen years old who all had a younger brother or sister with disabilities, (two of them had autism spectrum disorder, others had: Down syndrome, Speech delays, Attention Deficit, Hyperactive Disorder, Developmental Disabilities, and Intellectual disability). Through interviews, they shared about their relationships with their siblings and their knowledge about their siblings' disabilities. Positive perceptions about their siblings with disabilities among siblings of children with autism were observed to be the lowest compared with the other participants. Their perceptions were attributed to the behaviors and communication defects of their siblings, as also to lack of knowledge about the brothers' disability and misunderstanding of why they behave in a way they do. Based on the results, in this study, children with disabilities in the Indian society described as "not always welcome", which was reflected in having no opportunities to play or to be engaged in peer interaction, other children' reactions that include teasing or bullying, that also affects their typically developing siblings by limiting access to play with peers. The unrealistic wishes obtained, such as the hope of "healing" or the expectation of a brilliant future of the brother or sister with a disability, indicated the lack of information and misconceptions about the disability among Indian siblings and highlighted to need for supporting and awareness programs (Bhattashali et al., 2018).

One thesis that adopted the quantitative methods, conducted in Turkey among 2 groups of 6th-8th grades student in Istanbul. The study group contained 42 students who have a sibling with autism and a control group of 62 siblings of a typically developing child. Sibling relationship, self-estimating, and stress management have been examined using a self-esteem scale, stress-manage scale, and sibling relationship survey. Results indicated differences between the groups in some subfields like self-preservation, avoidance, superstition, self-preservation, behavior, and adjustment problems. Typical developing siblings of children with autism take over responsibility, have difficulty in accepting their sibling's situation, and indicated their social support needs. additionally, it has found that they try to rationalize accepting the condition of the autism of the sibling to fatalism and superstition (Kızılap, 2018).

One general review study aimed to review the results of studies conducted about siblings of special needs children in Turkey. Few of the 15 studies that have been reviewed examined the category of siblings of children with autism, besides, most of these studies have examined the psychological and emotional aspects. The study indicated the lack of research among the siblings of the children with autism in Turkey, the neglect of attention given to them by parents and in the professional field. According to the results, in Turkey it can be said that there is no support program or any interventions for siblings of disabled children; Despite the need to learn about disability, how to contact a disabled brother and how to overcome problems (Aytekin, 2016).

Typically developing siblings of children with autism, aged between 7–17 years old from 94 "white" families in the UK, were recruited to explore whether siblings' self-reported behavior problems and sibling relationships were associated with their psychological adjustment. Based on the Sibling Relationship Questionnaire, siblings reported very high levels of behavioral and emotional problems; These problems risk increase when the child with autism spectrum disorder has significant behavior problems. In other words, the behavior problems of the child with autism predicted less warmth and more conflictual relationship among the siblings (Hastings & Petalas, 2014).

Psychosocial characteristics that included school adjustment, self-esteem, social relations, and attitudes of peers toward children with autism had investigated among 22 siblings of children with autism aged between 8-18 years and their parents in Greece. Using a semi-structured interview with the siblings and a sibling problems questionnaire filled by the parents. Relying on parental reports, the majority described good relationships between the siblings and tend to believe that their typically developing children overall had no emotional or behavior problems, they even claimed that they have well-developed pro-social skills. However, siblings reported about changes in their daily routine, they revealed that their relationship with their siblings with autism sometimes evokes feelings of self-doubt and a burden-bearing in taking over responsibilities more than they can handle. In terms of friendships and peer acceptance skills, they were unsatisfied. The siblings described their parents 'and their friends' attitude toward the sibling with autism, neither positive nor negative, they indicated that they feel uncomfortable when friends visiting at home because of their sibling's condition which they find it difficult to explain to their friends (Stampoltzis et al., 2014b).

A qualitative collective case study conducted among 12 siblings (7–15 years) in the United States to explore sibling experiences of individuals with autism and identify their support needs through semi-structured interviews. Data support mixed findings on sibling cohesion. On a positive note, participants infrequently quarreled with their siblings, enjoyed mutual activities, and were friends with their siblings. Also, higher levels of empathy and patience in siblings of individuals with disabilities. On the other hand, negative reports focused on their embarrassment or frustration with their siblings' aggressive or socially inappropriate behavior, feeling unsafe, and anxiety when their siblings manifested aggressive behavior. Siblings of individuals with autism spectrum disorder's needs as supporting methods reported in this study included private time for themselves when situations were stressful, talking with others who understood their situation, educating others about autism spectrum disorders, and implementing techniques to assist their siblings with autism spectrum disorders (Angell et al., 2012).

A study by (Meyer et al., 2011) aimed to examine the relationship between child autism severity, presence of the broader autism phenotype (BAP), and adjustment problems among typically developing siblings of children with autism. The sample consisted of 70 mothers from Caucasian families, each one of them, had at least one child with autism and at least one typically developing child aged 6–18. Multi parent-report questionnaires were passed on to the mothers in order to: describe the severity of autism for the child with autism, to identify the effect of the child with autism on the family, to identify children at risk for autism spectrum disorder, and to measure of siblings' behavioral adjustment. According to the findings, siblings of children with autism had more adjustment problems compared to children in a normative sample; The effect of a child with autism on sibling has been observed to be associated with the severity of autism, and with adjustment of the sibling. Another important finding was that many of the siblings in this study were experiencing a significant number of autism characteristics, thus, the greater number of BAP characteristics exhibited, the more difficult adjustment of the siblings of children with autism spectrum disorder was found. However, the study had one big limitation, in that they gained the data quantitatively from the children's mothers, which may be misinformed and maybe was reflected wrongly and do not necessarily reflect the experience of children.

Through describing the dynamic relationship between them and their sibling with autism spectrum disorder, nine domains of their quality of life were identified. The study showed that the positive and the negative experiences are inextricably linked to the sibling relationship. As an impact on their lives, siblings meanly mentioned bothersome and negative behaviors and communicating difficulties with their autism spectrum disorder siblings, some of them liked private times when alone and shared worries about the sibling with autism spectrum disorder. As a support method, they indicated the importance to meet other siblings of children with autism, their need for support from parents, and together time. This study also referred to the "invisibility" of autism spectrum disorder in which individuals with autism have a “typical” physical appearance as an issue that influences the experience of typically developed siblings, while this invisibility brings relief because sometimes everything looks “normal”, it can on the other hand cause siblings and the outside world to doubt and to have a lack of understanding about the diagnosis. The sibling's dilemma about being allowed to tell others was also highlighted in this study, the dilemma about whether to keep silent about autism spectrum disorder causes a lot of stress and tension for siblings of children with autism spectrum disorder (Moyson & Roeyers, 2011).

Hwang and Charnley (2010) used visual ethnographic methods to explore children's experiences and perspectives of living with a sibling with autism among 9 children from South Korea, aged 7-15 years. The study found that siblings of children with autism faced ‘Ijil’ (the shame of difference) created by stigmatizing attitudes to autism; They experienced shame and embarrassment, did not speak openly about autism, got used to strange behaviors, experienced prejudice from others and referred to autism as a “sickness”. Simultaneously, the children valued and took pride in the abilities of their siblings with autism. The findings suggested that the power of the social model of disability is unequally distributed across different socio-cultural settings (Hwang & Charnley, 2010).

In a qualitative descriptive, (Barak-Levy et al., 2010) compared the views of Israeli parents of children with autism to the views and feelings of their healthy children regarding their social and emotional adjustment and levels of behavioral problems, through both parental and sibling report, among 27 children who have siblings with autism and 27 children with no disabled sibling. As a result, by qualitative information in a deep analysis, two major difficulties confronting healthy siblings of children with autism were revealed. Unlike children in the control group, these children have a much lower level of participation in child activities and poorer social relations and school performance. Simultaneously, they are seen and see themselves as responsible for the considerably higher levels of assistance within the home. Unlike their peers, the vast majority (over 80%) of the siblings of children with autism in this study were enrolled in very few extracurricular activities, if any. Researchers' explanations were given as in several options: first, as a result of the lack of parents' time and attention in arranging extracurricular activities because they must care for a child with autism. Second, the family's financial resources make it difficult to pay for extracurricular classes and activities. Genetic aspect of autism may yet provide another explanation in which a genetic trait of the typically developed siblings, causes them to be more internalized and introverted and less active than other children, expressing a ‘broad phenotype’, which causes them to prefer staying home and not participate in social activities (Barak-Levy et al., 2010).

One thesis study investigated the thoughts and feelings of three participants aged between 15-16 years old toward their younger siblings with autism, within a narrative inquiry, using photographs and semi-structured interviews. Results indicated the lack of knowledge about autism among the participants, also pointed the participants' feelings of embarrassment about their siblings' behaviors, dissatisfaction with the time they spend with their parents, as well as their concerns about their siblings' future (Alagözoğlu, 2016).

CHAPTER III

3. METHOD

3.1. Theoretical Framework and Study Design

The purpose of this study is not to test a hypothesis, and not to evaluate participants' ideas. Instead, it tries to understand participants' lived experiences, focusing on the meanings they emphasize for their experiences. Thus, this study has been led by the phenomenological approach, which established by Edmund Husserl and others at the beginning of the 20th century, characterized as a philosophy that studies lived experiences, depending on descriptions but not interpretations as experienced and the meanings they create, from the subjective first-person point of view (Dowling, 2007).

Guided by the constructionist perspective methodology which is in line with the phenomenological approach. The Constructionist Perspective contends that people attribute meanings to their experiences through past and present interactions in the world (Michael Crotty, 2012). Thus, the experience of having a sibling diagnosed with autism spectrum disorder may carry different implication for different children and may be affected by many past and present circumstances, including age, the order of birth, number of siblings, understanding of an autism spectrum disorder diagnosis, available social support, parental interactions, and other factors.

There have been few studies that have allowed siblings of persons with disabilities to explore the meanings of their experiences. Also, most research has focused on the adversity faced by siblings of persons with disabilities. Our goal in this study was to capture a more holistic picture of these lived experiences as judgmentless as possible and for that constructionist methodology was be chosen allowing voices of the participants to be heard, in which individual interpretations can vary considerably from each other but still considered valid (Ernesto, 2005; Michael Crotty, 2012).

3.2. The Researcher

After finishing my occupational therapy bachelor's degree from the University of Haifa- Israel, I worked as an occupational therapist basically with kindergarten children that have been diagnosed with autism in the Arab community in Israel. The interventions were direct with the individuals, and as a holistic view of seeing the child, I was involved in the weekly para-medical professionals meeting as well, in addition to the parents meeting that conducted often. At the same time, I worked in an Institute for multidisciplinary psychological and developmental care and as part of the Institute's vision of intervention in the individual and his family from a comprehensive and integrative perspective, I have witnessed the dynamics of siblings when a child had particular challenges.

Later, as part of my master's degree studies in the department of applied behavior analysis in the University of Anadolu- Turkey, as part of the implementation and observations I had in the developmental support unit I was exposed also to the impact and the value granted to siblings in the life of the child with autism. I observed the interaction between siblings when accompanying, how siblings amuse and scrimmage, and above all, the apparent bond they have, in caring, loving, or even fighting and the way they communicate, play together, and share.

Which made me interested in this effect in reverse, thus, the impact of having a child with autism on the siblings (the side that is less under the spotlight as I assume), their own perspectives on the experiences of growing up with a sibling with autism.

After studying the subject, which was rarely highlighted in a cultural context, much of the literature that invested siblings' adjustment used a parents' or teachers' reports or used quantitative methods without analyzing the impact in depth.

In the framework of my thesis, I wanted to focus on siblings' experiences from their own perspective, the knowledge they have about autism, and the needs they may have in Turkish society through a qualitative study.

3.3. Participants Selection and Recruitment

Seven participants from 6 families were recruited using a “snowball” approach (Hays & Singh, 2012). Thus, depending on the initial participants who met the criteria (I came to this family by chance as a neighbor of a friend), other families (who reside in the city of Eskişehir) known to the first family were purposefully contacted. One family agreed to participate, another family did not meet the criteria, (Notable to mention that most of the families with a child who has autism, were families with few children, one or two children when the sibling does not meet the age criterion), it continued in this way (from family to family), two families where contacted but did not agree to participate in the study. Interview appointment was in accordance with the family, and in that period, some families were on vacation in another city, thus, just upon his return, the process kept on. Thus, until recruited 6 families in a period of two months.

Families recruited were meeting the following inclusion criteria: (a) Turkish family who lived in Turkey, (b) the family has a child member who had received a diagnosis of autism spectrum disorder from medical or Psychiatric professional, and (c) have another child and both siblings reside at home with their biological parents.

A participant from each family: (a) was a sibling with typically developing. (b) aged between 8 and 18 years old. Siblings who had significant developmental disabilities were not included in this study. Both male and female siblings were recruited without discrimination or preference regarding gender as well as socio- economic background.

Participants were contacted by phone, what's up, or in-person to determine a meeting location and time and to provide them with the consent form (attached as appendix A). after being approved by the thesis supervisor Prof. Dr. Elif Tekin İftar at Anadolu University- The research institute for the handicapped.

Upon receiving informed consent, the interviews scheduled at times and locations convenient for the participants. Any questions or concerns have been answered as possible in a clear way prior to obtaining their signature for consent.

A demographic form was filled by parents, then interviewing the sibling take place in individual form and was taped, then the KAQ questionnaire that translated to Turkish by the author was passed to the siblings, consisting of 21 statements that answered by "true" or "false" or "I do not know".

3.4. Measures

3.4.1. Demographic questionnaire

The questionnaire included demographic information about the family status, the child with autism spectrum disorder, and the typically developing sibling as mainly. Parents reported their marital status, and their level of education, monthly income, field, and hours of job. Information about the participants as siblings including age, gender, birth order, health conditions, and involvement in any activity outside the education framework. And regarding the child with autism spectrum disorder including age, gender, birth order, diagnostic classification, year of diagnosis (Demographic form attached as appendix B, and in his Turkish version attached as appendix C).

3.4.2. Semi-structured interview

To describe the siblings' experiences and follow a review of the literature, a semi-structured interview guide of 22-questions based on previous research was developed by the researcher. The semi-structured interview used allowing the researcher to be prepared before the interview and to manage the interview competently especially with the fact that I'm not a native speaker of the Turkish language, but also, it is semi-structured, in the concept of enabling the participants to express their thoughts and views freely according to their terms.

The interview questions were written and sent by e-mail to experts in order to determine the appropriateness of the interview form. The questions were reduced to 20 questions (Interview protocol attached as appendix D).

Interview questions were related to the three items: The first section focused on the siblings' relationship and their awareness of the brother's disability (e.g. How do you think your brother is different? Tell me about some of the things you do with (name of the sibling with autism spectrum disorder). What is the best part of being a sibling to (name of the sibling with autism spectrum disorder? The second section addressed participant understanding of autism spectrum disorder within five questions (e.g. How would you explain autism to someone who had never heard it before? / How do you think people get autism?). The third section included three questions focusing on siblings' needs and suggestions (e.g. what things that help you handle the difficult parts/ situations?/ What advice would you give to other kids who have a brother or a sister with autism spectrum disorder).

3.4.3. Knowledge of autism questionnaire (KAQ)

To achieve the second goal of this study in assessing autism siblings' knowledge of autism spectrum disorder, Knowledge of Autism Questionnaire (KAQ) developed by Ross and Cuskelly (2006) has been used. The KAQ was designed with input from three experts in the field of autism to increase content validity (Ross & Cuskelly, 2006). It has not been officially published yet, though it has been used in previous studies, like in their study of (Mavropoulou & Sideridis, 2014).

KAQ was available by request from the first author; After receiving it by contacting the author and getting the permission for translation and using, the tool had been translated and was handed over to a team of four Turkish-speaking experts in the field of autism spectrum disorder to ensuring clear translation. Then the Turkish version was passed to four native speaker children aged between 8-12 years old to ensure understandable translation.

The questionnaire contains 21 items based on definitions and criteria provided in the Diagnostic and Statistical Manual of Mental Disorders – 4th Edition (American Psychiatric Association, 1994) covering aspects of the disorders such as course, prevalence, etiology, cognitive ability, and associated features. The questionnaire has been designed and used with middle-aged (range 8–15) typically developing siblings. Through it, participants were asked to read each statement about their sibling’s disorder (for these who was not easy to read, each statement has been read to them), and then he/she was asked to rate it as either true or false. The questionnaire was used as a continuous measure – thus, the more correct answers, the more the child understood about autism. (The questionnaire as received from his author attached as appendix E).

3.5. Data Collection

The data needed for this study were obtained in the following sequence: Upon receiving participation consent signed by the parents. Information about the family status obtained via the demographic form filled by parents, then the interview took place in individual form, then the Turkish version of the KAQ questionnaire was passed to the participant.

Data from the siblings about their experiences, perceptions about their brother's diagnosis, and their suggestions were obtained through interviews. Every interview was conducted at a place and time convenient for the family. All but one interview was conducted in the family home, allowing comfortable for the participants, and observing the siblings in their home environment. Each interview conducted individually with a participant, in the presence of the parent proximity (in another room in the home) and lasted about 30 minutes. All interviews were audio-recorded using a Galaxy-phone and then transcribed verbatim. Since the participants were interviewed in Turkish, the interview data were transcribed into English. While transcribing, the researcher typed the interviewer and interviewees' comments to identify them easily while analyzing the data. The total number of transcript pages was 62 with the range was 6-12 pages per participant.

As mentioned above, to achieve a view of siblings' knowledge about autism spectrum disorder, participants were asked to fill the Knowledge of Autism Questionnaire

(KAQ) by rating each statement of it as either true or false, in order to distinguish between the lack of knowledge and mis-knowledge "I do not know" was added as a third choice for each statement. (The translated KAQ including the modification attached as appendix F).

3.6. Ethical Considerations

The study was designed and carried out according to the Ethical Code of Anadolu University and the American Psychological Association (APA). Before commencing the participant recruitment process, the participating consent form was checked and approved via the supervisor.

After obtaining the participants' oral approval to be part of the study, parent information sheets were provided to the families. Parents signed parent consent and were able to maintain confidently by choosing to use pseudonyms. It was clarified for each participant before interviewing that the interview would be recorded and transcribed verbatim, and their permission was taken directly from the participant and his family.

3.7. Data Analysis

Following the description of Liamputtong (2013) data analysis was completed in the order: data immersion, coding, themes identification, and reviewing themes. Data immersion involves verbatim transcription of the audio- recorded interviews and reading through the transcripts without any interpretation (Liamputtong, 2013).

To explore the data at an initial level and for accuracy purposes, a partner working on a similar type of research method was used for a reliability check after the interviews took place. Both the researcher and the partner read through each of the transcriptions. Codes were refined gradually devising manually by the author based on summaries of meaning and basic notes that were taken while reading the transcriptions (Alan, 2008). Data were organized into a table, with each participant's information placed in a column separately on the table to create different codes of the data. Based on these codes, as the data were combined across participants, detailed descriptions of siblings' experiences emerged, and consequently, categories began to emerge within each theme. Thus, codes were organized into potential themes. All data within a potential theme was read and discussed to ensure that it belonged under that theme.

Since the number of participants is small, the data analysis from the demographic and autism knowledge of the autism questionnaire was done manually.

4. CHAPTER IV: RESULTS

4.1. Demographics of the Participants

This study included a small sample size of seven adolescents (M_{age} = 11.9 years, SD = 3.4, range: 8-18; three males and four females). All the participants and siblings were Turkish lived in the city of Eskişehir in Turkey.

In four cases, the participant was a younger sibling of the brother/ sister with an autism spectrum disorder and in three cases he or she was an older sibling. The number of children in the home ranged from two to three (M= 2.28, SD = 0.45, mode = 2). Two of the participants were siblings of the same family when one is older than the diagnosed child, and the other one is younger. Six of the participants were from two married parent families and one was from single parents after the death of the father. In four cases, the child's autism diagnosis in the family was over ten years, while in the other 3 cases was between 1-3 years before (see Table 4.1)

Table 4.1. *Profile of participants.*

	Profile of participant			**Profile of sibling with an autism spectrum disorder**			**Family situation**		
	Gender	Age (Year)	Involving in any activity	Diagnosis (year of diagnosis)	Age (Year)	Gender	Marital status	Number of Children	Monthly income
P1	Male	13	Second Language	Atypical autism +ADHD (2007)	16	Male	Married	2 Male	More than 8000 TL
P2	Male	10	Taekwondo	Autism 2000	21	Male	Married	2 M	2001-4000 Tl
P3	Male	8	None	Autism (2018)	10	Female	Married	2 (1 M, 1 F)	Less than 2000 TL
P4	Female	18	None	Autism (2005)	16	Male	Single parent (Father is dead)	2 (1 M, 1 F)	2001-4000 Tl

Table 4.2. (Continuous) *Profile of participants*.

P5	**Female**	**8**	**Taekwondo**	**Atypical autism (2016)**	**6**	**Male**	**Married**	**3 (2 F, 1 M)**	**2001-4000 Tl**
P6	Female	15	None	Atypical autism (2016)	6	Male	Married	3 (2 F, 1 M)	2001-4000 Tl
P7	Female	11	Swimming	Autism (2008)	13	Female	Married	2 F	4001-6000 TL

4.2.Participants' Experiences of Being a Sibling of a Child with Autism Spectrum Disorder

Following data analysis, four major themes, with 10 sub-themes emerged from the essences of the participants' lived experiences.

4.2.1. Thematic

The thematic clusters and subthemes are described below regardless of hierarchical order. Additionally, siblings' quotations were cited to illustrate their points of view as enriching in reflecting on their experiences. For clarity, the quotes are labeled P1, P2,... where the letter (P) identifies the participant.

4.2.1.1. Thematic cluster #1: understanding of autism spectrum disorder

This theme includes the siblings' understanding of autism spectrum disorder, as it relates to subthemes of the *knowledge essence they have about the diagnosis*, as the *resource of this understanding* and recognizing *the impact of the autism spectrum disorder on the lives of their brothers and sisters.*

Six participants out of seven defined their sibling's difference mainly as a verbal disability clarified by lack of ability to talk, pronunciation problems, or echolalia. Three answers explained it as a mental problem saying that their brain works differently; Aspect of repetitive patterns, behavioral disturbances, and limited interest was mentioned in the incidence of four times, while two answers included social interaction problems concentrates on social withdrawal and being introverted. P3 and P7 started their answers with the description of "no difference" explaining that their sibling is normal kids.

All participants (apart from one who still does not know what autism is) shared that they had not heard about autism before the sibling has diagnosed, and they were told by the parents, with the most common description of the diagnosis as "a gift or a test from Allah/ Allah gave to us because he loves us ", parents are considered the main informative resource. P1 shared about his curiosity when tried to search about autism on the internet mainly to know how to deal with his big brother, but as shared " There are many different things on the internet, which I cannot decide what things to believe. For example, I have read somewhere, that children with autism get angry when there is a lot of voices or something, but my brother does not! I guess it is depending on the person, it may be different, for example, as I read some children with autism can do big things."

Understanding of autism spectrum disorder based on individual conclusions that were reflected by examples and stories told by the siblings included indicating the impact the autism spectrum disorder had on the diagnosed brother/sister. Thus, regarding the know-how about information about autism, the hesitation was evident for all participants, consequently, answers to questions of knowledge initiated with "I am not sure/ I guess/ I assume/ but it can be wrong". Accordingly, four participants guessed that autism spectrum disorder maybe from birth, three added that they have no idea, P4 added that autism spectrum disorder may be transmitted through genes, and P6 mentioned "vaccines or some medicament" as a probable cause.

Three participants do not think that autism is something that one can get rid of or be fixed but can get lighter by interventions. P3, P5, and P7 think that autism is something that can be disposed of. Those participants were the youngest and defined autism spectrum disorder as just a verbal disability. Thus, P7 explained that according to the neighbor, one child who cannot talk from birth, later he talked in a miracle. P3 and P5 believed that "after intensive teaching, my sister/brother can talk and be normal like me". While P6 thinks that maybe, after long years ahead, scientists can find a cure for autism.

Reviewing the understanding of autism spectrum disorder implications on the child with autism spectrum disorder, siblings were asked what they think their brother/ sister who deal with autism will do when growing up. P2, P4, and P5 described their siblings as a with high-functioning autism, suggesting that depending on their interests or obsessions he/she can work as a waiter/ repairman/ driver or a car cleaner. P5 added a very gentle thought with the words "he will be a good person, with self-confidence, he will be someone who will love his family and his friends". P1 and P6 think that he/she will stay at home, under their families' care, P6 added: "I will be there for him". P3 and P7 answered that he/she will be "like me" with a normal future as others with a job they want, "she wants to be a doctor, and I believe she will be".

Observed from information collected from the siblings that there is a lack of awareness, especially for the youngest participants whose siblings have been diagnosed in the last two years. Parallelly, the lack of autism spectrum disorder awareness by the wider community puts siblings in the face of negative emotions, thus P7 shared "in public, some people stare, I get angry, as if she did it on purpose!"

4.2.1.2. Thematic cluster #2: relationships and interactions between the siblings.

This category includes the subthemes of *describing the sibling bond depending on the lived experiences including activities shared; challenges and advantages of being a sibling to an autism spectrum disorder brother/sister*; and lastly, *the role of the parent on the siblings' relationship*.

In describing their relationships with the autism spectrum disorder sibling, seven participants spontaneously described it positively as a lovely and enjoyable relationship, however, by illustration, they explained it as neutral in that they do not play together, never fought; and usually cannot communicate or share things. Four of them mentioned also negative vibes represented in mentally fatigued, uncomfortableness, and enraging when causing damage. It is noteworthy that those who shared these feelings were younger than their diagnosed siblings.

Indicating games or activities they do together with the sibling with autism, activities that need no direct interaction were the most common, thus, five of them mentioned sports activities (e.g. swimming), bike riding, and games with the ball. Four mentioned spending time on smartphones or watching television as an activity they both shares. Activities under the supervision of the parents like going out to parks or markets mentioned twice, doing creative art activities (drawing, painting), instrumental activity of daily living like shopping, and housekeeping mentioned twice (for each field), while interactive games like hiding and seek or pretend game mentioned by two participants.

From their experience, siblings were asked about the best part of being a sibling to his/her sibling with autism, four participants indicated having a play partner, P2 and P7 participants mentioned that the best part is having no disturbing or quarrels as usually between siblings. P4 and P6 mentioned the positive influence on the character (as they described) in being patient and feeling responsible.

Parallelly, in indicating the hardest part of being a sibling to his/her sibling with autism; Insisting on illogical things, non-receipt of changes and non-obedience were the most common answers. P4 shared: "His life so restricted to his rules and routines, for example, just him is entitled to insert the TV plug and no one else is allowed to do that but him, when we have to do for having little time, then he gets angry, shout, scream, ourselves get more annoyed, so these times when running out of patience are the hardest for me". P1, P2, and P5 mentioned situations of getting a tantrum and being a witness for self-harm or hitting others. P1 touched in his answer the specific element of paying attention continuity not to harm himself.

As described from most of the participants, in hard times parents (the mother in general) showed understanding toward the siblings and continually asked from them to show tolerance toward the diagnosed brother/ sister. P1 " sometimes I tell my mother and we talk about that, my father is at his work in general, he already knows so I can't tell him every time, so I tell my mother".

4.2.1.3. Thematic cluster #3: emotional dealings

Emotional dealings were particularly prominent in the siblings' stories. This category includes two main subthemes: *siblings' emotions toward their siblings who have autism*. And into themselves reflected in the *Emotion-focused coping* they use to reduce negative emotional responses.

Relying on previous studies, siblings of people with autism spectrum disorder have described various emotions such as anger, love, and embarrassment. This was particularly noticeable when the sample included children at an early age, so detecting mostly negative emotions may be more spontaneous among this population. And so, this sample appealed to the population of a young age to produce as true a description as possible with comfortable. Based on that, participants were asked to describe the emotions they feel regarding the relationship toward the sibling with autism. Seven participants described love as the main feeling, three answers included anger feeling when getting hit by the sibling with autism or toward people when staring at him/her. P1 and P5 mentioned embarrassment when showing stereotypes or behaving unsuitably in public, P2 and P4 shared that they used to feel embarrassed when they were younger but not anymore. P4 added feeling sorry and sadness when making his sibling upset.

For more reliability, this topic came up within a different question with a 0-10 measurable of how much the participant likes being a sibling to his/her brother/sister with autism spectrum disorder, each one had to pick a number; when 0 reflects "disliking" while 10 reflects "really liking it". Six of the seven participants picked the number 10 and clarified this from the point of relative bond that the sibling is a part of the soul, or by describing him/her as a good person even when things get bad, and for the fact that being without sibling means having no partner. P5 picked the number 9 explained it by being upset sometimes for getting hit from the sibling.

In indicating ways of dealing with hard situations, siblings tend in the first place to illustrate that they are strong individuals who can handle also hard stuff, thus, statements like " I am a strong person/ patient person/ I stand hard things/ I control myself/ I don't complain/ I do not care much/ I keep calm/ I can handle things myself" were frequent.

Most of the participants sharing their hard experiences with parents, specifically with the mother, or with a close friend. P1 shares with his close friend, who (as he described) cannot do a thing but to console him. Three of the participants P3, P4 and P5 shared that crying helps them to release. While P6 and P7 shared that going outdoor, taking some fresh air, or listening to music, painting, or playing with the smartphone is their way to skip difficult situations.

4.2.1.4. Thematic cluster #4: The value of siblinghood

Siblinghood value reflected within the two subthemes: Participants' image of the *sibling bond they aspire to reach*. In addition to their *piece of advice to other children* who have an autism spectrum disorder diagnosed sibling.

In describing what would their interaction looks like if their sibling was not diagnosed with autism, five participants suggested that they would do things together: playing, hanging out, traveling, and enjoying, "being friends", having conversations, and sharing things. Three answers included better interaction since he/she would be able to speak better, to express himself, and would be understandable. Two participants took the question from another point of view, suggesting that it is better to be with autism since it is "comfortable" having no fights and less cost to the whole family. P4's answer included the diagnosed sibling's future consideration, suggesting that his future could be better by establishing his own life.

One hypothetical question was If the participant could wave a magic wand, what things about his diagnosed sibling he/she would change. Three participants wished they could change the bond between the two of them in being able to talk deeply, understand each other's feelings, the way they play, or share activities.

P4 " I would like to tell him everything that I keep deeply in myself and parallel, I want to hear from him and know his feelings, for example when we lost my father, he did not share anything yet, I would know about that, what he thinks about me, am I a good sister for him". P3 shared "I would teach her how to ride the scooter outside".

Three participants addressed the behavioral problems desiring not to cause self-harm or to others, thus, P2 shared "I wish he never hurt himself". Two answers started with the wish to get recover directly and being "a normal child". Two answers included granting him/her the ability to talk. P5 " I would like him not to hit me, I would like him to talk to me, for example, to be able to explain what he wants or need".

Beyond the autism spectrum disorder and lived experiences when having a diagnosed sibling, in their good and hard aspects, sibling bond was vast and rooted within this study, which may be related to the sibling's values emphasized in the Turkish society. Thus, even when describing tough situations, touching statements like:

> P1 "he is my soul, even he is with autism after all he is my brother in the first place"
>
> P2 "he is so unique, and for me being with autism is a good thing, we don't fight, he doesn't cost much expense, and I love him in this form."
>
> P3 "I am the only one that can understand her".
>
> P4 "I love him so much, he is the person I love the most from my family, no one else, I also love my mother, but his place is different, just hearing his voice, it's like the world is mine".
>
> P5 "when I play with him, I forget about all troubles"
>
> P6 " when he will grow up, so I will, thus, no worry I will be for him".
>
> P7 "she is so cute, and I love her so much"

Asking their advice to other kids who have a brother or sister like theirs, three participants emphasize the importance of finding a communicate way with the sibling that have autism, spending time with, encouraging them, accepting each one of them as he/she is, and trying to understand their needs. P1 and P4 supposed that they must be very patient and show tolerance toward their sibling with autism. Two participants advised not to evoke their anger. P1 mentioned the advice of the necessity of self-defense in difficult situations.

All the siblings showed willingness and a desire for joining a course devoting to siblings of children with autism to educate and raise awareness about autism, sharing, and getting consultations. This willingness stemmed mainly from the need to find ways to deal and communicate with the diagnosed sibling, and as P6 clarify "to gain methods to teach him, so I also can pass this information to my mother to help him get to improve". It should be noticed that all the families participating in the study are families with only two children (except one family of 3 children), each one of the mothers stays at home most of the time and devotes all her time to the children, taking into account the needs of the child with autism but also showing concern and care for the other child as well.

4.3. Participants' Knowledge About Autism Spectrum Disorder- Results of Knowledge of Autism Questionnaire (KAQ)

Results of the answers on the questionnaire are summarized in Table 4.2, ranked hierarchy according to the most correct choices. Thus, Participant number 4 got 20 correct answers, and one statement she "did not know".

Table 4.2. *KAQ's results: the number of correct, incorrect, and unknown answers for each participant*.

	True Answer	**False answer**	**Did not know**
P4	20	0	1
P6	17	3	1
P1	16	4	1
P2	15	3	3
P5	12	5	4
P7	12	9	0
P3	5	15	1

The table was ranked according to the highest number of correct answers. Thus, The participant that got the most correct answers was with the profile of:

Female, aged 18 years old, have just one brother who diagnosed from 2005 with autism. She mentioned that she learned a lot, from her experience with her brother she became more aware of autism in general and for his brother in particular.

While, P3 exhibited less knowledge about autism, with the profile of:

Male, aged 8 years old, have one sister who diagnosed recently in 2018 with autism. There was also lack of knowledge for the diagnosis in the first place, he did not know the term "Autism" and for this reason, for the length of the participants also within the interview, the term was not used, however, explanations like (children who are in the same situations as your sister) were used.

Regarding the questionnaire statements, Table 4.3 presents each statement with the number of right/wrong choices or lack of knowledge which was chosen as "don't know" choice.

Table 4.3. *Results regarding KAQ's statements: number of correct, incorrect, and unknown chooses for each statement*.

	Right choice	**Wrong choice**	**Lack of knowledge**
Statement 1	4	0	3
Statement 2	6	1	0
Statement 3	6	1	0
Statement 4	5	2	0
Statement 5	1	4	2
Statement 6	3	4	0
Statement 7	2	3	2
Statement 8	6	1	0
Statement 9	7	0	0
Statement 10	5	2	0
Statement 11	5	2	0
Statement 12	5	2	0
Statement 13	6	1	0
Statement 14	5	1	1
Statement 15	6	1	0
Statement 16	5	1	1
Statement 17	2	5	0
Statement 18	5	2	0
Statement 19	4	2	1
Statement 20	5	2	0
Statement 21	4	2	1

Statements that answered with many wrong choices were:

- Statement number five "Autism is more common in families who have a history of the disorder (e.g. more likely to have autism if grandparents have autism)" only one participant chose the correct answer.
- Statement number seven " Most children with autism do very well at school" and statement number seventeen "Many children with autism don't make friends" with just two correct choices on it.
- Statement number three " All children with autism deliberately hurt themselves" and statement number six " Not many people have autism in the world – it is quite rare" with three correct choices on it.

When on statement number nine " You can “catch” autism from children who have it – it's a disease like chickenpox" all the participants answered it rightly.

Statements number 2, 3, 8, 13, and 15 were commonly answered right too (six participants picked the right choice on each of it).

5. DISCUSSION

5.1.Thematic

The current research presents a phenomenological view of siblings of autism spectrum disorder diagnosed children among seven participants aged between 8-18 years of old belonged to Turkish families. Without generalizable either to all siblings in Turkish society, neither to all children with a sibling with an autism spectrum disorder. Each thematic cluster was separately discussed and compared with the relevant literature.

5.1.1. Thematic Cluster #1: Understanding of autism spectrum disorder

This thematic presents essence knowledge that siblings have about the autism spectrum disorder diagnosis, results showed that autism was defined by most of the participants as a verbal disability, and so it was when indicating first thing they felt their brother's/ sister's difference, most of the participants explained that first thing they turned to ask their parents was why their brother cannot talk or not able to communicate verbally as supposed. That was stated in their book of Bryna Siegel and Stuart Silverstein (Bryna & Stuart, 2001), thus, children in the ages of preschool are aware that speech is a universal feature for children who are not infants, so this field is the first they note and start to ask why their brother or sister can't talk, while recognition of behavioral (as opposed to physically traits disorder) requires a higher cognitive level, thus, depending on its severity, behavioral differences will be noticeable to siblings at different ages.

As a resource of the understanding of autism spectrum disorder among the siblings, parents found as the main resource for gaining information, however, the most common explanation provided by the parents was "we have a unique child and it is a test or a gift from Allah". These were interpreted that sometimes parents hesitate to tell the siblings anything about what is wrong, either because they do not yet fully understand themselves, or because they fear to stigmatize one of their children in the eyes of the others (Bryna & Stuart, 2001).

Indeed, parents need to be aware that when children have none of the answers, they tend to create their own ideas about autism and their sibling in particular. These may include misconceptions, for example, they may feel guilty (my brother doesn't play with me because he doesn't like me) or may worry about them (my brother is sick and may die) and other assumptions that can be very damaging (Shira, 2000).

Whereas, siblings in this study found to form their concept of autism based on conclusions from what is experienced by the diagnosed brother/ sister and recognizing the impact of the autism spectrum disorder on the lives of their brothers and sisters. It has been suggested that acceptance of the siblings towards their brother or sister with autism spectrum disorder increased with improving the understanding of the diagnosis and its impact on their sibling's behavior (Hoskinson, 2011). This understanding usually became more advanced with age (Angell et al., 2012; Harris & Glasberg, 2012; Hastings & Petalas, 2014). Yet, it is important to provide objective knowledge and a language suitable to a child's needs in order to be able to cope with his feelings toward situations that may arise, allowing him to have a better understanding of the behavior that his diagnosed brother/ sister may exhibit.

In parallel, lack of awareness among the community, which demonstrates sometimes when being in public in the company of the diagnosed brother/ sister, evoked a feeling of the anger of some participants. In line with the literature, a lack of autism spectrum disorder understanding among the wider community has reportedly added to the negative experiences of the siblings (Hastings & Petalas, 2014; Petalas et al., 2009, 2012). For instance, in positions of dealing with questions from peers or the wider community regarding their brother/sister in public (Petalas et al., 2009).

5.1.2. Thematic Cluster #2: Relationships and interactions between the siblings.

The relationship between the siblings was described by the participants in this study as a lovely and enjoyable relationship. Consistent with previous work, indicating that as siblings, children between the ages of 6-15 share mostly positive things about their brother or sister, regardless of whether the sibling had autism, mental retardation, or was developing typically (McHale et al., 1986). In some research, when having a child with autism, sibling relationships have reported as less competitive and conflicted than normally developing sibling groups (Kaminsky & Dewey, 2001), which fit with the descriptions told by the participants in this study by reporting having no fights or disturbing. Parenting styles also found as impacted on the sibling experience (Sage & Jegatheesan, 2010; Seltzer et al., 2010).

While shared activities with the brother / sister with autism spectrum disorder, reported more among younger siblings than the older ones, those activities included activities that need no direct interaction, like watching Tv, riding a bike, or swimming.

5.1.3. Thematic Cluster #3: Emotional dealings

Emotions that expressed toward the siblings with autism spectrum disorder were in total positive and characterized by compassion, while anger was mentioned in cases were the brother/ sister with autism spectrum disorder with behaviour problems and was causes hurts or damage to things.

Some studies suggest that siblings of autism spectrum disorder children tend to share increased patience, more tolerant of differences in people, and show acceptance and empathy toward others with special needs (Sicile-Kira, 2014). Whilst aggressiveness in children with autism spectrum disorder is a predictive factor in the social and emotional adjustment of their siblings, thus, the more aggressive behaviours of the children with autism spectrum disorder exhibit, the more problems of self-regulation the sibling of the child with autism spectrum disorder presents (Hastings, 2007; Mascha & Boucher, 2006; Ross & Cuskelly, 2006).

Regarding Emotion-focused coping, some studies indicated that most of the children who have a sibling with autism learn to handle the experience and show no major ill effects (Grissom & Borkowski, 2002; McHale et al., 1986). The thing that as an implication could result in less referencing toward the siblings and their emotional dealing, which can be individually different, deep, and changed with age. Thus, while turning to parents to gain the parental consent to participate in the study, one parent claimed that the study should be conducted among parents because they deal with the whole things, for him, there is nothing to worry about the sibling, he has all the things he needs from the tablet to the new phone and a second language course and he supposed to be in well-being, while particularly his own son shared about feeling psychological fatigue as a result of continuous anxiety for his big brother diagnosed with autism and behavior problems, from reaching the key or leave the house suddenly, either eating inedible things that may harm him.

As for coping ways, most of the participants share their hard experiences with parents, however, as shared "nothings changes, they cannot do a thing, we used to that", which at some point may cause to despair. Thus, siblings of children with autism spectrum disorder need to feel comfortable asking questions, and getting effective answers, when their diagnosed brother or sister has behavior problems, they need tools and to be told explicitly that they do not have to worry about safety, preparing them for difficult situations that can take place in public in response to questions or probable ridicule from friends, they also need peer support, in knowing that there are other children like them in the same situation.

5.1.4. Thematic Cluster #4: Value of siblinghood

The findings of the study provided much insight into the value of the sibling in Turkish society. All the participants expressed love and concern toward the diagnosed sibling and shared emotional bonds with no influence by either exhibiting behavior problems or hard situations. They illustrate their desire in joining a course to understand autism as getting a better understanding to help their brothers and to find ways to communicate with them more than joining to share and relief their emotions.

Contrary to literature reported on siblings' negative feelings like resentment toward taking responsibility for their siblings (Allgood, 2010). These feelings were not raised among participants in the current study, although some of them do play a role in helping and caring for a brother with autism, which may rely on the cultural context of providing emotional support to the sibling, keeping the family united, and taking the instrumental role of housework as the expressive role of the siblings in the Turkish society (Ataca, 2009). And maybe explained by the fact that the mothers are constantly available at home and show caring and concern for the siblings as well, and can also be explained by the small number of children in the family so that siblings have one experience without any comparison.

5.2. Siblings' Knowledge of Autism

In total, according to the questionnaire, participants showed knowledge of autism. The item that included etiology (Autism is more common in families who have a history of the disorder) got most of the wrong answers, showing a lack of information. While misinformation like (You can “catch” autism from children who have it) was clear to all the participants as a wrong statement. Sentences that contained a generalization form, were the statements that confused the participants (e.g. " All children with autism deliberately hurt themselves"). This indicates that siblings' conclusion and the formation of their knowledge based on their own experiences with their diagnosed brothers/ sisters.

However, some of these understandings are unreliable and do not reflect a clear awareness about autism, thus, they still find it difficult to explain autism to other people around them.

Studies showed that acceptance of the siblings towards their brother or sister with autism spectrum disorder increased with improving the understanding of the diagnosis and its impact on their sibling's behavior (Hoskinson, 2011). This understanding usually became more advanced with age (Angell et al., 2012; Harris & Glasberg, 2012; R. P. Hastings & Petalas, 2014). Studies also show that when social support increases, the stress level of their families decreases (Coşkun & Akkaş, 2009)

5.3.Limitations

I am not going to point out the size of the small sample as a limitation, as it is a qualitative study that aimed to provide an in-depth understanding of the participants' experience, with no purpose for generalizing the results regarding all siblings of children with autism. however, it can be mentioned the recruitment process was a challenging process, not every family was willing to participate in the study.

Conducting interviews with young children in their own language that is not my mother tongue was a bit challenging, since understanding the language at this age is concrete, and I had to be careful with each letter's accent. It also robbed me of a lot of effort and time to rewrite and translate the questionnaires and the collected data.

5.4. Clinical Implications

As mentioned in the first chapter, a positive sibling bond contributes to the quality of the individual's life and has the great impact on the family as a unite, which emphasizes the importance of the deep understanding of parents, mental health professionals, clinicians, and paramedical workers on this issue.

Having a child with a diagnosis of autism, create an atypical interaction between the family members, including on siblings. Impact on siblings has little highlighted in the literature, thus, this study exhibited this effect and its implication may be produced.

To facilitate positive interaction between the siblings, support should be offered for children who have a sibling with a diagnosis. Therapeutic programs, for instance, a therapy group led by professional experts intended to the siblings as a source of reliable information, in order to grant knowledge and awareness about autism and avoiding confusing ideas or any incorrect knowledge. It can be a safe space, where the individual feels relief that everybody in the group is in the same boat, which could allow for emotional sharing and feeling free to ask about anything related to autism, as well as a professional address for getting a consultation related to their experiences. Such groups also may extend to include dyad therapy sessions with parents or siblings, for the purpose of processing interactions between the siblings or the parents individually.

By both increasing their awareness theoretically and practically by supplying them tools and methods, communication between the siblings may be streamlined, enabling the siblings to deal with any challenging situations.

5.5. Future Directions

This study can evolve through a variety of data collection tools to include video tapings of direct interaction between siblings in their home natural environment within diverse contexts, and this is to point out things that perhaps as individuals themselves the siblings are unaware of.

This study can also be among participants with different demographic features, such as the number of children in a family or the busyness of both parents.

This study can also be continued by providing the intervention offered to the siblings and then comparing the contents before and after the intervention to identify therapeutic programs' effectiveness. Additionally, expanding this study can be among siblings from various cultural backgrounds would add richness and depth for sibling experiences.

Reliability and validity study for the Turkish version of the Knowledge of Autism Questionnaire (KAQ) also could be a suggestion for a future study.

As individual's well-being get a focus emphasized by social studies in the last few years, siblings' coping strategies and their quality of life could also maybe another topic for a future study.

6. REFERENCES:

Abrahams, B. S., & Geschwind, D. H. (2008). Advances in autism genetics: on the threshold of a new neurobiology. *Nature Reviews Genetics*, *9*(5), 341–355.

Aguilar, B., Brien, K. M. O., August, G. J., Aoun, S. L., & Hektner, J. M. (2001). *Relationship Quality of Aggressive Children and Their Siblings : A Multiinformant, Multimeasure Investigation*. *29*(6), 479–489.

Akhtar, S. M. D., & Kramer, S. M. D. (1999). *Brothers and Sisters: Developmental, Dynamic, and Technical Aspects of the Sibling Relationship*.

Aksoy, A. B., & Yıldırım, G. B. (2008). Farklı Engel Grubundan Engelli Kardeşe Sahip Çocukların Kardeş İlişkileri İle Kardeşlerini Kabullenmeleri Arasındaki İlişkinin İncelenmesi. *Educational Sciences: Theory & Practice*, *8*(3), 751–779.

Alagözoğlu E. (2016). Otizm Spektrum Bozukluğundan Etkilenmiş Kardeşi Olan Bireylerin Aileleri İle İlgili Duygu Ve Düşünceleri, Yüksek Lisans Tezi, Anadolu Üniversitesi Sosyal Bilimler Enstitüsü, Eskişehir.

Alan, B. (2008). *Social Research Methods*.

Allgood, N. R. (2010). *The Perspective of Young Adult Siblings of Individuals With Asperger Syndrome and High Functioning Autism: An Exploration of Grief and Implications for Developmental Transition*.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders : DSM-5*.

Angell, M. E., Meadan, H., & Stoner, J. B. (2012). Experiences of Siblings of Individuals with Autism Spectrum Disorders. *Autism Research and Treatment*, 1–11.

Arnett, J. J. (2004). Chapter 1: A longer road to adulthood. In *Emerging adulthood: The winding road from the late teens through the twenties*.

Ataca, B. (2009). Turkish family structure and functioning. *Cambridge University Press*, 108–125.

Aycicegi-Dinn, A., & Kagitcibasi, C. (2010). The value of children for parents in the minds of emerging adults. *Cross-Cultural Research*, *44*(2), 174–205.

Aytekin, C. (2016). Siblings of Disabled Children: A General Overview in terms of

Academic Studies. *International Journal of Innovation and Applied Studies*, *16*(3), 522–527.

Bågenholm, A., & Gillberg, C. (1991). Psychosocial effects on siblings of children with autism and mental retardation: a population- based study. *Journal of Intellectual Disability Research*, *35*(4), 291–307.

Baham, M. E. (2009). *Sibling relationship quality and psychosocial outcomes in European- and Mexican-American adolescents: The moderating role of familism*.

Baio, J. (2012). Prevalence of autism spectrum disorders--Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008. *Morbidity and Mortality Weekly Report. Surveillance Summaries*, *61*(3), 1–19.

Bank, S. P., & Kahn, M. (1982). *The Sibling Bond*.

Barak-Levy, Y., Goldstein, E., & Weinstock, M. (2010). Adjustment characteristics of healthy siblings of children with autism. *Journal of Family Studies*, *16*(2), 155–164.

Barden, R. C., Ford, M. E., Jensen, A. G., Rogers-salyer, M., Barden, R. C., Ford, M. E., Jensen, A. G., Rogers-salyer, M., & Salyer, K. E. (1989). Effects of Craniofacial Deformity in Infancy on the Quality of Mother-Infant Interactions. *Society for Research in Child Development*, *60*(4), 819–824.

Baron-Cohen, S., Scott, F. J., Allison, C., Williams, J., Bolton, P., Matthews, F. E., & Brayne, C. (2009). Prevalence of autism-spectrum conditions: UK school-based population study. *British Journal of Psychiatry*, *194*(6), 500–509.

Bass, M. B., & Riggio, E. G. (2006). *Transformational Leadership*.

Bekman, S., & Aksu-Koç, A. (2009). Perspectives on human development, family, and culture. In *Perspectives on Human Development, Family, and Culture*.

Bengtson, V. L., Acock, A. C., Allen, K. R., Dilworth-Anderson, P., & Klein, D. M. (2005). *Sourcebook of Family Theory and Research*.

Bengtson, V. L., Acock, A. C., Allen, K. R., Dilworth-Anderson, P., & Klein, D. M. (2006). *Sourcebook of Family Theory and Research*.

Bhattashali, A., Ostrosky, M. M., & Monda-amaya, L. (2018). Perceptions of typically developing children in India about their siblings with disabilities. *International*

Journal of Inclusive Education, *22*(12), 1257–1271.

Bornstein, M. H., Davidson, L., Keyes, C. L. M., & Moore, K. A. (2003). *Well-Being Positive Development Across the Life Course*.

Bouchey, H. A., & Shoulberg, E. K. (2010). Longitudinal Links between Older Sibling Features and Younger Siblings' Academic Adjustment during Early Adolescence. *Journal of Educational Psychology*, *102*(1), 197–211.

Boyle, K., Sridhar, R., & Scott R. Nodzo. (2018). Centers for Disease Control and Prevention 2017 Guidelines for Prevention of Surgical Site Infections: Review and Relevant Recommendations. *Current Reviews in Musculoskeletal Medicine*, *11*(3), 357–369.

Brody, G. H. (1998). SIBLING RELATIONSHIP QUALITY : Its Causes and Consequences. *Annu. Rev. Psychol.*, *49*, 1–24.

Brody, G. H., Kim, S., Murry, V. M. B., & Brown, A. C. (2003). Longitudinal Direct and Indirect Pathways Linking Older Sibling Competence to the Development of Younger Sibling Competence. *Developmental Psychology*, *39*(3), 618–628.

Bryna, S., & Stuart, S. (2001). *What About Me? Growing Up with a Developmentally Disabled Sibling*.

Buhrmester, D. (1992). *The developmental courses of sibling and peer relationships*.

Cassidy, A., McConkey, R., Truesdale-Kennedy, M., & Slevin, E. (2008). Preschoolers with autism spectrum disorders: The impact on families and the supports available to them. *Early Child Development and Care, 178*(2), 115–128.

Cicirelli, V. G. (1995). *Sibling Relationships Across the Life Span.*

Cicirelli, V. G. (1996). *Sibling relationships in middle and old age*.

Coldwell, J., Pike, A., & Dunn, J. (2008). Maternal differential treatment and child adjustment: A multi-informant approach. *Social Development*, *17*(3), 596–612.

Conger, K. J., & Little, W. (2010). Sibling relationships during the transition to adulthood. *Child Development Perspectives*, *4*(2), 87–94.

Conger, R. D., & Conger, K. J. (2002). Resilience in Midwestern Families, Selected Findings from the First Decade of a Prospective, Longitudinal Study. *Journal of*

Marriage and Family, *64*(2), 361–373.

Connidis, I. A., & Barnett, A. E. (2018). *Family Ties and Aging*.

Corcoran, J., & Walsh, J. M. (2009). *Mental Health in Social Work: A Casebook on Diagnosis and Strengths Based Assessment*.

Damiani, V. B. (2013). Responsibility and Adjustment in Siblings of Children with Disabilities: Update and Review. *Families in Society: The Journal of Contemporary Social Services*, *80*(1), 34–40.

De Andrés-García, S., Moya-Albiol, L., & González-Bono, E. (2012). Salivary cortisol and immunoglobulin A: Responses to stress as predictors of health complaints reported by caregivers of offspring with autistic spectrum disorder. *Hormones and Behavior*, *62*(4), 464–474.

Deater-deckard, K., Dunn, J., & Lussier, G. (2002). Sibling Relationships and Social-emotional Adjustment in Different Family Contexts. *Social Development*, *11*(4), 571–590.

DeHart, G. (1999). *Conflict and averted conflict in preschoolers' interactions with siblings and friends*.

Dellve, L., Cernerud, L., & Hallberg, L. R.-M. (2000). Siblings of Children with DAMP and Asperger Syndrome's Experiences of Coping with Their Life Situations. *Scandinavian Journal of Caring Sciences*, *14*(3), 172–178.

Dervishaliaj, E., & Murati, E. (2014). Families of Children With Developmental Disabilities: Perceptions and Experiences of Adolescent Siblings of Children With Developmental Disabilities. *European Scientific Journal*, *10*(2), 129–142.

Diana T. Slaughter-Defoe. (1995). Revisiting the Concept of Socialization. *American Psychologist*, *50*(4), 276–286.

Dowling, M. (2007). From Husserl to van Manen. A review of different phenomenological approaches. *International Journal of Nursing Studies*, *44*(1), 131–142.

Dunn, J. (1992). *Sisters and brothers: Current issues in developmental research*.

Elsabbagh, M., Divan, G., Koh, Y. J., Kim, Y. S., Kauchali, S., Marcín, C., Montiel-Nava, C., Patel, V., Paula, C. S., Wang, C., Yasamy, M. T., & Fombonne, E. (2012). Global Prevalence of Autism and Other Pervasive Developmental Disorders. *Autism Research, 5*(3), 160–179.

Erdogan, B., & Liden, R. C. (2006). Collectivism as a moderator of responses to organizational justice: Implications for leader-member exchange and ingratiation. *Journal of Organizational Behavior, 27*(1), 1–17.

Ernesto, S. (2005). *The Interpreted world: an Introduction to Phenomenological Psychology*.

Ferraioli, S. J., Hansford, A., & Harris, S. L. (2012). Benefits of Including Siblings in the Treatment of Autism Spectrum Disorders. *Cognitive and Behavioral Practice, 19*(3), 413–422.

Fiedler, C. R., Simpson, R. L., & Clark, D. M. (2006). *Parents and Families of Children with Disabilities: Effective School-Based Support Services*.

Fisman, S., Wolf, L., Ellison, D., Gillis, B., Freeman, T., & Szatmari, P. (1996). Risk and protective factors affecting the adjustment of siblings of children with chronic disabilities. *Journal of the American Academy of Child and Adolescent Psychiatry, 35*(11), 1532–1541.

Gass, K., Jenkins, J., & Dunn, J. (2007). Are sibling relationships protective? A longitudinal study. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 48*(2), 167–175.

Gau, S. S. F., Chou, M. C., Chiang, H. L., Lee, J. C., Wong, C. C., Chou, W. J., & Wu, Y. Y. (2012). Parental adjustment, marital relationship, and family function in families of children with autism. *Research in Autism Spectrum Disorders, 6*(1), 263–270.

Georgas, J., Mylonas, K., Bafiti, T., Poortinga, Y. H., Kagitcibasi, C., Kwak, K., Ataca, B., Berry, J., Orung, S., Sunar, D., Charalambous, N., Wang, W., Angleitner, A., Stepanikova, I., Pick, S., Iv, M. G., Zhuravliova-gionis, I., Konantambigi, R., Gelfand, J. Christakopoulou, S. (2001). Functional relationships in the nuclear and extended family : A 16-culture study. *International Journal of Psychology, 36*(5), 289–300.

Gold, N. (1993). Depression and social adjustment in siblings of boys with autism. *Journal of Autism and Developmental Disorders*, *23*(1), 147–163.

Göregenli, M. (1997). Individualist-collectivist tendencies in a Turkish sample. *Journal of Cross-Cultural Psychology*, *28*(6), 787–794.

Gray, D. E. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual and Developmental Disability*.

Gray1, D. E., & Holden, W. J. (1992). Psychosocial wellbeing among the parents of children with autism. *Australia and New Zealand Journal of Developmental Disabilities*, *18*(2), 83–93.

Greenberg, J. S., Seltzer, M. M., Hong, J., & Orsmond, G. I. (2006). Bidirectional Effects of Expressed Emotion and Behavior Problems and Symptoms in Adolescents and Adults With Autism. *American Journal on Mental Retardation*, *111*(4), 229.

Grissom, M. O. K., & Borkowski, J. G. (2002). Self-efficacy in adolescents who have siblings with or without disabilities. *American Journal on Mental Retardation*, *107*(2), 79–90.

Guzman, N. S. (2009). Graduate School of Education and Psychology A Psychoeducational Group For Siblings Of Children With Autism A clinical dissertation submitted in partial satisfaction of the requirements for the degree of Doctor of Psychology by Joanne Hedgespeth , Ph . D . *Evaluation*, 1–1136.

Hallmayer, J., Cleveland, S., Torres, A., Phillips, J., Cohen, B., Torigoe, T., Miller, J., Fedele, A., Collins, J., Smith, K., Lotspeich, L., Croen, L. A., Ozonoff, S., Lajonchere, C., Grether, J. K., & Risch, N. (2011). Genetic heritability and shared environmental factors among twin pairs with autism. *Archives of General Psychiatry*, *68*(11), 1095–1102.

Harris, S. L., & Glasberg, B. A. (2012). *Siblings of Children With Autism: A Guide for Families*.

Hastings, & Petalas. (2014). Self-reported behaviour problems and sibling relationship quality by siblings of children with autism spectrum disorder. *Child: Care, Health and Development*, *40*(6), 833–839.

Hastings, R. P. (2003). Behavioral adjustment of siblings of children with autism engaged in applied behavior analysis early intervention programs: The moderating role of social support. *Journal of Autism and Developmental Disorders*, *33*(2), 141–150.

Hastings, R. P. (2003). Brief report: Behavioral adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders*, *33*(1), 99–104.

Hastings, R. P. (2007). Longitudinal relationships between sibling behavioral adjustment and behavior problems of children with developmental disabilities. *Journal of Autism and Developmental Disorders*, *37*(8), 1485–1492.

Hastings, R. P., & Brown, T. (2002). Behavior Problems of Children With Autism, Parental Self-Efficacy, and Mental Health. *American Journal on Mental Retardation*, *107*(3), 222–232.

Hays, D. G., & Singh, A. (2012). *Qualitative Inquiry in Clinical and Educational Settings*.

Higgins, D. J., Bailey, S. R., & Pearce, J. C. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism*, *9*(2), 125–137.

Hodapp, R. M., & Urbano, R. C. (2007). Adult siblings of individuals with Down syndrome versus with autism: Findings from a large-scale US survey. *Journal of Intellectual Disability Research*, *51*(12), 1018–1029.

Horton, P. B., & Hunt, C. L. (1980). *Sociology*.

Hoskinson, J. E. (2011). How does having a sibling with autism spectrum conditions impact on adolescents' psychosocial adjustment?

Howard, B., Cohn, E., & Orsmond, G. I. (2006). Understanding and negotiating friendships: Perspectives from an adolescent with Asperger syndrome. *Autism*, *10*(6), 619–627.

Howe, N., Petrakos, H., & Rinaldi, M. C. (1998). " All the sheeps are dead . He murdered them ": Sibling Pretense , Negotiation , Internal State Language , and Relationship Quality. *Child Development*, *69*(I), 182–191.

Hwang, S. K., & Charnley, H. (2010). Making the familiar strange and making the strange familiar: Understanding Korean children's experiences of living with an autistic sibling. *Disability and Society*, *25*(5), 579–592.

Kahraman, Ö. G., & Karadayı, N. S. (2015). Engelli Kardeşe Sahip Olan Çocuklarin Engelli Kardeşleriyle Deneyimlerine İlişkin Görüşleri. *Hacettepe University Faculty of Health Sciences Journal*, *1*(2), 390–408.

Kaminsky, L., & Dewey, D. (2001). Siblings Relationships of Children with Autism. *Journal of Autism and Developmental Disorders*, *31*(4), 399–410.

Kaminsky, L., & Dewey, D. (2002). Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, *43*(2), 225–232.

Kiburz, J. A. (1994). Perceptions and concerns of the school-age siblings of children with myelomeningocele. *Issues in Comprehensive Pediatric Nursing*, *17*(4), 223–231.

Kim, J. Y., McHale, S. M., Crouter, A. C., & Osgood, D. W. (2007). Longitudinal Linkages Between Sibling Relationships and Adjustment From Middle Childhood Through Adolescence. *Developmental Psychology*, *43*(4), 960–973.

Kitzmann, K. M., Cohen, R., & Lockwood, R. L. (2002). Are only children missing out? Comparison of the peer-related social competence of only children and siblings. *Journal of Social and Personal Relationships*, *19*(3), 299–316.

Kızılap, C. (2018). Kardeşi otizmli olan ve olmayan çocukların kardeş ilişkileri, benlik saygıları ve stresle başa çıkma yolları. In *Maltepe Üniversitesi, Sosyal Bilimler Enstitüsü, İstanbul.* (Vol. 1, Issue 1).

Klein, P. S., Feldman, R., & Zarur, S. (2002). Mediation in a Sibling Context : The Relations of Older Siblings ' Mediating Behaviour and Younger Siblings ' Task Performance. *Infant and Child Development*, *11*, 321–333.

Knott, F., Lewis, C., & Williams, T. (1995). Sibling Interaction of Children with Learning Disabilities: A Comparison of Autism and Down's Syndrome. *Journal of Child Psychology and Psychiatry*, *36*(6), 965–976.

Kowal, A., & Kramer, L. (1997). Children's Understanding of Parental Differential Treatment. *Child Development*, *68*(1), 113–126.

Liamputtong, P. (2013). *Qualitative Research Methods*.

Lukie, I. K., Skwarchuk, S. L., LeFevre, J. A., & Sowinski, C. (2014). The Role of Child Interests and Collaborative Parent-Child Interactions in Fostering Numeracy and

Literacy Development in Canadian Homes. *Early Childhood Education Journal, 42*(4), 251–259.

Macks, R. J., & Reeve, R. E. (2007). The adjustment of non-disabled siblings of children with autism. *Journal of Autism and Developmental Disorders, 37*, 1060–1067.

Mascha, K., & Boucher, J. (2006). Preliminary Investigation of a Qualitative Method of Examining Siblings' Experiences of Living with a Child with autism spectrum disorder. *The British Journal of Development Disabilities, 52*(102), 19–28.

Masi, A., DeMayo, M. M., Glozier, N., & Guastella, A. J. (2017). An Overview of Autism Spectrum Disorder, Heterogeneity and Treatment Options. *Neuroscience Bulletin, 33*(2), 183–193.

Mates, T. E. (1990). Siblings of autistic children: Their adjustment and performance at home and in school. *Journal of Autism and Developmental Disorders, 20*(4), 545–553.

Mavropoulou, S., & Sideridis, G. D. (2014). Knowledge of autism and attitudes of children towards their partially integrated peers with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 44*(8), 1867–1885.

McGoldrick, D. (2011). Religion in the European public square and in European public lifeçcrucifixes in the classroom? *Human Rights Law Review, 11*(3), 451–502.

Mcguire, S., & Shanahan, L. (2010). Sibling Experiences in Diverse Family Contexts. *Child Development Perspectives, 4*(2), 72–79.

McHale, S. M., Sloan, J., & Simeonsson, R. J. (1986). Sibling relationships or children with autistic, mentally retarded, and nonhandicapped brothers and sisters. *Journal of Autism and Developmental Disorders, 16*(4), 399–413.

Meadan, H., Stoner, J. B., & Angell, M. E. (2010). Review of literature related to the social, emotional, and behavioral adjustment of siblings of individuals with autism spectrum disorder. *Journal of Developmental and Physical Disabilities, 22*(1), 83–100.

Merrell, S. (1995). *The Accidental Bond: The Power of Sibling Relationships*.

Meyer, K. A., Ingersoll, B., & Hambrick, D. Z. (2011). Factors influencing adjustment in siblings of children with autism spectrum disorders. *Research in Autism Spectrum*

Disorders, *5*(4), 1413–1420.

Michael Crotty. (2012). THE FOUNDATIONS OF SOCIAL RESEARCH. *Doing Sociology of Education (RLE Edu L)*, 1–15.

Moyson, T., & Roeyers, H. (2011). The quality of life of siblings of children with autism spectrum disorder. *Exceptional Children*, *78*(1), 41–55.

Namal, N., Vehit, H., & Koksal, S. (2009). Do autistic children have higher levels of caries? A cross-sectional study in Turkish children. *Journal of Indian Society of Pedodontics and Preventive Dentistry*. *25*(2), 97–102.

Natsuaki, M. N., Ge, X., Reiss, D., & Neiderhiser, J. M. (2009). Aggressive Behavior between Siblings and the Development of Externalizing Problems: Evidence from a Genetically Sensitive Studyss. *Dev Psychol*, *45*(4), 1009–1018.

Noller, P. (2005). Sibling relationships in adolescence: Learning and growing together. *Personal Relationships*, *12*(1), 1–22.

Orsmond, G. I., & Seltzer, M. M. (2007). Siblings of individuals with autism or Down syndrome: Effects on adult lives. *Journal of Intellectual Disability Research*, *51*(9), 682–696.

Peter Schuntermann (2009). Growing up with a developmentally challenged brother or sister: A model for engaging siblings based on mentalizing. *Harvard Review of Psychiatry*. *10*(1), 56–67.

Padilla-Walker, L. M., Harper, J. M., & Jensen, A. C. (2010). Self-regulation as a mediator between sibling relationship quality and early adolescents' positive and negative outcomes. *Journal of Family Psychology*, *24*(4), 419–428.

Perner, J., Ruffman, T., & Leekam, S. R. (1994). Theory of Mind Is Contagious : You Catch It from Your Sibs. *Child Developmen*, *65*(4), 1228–1238.

Petalas, M. A., Hastings, R. P., Nash, S., Dowey, A., & Reilly, D. (2009). "I like that he always shows who he is": The perceptions and experiences of siblings with a brother with autism spectrum disorder. *International Journal of Disability, Development and Education*, *56*(4), 381–399.

Petalas, M. A., Hastings, R. P., Nash, S., Reilly, D., & Dowey, A. (2012). The perceptions and experiences of adolescent siblings who have a brother with autism spectrum disorder. *Journal of Intellectual and Developmental Disability, 37*(4), 303–314.

Pike, A., Coldwell, J., & Dunn, J. F. (2005). Sibling relationships in early/middle childhood: Links with individual adjustment. *Journal of Family Psychology*, *19*(4), 523–532.

Pike, A., Mcguire, S., Reiss, D., Hetherington, E. M., & Plomin, R. (1996). Family Environment and Adolescent Depressive Symptoms and Antisocial Behavior : A Multivariate Genetic Analysis. *American Psychological Association*, *32*(4), 590–603.

Pilowsky, T., Yirmiya, N., Doppelt, O., Gross-Tsur, V., & Shalev, R. S. (2004). Social and emotional adjustment of siblings of children with autism. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, *45*(4), 855–865.

Presmanes Hill, A., Zuckerman, K., & Fombonne, E. (2007). Epidemiology of Autism spectrum disorders. *Translational Approaches to Autism Apectrum Disorder*, *28,* 235–258.

Richmond, M. K., Stocker, C. M., & Rienks, S. L. (2005). Longitudinal Associations Between Sibling Relationship Quality , Parental Differential Treatment , and Children ' s Adjustment. *Journal of Family Psychology*, *19*(4), 550–559.

Riedmann, A., & White, L. (1996). *Adult sibling relationships: Racial and ethnic comparisons*.

Rivers, J. W., & Stoneman, Z. (2003). Sibling relationships when a child has autism: Marital stress and support coping. *Journal of Autism and Developmental Disorders, 33*(4), 383–394.

Roeyers, H., & Mycke, K. (1995). Siblings off a child with autism, with mental retardation and with a normal development. *Child: Care, Health and Development*, *21*(5), 305–319.

Ross, P., & Cuskelly, M. (2006). Adjustment, sibling problems and coping strategies of brothers and sisters of children with autistic spectrum disorder. *Journal of Intellectual and Developmental Disability*, *31*(2), 77–86.

Sage, K. D., & Jegatheesan, B. (2010). Perceptions of siblings with autism and relationships with them: European American and Asian American siblings draw and tell. *Journal of Intellectual and Developmental Disability, 35*(2), 92–103.

Sameroff, A. J. (1990). Neo-environmental perspectives on developmental theory. *Issues in the Developmental Approach to Mental Retardation,* 93–113.

Schall, C. (2000). Family Perspectives on Raising a Child with Autism. *Journal of Child and Family Studies*, *9*(4), 409–423.

Scharf, M., Shulman, S., & Avigad-Spitz, L. (2005). Sibling relationships in emerging adulthood and in adolescence. In *Journal of Adolescent Research*.

Selin, H. (2014). *Parenting Across Cultures: Childrearing, Motherhood and Fatherhood in Non-Western Cultures*.

Seltzer, M. M., Greenberg, J. S., Hong, J., Smith, L. E., Almeida, D. M., Coe, C., & Stawski, R. S. (2010). Maternal cortisol levels and behavior problems in adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. *40*(4), 457–467.

Shira, R. (2000). *Raising a Child with Autism: A Guide to Applied Behavior Analysis for Parents*.

Shivers, C. M., & Plavnick, J. B. (2015). Sibling Involvement in Interventions for Individuals with Autism Spectrum Disorders: A Systematic Review. *Journal of Autism and Developmental Disorders*, *45*(3), 685–696.

Shortt, J. W., & Gottman, J. M. (1997). Closeness in Young Adult Sibling Relationships: Affective and Physiological Processes. *Social Development*, *6*(2), 142–164.

Sicile-Kira, C. (2014a). *Autism Spectrum Disorder: The Complete Guide to Understanding Autism*.

Sicile-Kira, C. (2014b). *Autism Spectrum Disorder (revised): The Complete Guide to Understanding Autism*.

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry*, *47*(8), 921–929.

Sivberg, B. (2002). Family system and coping behaviors: A comparison between parents of children with autistic spectrum disorders and parents with non-autistic children. *Autism*. *6*(4), 397–409.

Smalley, S. L., McCracken, J., & Tanguay, P. (1995). Autism, affective disorders, and social phobia. *American Journal of Medical Genetics - Neuropsychiatric Genetics, 60*(1), 19–26.

Stacker, C. M., & Lanthier, R. P. (1997). Sibling Relationships in Early Adulthood. *Journal of Family Psychology, 11*(2), 210–221.

Stampoltzis, A., Defingou, G., Antonopoulou, K., Kouvava, S., & Polychronopoulou, S. (2014). Psycho-social characteristics of children and adolescents with siblings on the autistic spectrum. *European Journal of Special Needs Education, 29*(4), 474–490.

Stewart, R. B., Kozak, A. L., Tingley, L. M., Goddard, J. M., Blake, E. M., & Cassel, W. A. (2001). Adult sibling relationships: Validation. *Personal Relationships*, *8*(3), 299–324.

Stewart, S. H., & Kushner, M. G. (2001). Introduction to the Special Issue on '" Anxiety Sensitivity and Addictive Behaviors ."' *Addictive Behaviors, 26*(6), 775–785.

Stocker, C. M. (1994). Children's Perceptions of Relationships with Siblings, Friends, and Mothers: Compensatory Processes and Links with Adjustment. *Journal of Child Psychology and Psychiatry, 35*(8), 1447–1459.

Stocker, C. M., Burwell, R. A., & Briggs, M. L. (2002). Sibling Conflict in Middle Childhood Predicts Children ' s Adjustment in Early Adolescence. *Journal of Family Psychology, 16*(1), 50–57.

Stoneman, Z. (2001). Supporting positive sibling relationships during childhood. *Mental Retardation and Developmental Disabilities Research Reviews*, *7*, 134–142.

Stoneman, Z., Brody, G. H., Davis, C. H., Crapps, J. M., & Malone, D. M. (1991). Ascribed role relations between children with mental retardation and their younger siblings. *American Journal on Mental Retardation, 95*(5), 537–550.

Stormshak, E. A., Bellanti, C. J., & Bierman, K. L. (1996). *The Quality of Sibling Relationships and the Development of Social Competence and Behavioral Control in Aggressive Children*. *32*(1), 79–89.

Suggs, P. K. (1989). Predictors of Association Among Older Siblings: A Black/White Comparison. *American Behavioral Scientist*, *33*(1), 70–80.

Sullaway, M., & Dunbar, E. (1996). Clinical manifestations of prejudice in psychotherapy: Toward a strategy of assessment and treatment. *Clinical Psychology: Science and Practice*, *3*(4), 296–309.

Sunar, D., & Fişek, G. O. (2005). CONTEMPORARY TURKISH FAMILIES. *Families in Global Perspective*, 169–183.

Sutton-Smith, B., & Rosenberg, B. G. (1970). *The sibling*.

Clare Connors, Kirsten Stalker (2005). The Views and Experiences of Disabled Children and Their Siblings: A Positive Outlook.. *The Canadian Child and Adolescent Psychiatry Review*, *24*(4), 1–123.

Toman PhD, W. (1992). *Family Constellation: Its Effects on Personality and Social Behavior*.

Tucker, C. J., Mchale, S. M., & Crouter, A. C. (2001). Conditions of Sibling Support in Adolescence. *Journal of Family Psychology*, *15*(2), 254–271.

Tucker, C. J., Updegraff, K. A., McHale, S. M., & Crouter, A. C. (1999). Older siblings as socializers of younger siblings' empathy. *Journal of Early Adolescence*, *19*(2), 176–198.

Tucker, S., Strange, C., Cordeaux, C., Moules, T., Tucker, S., Strange, C., Cordeaux, C., Moules, T., & Tucker, S. (1999). Developing an interdisciplinary framework for the education and training of those working with children and young people. *Journal of Interprofessional Care*, *13*(3), 261–270.

Uskul, A. K., Hynie, M., & Lalonde, R. N. (2004). Article Interdependence As A Mediator Between Culture And Interpersonal Closeness For Euro-Canadians And Turks. *Journal Of Cross-Cultural Psychology*, *35*(2), 174–191.

Verté, S., Roeyers, H., & Buysse, A. (2003). Behavioural problems, social competence and self-concept in siblings of children with autism. *Child: Care, Health and Development*, *29*(3), 193–205.

Vogt Yuan, A. S. (2009). Sibling Relationships and Adolescents' Mental Health. *Journal of Family Issues*, *30*(9), 1221–1244.

Vollmer, T. R., Borrero, J. C., Lalli, J. S., & Daniel, D. (1999). Evaluating self-control and impulsivity in children with severe behavior disorders. *Journal of Applied Behavior Analysis*, *32*(4), 451–466.

Waldman, B., & Adler, K. (1979). Toad tadpoles associate preferentially with siblings. *Nature*, *282*(5739), 611–613.

Waterhouse, L. (2008). Autism overflows: Increasing prevalence and proliferating theories. *Neuropsychology Review*, *18*(4), 273–286.

Wheeler, K. M. (2012). Sibling Group Cohesion : A Definition , Validation , and Power in Predicting Perceived Personal Achievement. *The University of Texas at Austin*, 1–157.

Whiteman, S. D., Mchale, S. M., & Crouter, A. C. (2007). Explaining Sibling Similarities : Perceptions of Sibling Influences. *Journal of Youth and Adolescence*, *36*(7), 963–972.

Whiteman, S. D., Mchale, S. M., Crouter, A. C., & Pennsylvania, T. (2007). *Competing Processes of Sibling Influence : Deidentification*. *16*(4), 642–661.

Whyte, L. (2001). Sibling Relationships Over the Life Course: A Panel Analysis. *Journal of Marriage and Family*, *63*(2), 555–568.

Widmer, E. D., & Weiss, C. C. (2000). Do older siblings make a difference? The effects of older sibling support and older sibling adjustment on the adjustment of socially disadvantaged adolescents. *Journal of Research on Adolescence*, *10*(1).

Woodman, A. C., Mailick, M. R., & Greenberg, J. S. (2016). Trajectories of internalizing and externalizing symptoms among adults with autism spectrum disorders. *Development and Psychopathology*. 28(2): 565–581

Yavuz, M. (2014). Normal Gelişim Gösteren Bireyin Zihinsel Engelli Kardeşiyle Vakit Geçirme Durumu. *Journal of Turkish Studies*, *9*(8), 295–313.

Youngblade, L. M., & Dunn, J. (1995). *Individual Differences in Young Children's Pretend Play with Mother and Sibling : Links to Relationships and Understanding of Other People's Feelings and Beliefs*. *66*(5), 1472–1492.

Yemliha Coşkun, Günbey Akkaş (2009). Engelli Çocuğu Olan Annelerin Sürekli Kaygı Düzeyleri İle Sosyal Destek Algıları Arasındaki İlişki. *10*(1), 213–227.

7. APPENDIX

7.1. Appendix A: Research Study – Parental Consent Form- Turkish Version.

Görüşme İzin Formu

Amaç: Bu çalışmanın amacı, Anadolu Üniversitesi Otizm'de Uygulamalı Davranış Analizi Yüksek Lisans Proğramı, tez çalışması; "*Otizm spektrum bozukluğu tanısı olan kardeşe sahip normal gelişim gösteren çocukların otizme ilişkin bilgi ve deneyimleri*" belirlemektir.

Görüşmeci: Areej Awwad, Anadolu Üniversitesi Sosyal Bilimler Enstitüsü Uygulamalı Davranış Analizi Anabilim Dalı Otizmde Uygulamalı Davranış Analizi Yüksek Lisans Proğramı öğrencisidir.

Süreç: Görüşmelerin 60-90 dakika arasında sürmesi planlanmaktadır; görüşme sırasında istediğiniz anda görüşmeden çekilebilirsiniz.

Görüşme, ses kaydı ile kayıt altına alınacaktır. Görüşme kayıtları araştırma rapor edilecektir. Bu raporda izninize bağlı olarak isminiz geçebilir.

Görüşmeler sırasında isminizin kullanılmamasını tercih ediyorsanız, görüşme sizin belirleyeceğiniz bir rumuz adıyla sunulacaktır.

Bu çalışmada gizlilik esas alınmıştır, alınan ses kayıtları sadece öğrenci ve öğretim üyeleri tarafından dinlenecektir.

Bulgular sunulurken isminiz kullanılmayacak Kardeş 1, 2, 3 gibi kodlanacak ya da rumuz bir isim kullanılacaktır.

Katılım Şartları:

☐ Doğrudan alıntı yapılmayı kabul ediyorum.

☐ İsimsiz olarak alıntı yapılmayı kabul ediyorum.

☐ Yukarıda yazılanları dikkatle okudum ve bu çalışmada gönüllü olarak yer almayı kabul ediyorum.

İsim ve İmza　　　　　　　　　　　　Tarih

7.2. Appendix B: Demographic Form- English

Instructions: To be filled out by the participant's parent.

Form filled out by: ________________________________	**Date:** ______________________________
Contact Information	
City, state:	
Address:	
Phone number:	(________) ________ - ________________ ○ Home ○ Cell ○ Work Belongs to: ___________________________________
Email address:	

Family status	
Number of Children, Gender and Ages	_______Children ______________________________ _______ Male ______________________________ _______ Female ______________________________
How many people live in the household	Is there anyone other than parents and children live in the house? ○ Yes ○No
Parents status	○ Married ○ Separated

	○ Divorced ○ One of the parents has died
Mother	Name: ________________________________ Date of birth: ________ / _________/ ______________ Does the mother has any special health conditions? ○ Yes ○ No If Yes, what kind of condition__________________________ Mother's Education level: ○ Elementary school (Less than 6 th Grade) ○ Junior high school (7th – 9 th Grade) ○ High school (10th -12th Grade) ○ Associate Degree ○ University (BA.) ○ University degree (MA. or PhD.)
Father	Name: ______________________________ Date of birth: ________ / __________/ ______________ Does the father has any special health conditions? ○ Yes ○ No If Yes, what kind of condition__________________________ Father's Education level: ____
Working condition	Does the mother works outside the home? ○ Yes ○ No

	If Yes, what Job ___________________________ ○ Public sector employee ○ An employee in the private sector ○ Freelance work hours: ______________-_______________ Does the father works outside the home? ○ Yes ○No If Yes, what Job ___________________________ ○ Public sector employee ○ An employee in the private sector ○ Freelance work hours: ______________-_______________
Monthly income	○ Less than 2000 TL ○ Between 2001-4000 Tl ○ Between 4001-6000 TL ○ Between 6001-8000 TL ○ More than 8000 TL
Name of Child with Autism Spectrum Disorder: _____________________________________	
Gender	○ Male ○ Female
Birth order	
Date of birth	_________ / ___________/ _______________ Day Month Year
Place of birth	___________________ ___________________ _________________ City State Country

Autism Spectrum Disorder Diagnosis	Specific diagnosis / Level: ______________________________ When: ____ By whom: ____ Does there is any other special health conditions? ○ Yes ○No If Yes, what kind of condition __________________________ Is there any medicine that he/she uses regularly? ___________
Current Educational Framework	

Is the child will be interviewed and the child diagnosed with autism spectrum disorder a biological sibling?

○ Yes ○ No

Sibling, Name: ____	
Gender	○ Male ○ Female
Birth order	
Date of birth	________ / __________/ ______________ Day Month Year
Place of birth	_________________ _________________ _______________ City State Country
Health conditions	Does he/ she has any special health conditions? ○ Yes ○No If Yes, what kind of condition _________________________

	Is there any medicine that he/she uses regularly? ___________
Current Educational Framework **Which grade:**	
	Is he/she involved in any activity outside the education framework? ○ Yes ○ No If Yes, what kind of activity ___________________________ How many times and hours a week ______________________

NOTE:____

_____.

7.3. Appendix C: Demographic Form- Turkish Version. Demografik Bilgi Formu

Talimatlar: Katılımcının ebeveyni tarafından doldurulacak

Formu _______________________________ tarafından doldurdu.	**Tarih: ____________________________**

İLETİŞİM BİLGİLERİ	
Şehir, Bölge:	
Adres:	
Telefon Numarası:	(________) ________ - ________________ ○ Ev ○ Cep Telefonu ○ İş Telefonun Sahibi:___________________________________
Email Adresi:	

AİLENİN KİMLİK BİLGİLERİ	
Ailedeki Çocuk Sayısı, Cinsiyetleri ve Yaşları	___________ _______________________________ Erkek _____ _______________________________ Kız _______ _______________________________ _______________________________
Evde kaç kişi yaşıyor?	

Anne-baba ve çocuklar dışında bir kişi var mı?	○ Evet ○ Hayır ____
Ebeveynlerin durumu	○ Evli ○ Ayrılmış Yaşıyor ○ Boşanmış ○ Ebeveynlerden biri vefat etmiş
Anne	Adı: ____ Doğum tarihi: _________ / __________ / _______________ Annenin özel bir sağlık durumu var mı? ○ Var ○Yok Evet ise, ne tür bir durum __________________________ Annenin Eğitim durumu: ○ İlkokul (6. Sınıftan Az) ○ Ortaokul (7. - 9. Sınıf) ○ Lise (10. -12. Sınıf) ○ Ön Lisans ○ Üniversite ○ Lisansüstü (yüksek lisans ya da doktora)
Baba	Adı: ____ Doğum tarihi: _________ / __________ / _______________ Babanın özel bir sağlık durumu var mı? ○ Var ○Yok Evet ise, ne tür bir durum __________________________

	Babanın Eğitim durumu: ___________________________________
İş Durumu	Anne ev dışında çalışıyor mu? ○ Evet ○ Hayır Evet ise, Mesleği ____________________________ ○ Kamu ○ Özel ○ Kendi İşyeri Çalışma saatleri: _____________-______________ Baba ev dışında çalışıyor mu? ○ Evet ○ Hayır Evet ise, Mesleği ____________________________ ○ Kamu ○ Özel ○ Kendi İşyeri Çalışma saatleri: _____________-______________
Aylık Hane Gelir	○ 2000 TL altı ○ 2001-4000 Tl arası ○ 4001-6000 TL arası ○ 6001-8000 TL arası ○ 8000 ve üstü

OTİZM SPEKTRUM BOZUKLUĞU SAHİBİ OLAN ÇOCUĞUN ADI: ______________	
Cinsiyet	○ Erkek ○ Kız
Kaçıncı Çocuk	
Doğum tarihi	________ / __________/ ______________ Gün Ay Yıl
Doğum yeri	_________________ _________________ _______________ Şehir Bölge Ülke

Otizm Spektrum Bozukluğu Tanı	Belirli tanı/ Düzey: ____________________________________ Ne zaman alındı: ______________________________________ Kim tarafından verildi: _________________________________ Başka özel bir sağlık durumu var mı? ○ Evet ○ Hayır Evet ise, ne tür bir durum _____________________________ Sürekli kullandığı bir ilaç var mı?___________________________
Halihazırdaki eğitim alma durumu:	

Görüşme yapılacak olan çocuğunuz ile otizm spektrum tanısı olan çocuğunuz öz kardeşler mi? ○ Evet ○ Hayır

KARDEŞİ, ADI: ____	
Cinsiyet	○ Erkek ○ Kız
Kaçıncı Çocuk	
Doğum tarihi	________ / __________ / ______________ Gün Ay Yıl
Doğum yeri	________________ ________________ ______________ Şehir Bölge Ülke
Sağlık Durumu	Özel bir sağlık durumu var mı? ○ Evet ○ Hayır Evet ise, ne tür bir durum ____________________________

	Sürekli kullandığı bir ilaç var mı? ____________________
Halihazırdaki eğitim alma durumu: Kaçıncı sınıf:	
	Okul dışında eğitici, sportif ya da kültürel herhangi bir etkinliğe düzenli olarak katılıyor mu? ○ Evet ○ Hayır Evet ise, ne tür bir faaliyet ___________________________ Haftada kaç kere ve kaç saat?_________________________

NOT:____
____.

7.4. Appendix D: Interview Guide- Both English and Turkish Version

Part A: (Questions 1-11) Brotherhood: describing the relationship and the experience of being a sibling to a brother/ sister with autism from the perspective of the sibling.	
1- Can you tell me about yourself	1- Bana kendinden biraz bahseder misin?
2- Can you tell me about your family a little?	2- Bana ailenden biraz bahseder misin?
3- How do you think your brother is different?	3- Kardeşinin nasıl farklılıkları var sence?
4- Describe your relationships with (name of the sibling with autısm spectrum dısorder)?	4- Kardeşin ile aranda nasıl bir ilişki var, bahseder misin?
5- Tell me about some of the things you do with (name of the sibling with autısm spectrum dısorder).	5- (Otizmli kardeşin adı) ile birlikte yaptığınız bazı şeylerden bahseder misin?
6- If you had to measure how much you like being a sibling to (name of the sibling with autısm spectrum dısorder), with 0 meaning that you don't really like it at all and 10 meaning that you really like it, what number would you pick? Why?	6- Eğer bir kardeş olmaktan ne kadar hoşlandığını ölçmek zorunda olsaydın (Otizmli kardeş adı), 0 ile hiç hoşlanmadığını ve 10 gerçekten hoşlandığını belirtirseniz, hangi sayıyı seçersin? Neden?
7- What is the best part of being a sibling to (name of the sibling with autısm spectrum dısorder)?	7- (Otizmli kardeş adı) ile kardeş olmanın en iyi yönü nedir?
8- What is the hardest part of being a sibling to (name of the sibling with autısm spectrum dısorder)?	8- (Otizmli kardeş adı) ile kardeş olmanın en zor yönü nedir?
9- Other siblings of people with autısm spectrum dısorder have described feeling other emotions such as anger, love, embarrassment. Have you felt these	9- Araştırmalar otizmli kardeşi olan çoğu çocuğun farklı duygular (öfke, sevgi, utanç ve diğer duygular) hissestiğini göstermektedir. Sen de bu veya buna

emotions or others toward your sibling? If so, please describe it.	benzer duyguları hissettin mi? Eğer öyleyse, lütfen biraz benimle paylaşır mısın?
10- Have you other siblings without a disability? • If yes: Was there a difference between your sibling in how you interact with the disabled sibling? • If no: How do you think your life would have been different if your sibling was not diagnosed with autism?	10- Özel gereksinimli olmayan başka kardeşin/kardeşlerin var mı? • Varsa eğer: (Otizmli kardeşin adı) ile aranızdaki ilişkinin diğer kardeşinle olan ilişkinden farkı var mı, varsa nasıl bir fark var? • Hayır ise: Kardeşine otizm teşhisi konulmamış olsaydı hayatın nasıl farklı olacağını düşünüyorsun?
11- If you could wave a magic wand, is there anything you would change about how things are between you and ___?	11- Eğer sihirli bir değnek olsaydı, ___ ile arandaki ilişkide neyi değiştirmek istersin?
12- How did most people respond to your brother/sister?	12- İnsanlar kardeşine nasıl bir tepki veriyor?
Part B: (questions 12-16) General information about autism (knowledge of siblings).	
13- Have you ever heard of the word “Autism” before? tell me about it.	13- Daha önce “Otizm” kelimesini duydun mu? Anlat bana.
14- How would you explain Autism to someone who had never heard it before?	14- “Otizm” daha önce hiç duymamış birine nasıl açıklarsın?
15- How do you think people get Autism?	15- Sence insanlar neden otizmli olur?
16- Do you think that autism is something that you can get rid of?	16- Otizmin geçebilecek bir şey olduğunu düşünüyor musun?
17- What do you think (name of the sibling with autısm spectrum dısorder) will do when he/she grows up?	17- Büyüdüğünde kardeşine (autısm spectrum dısorder'li kardeşin adı) ne olacağını düşünüyorsun?
Part C: (Questions 17-19) Siblings' needs and suggestions.	

18- How do you deal with any difficult situation or trouble you experience (this trouble does not have to be with your brother)? What helps you handle it.	18- Yaşadığın herhangi bir sıkıntı (bu sıkıntı kardeşinle olmak zorunda değil) veya zorluk karşısında nasıl davranıyorsun?
19- What advice would you give to other kids who have a brother or sister like (name of the sibling with autısm spectrum dısorder)?	19- Otizmli kardeşi olan diğer çocuklara ne tavsiye edersin?
20- If there is a course for siblings of children wıth autism, intended to knowledge, sharing, and getting a consultation. Would you like to attend?	20- Otistik çocukların kardeşleri için bilgi, paylaşım ve danışma amaçlı bir kurs varsa. Katılmak ister misiniz?

7.5. Appendix E: Knowledge of Autism/Asperger Syndrome (Autism) Ross & Cuskelly (2006)

1. More girls have autism than boys	T	F
2. Many children with autism get upset if there are changes to routines at home or school (e.g. usually on Tuesday's they go swimming, but one day they can't)	T	F
3. All children with autism deliberately hurt themselves	T	F
4. All children with autism will become adults who have a job and live on their own (i.e. be independent)	T	F
5. Autism is more common in families who have a history of the disorder (e.g. more likely to have autism if grandparents have autism)	T	F
6. Not many people have autism in the world – it is quite rare	T	F
7. Most children with autism do very well at school	T	F
8. Children with autism don't seem to know how other people are feeling (e.g. they can't tell when you are feeling angry or sad)	T	F
9. You can “catch” autism from children who have it – it's a disease like chickenpox	T	F
10. Many children with autism have problems looking at you in the eye when you are talking to them	T	F
11. All children with autism will eventually “grow out” of the disorder and no longer be with autism as adults	T	F

12. Some children with autism sometimes get upset by different noises or when they are touched by people	T	F
13. All children with autism can talk well	T	F
14. Most children with autism prefer to play on their own	T	F
15. Some children with autism move their body in unusual ways – e.g. flap their hands	T	F
16. Many children with autism spend lots and lots of time on specific activities or things that interest them (e.g. Tom spends hours and hours playing with his train set)	T	F
17. Many children with autism don't make friends	T	F
18. Some children with autism repeat words or phrases that they have heard over and over again	T	F
19. Children with autism usually enjoy playing games with other children	T	F
20. All children with autism are good at making friends	T	F
21. All children with autism generally like to share their interests or enjoyment in activities with other people	T	F

7.6. Appendix F: Knowledge of Autism- Ross & Cuskelly (2006) Otizm Spektrum Bozukluğu Bilgi ve Anlama Soru Formu

Bu anket otizm hakkındaki bilgi seviyenizi test etmeyi amaçlamaktadır. Her cümleyi okuduktan sonra, doğru ise (D)'yi ya da yanlış ise (Y)'yi işaretle

1.	Otizm kızlarda erkeklerden daha fazladır.	D	Y	Bilmem
2.	Evde veya okuldaki rutinlerde değişiklikler yapıldığında, pekçok otizmli çocuk öfkelenir (örneğin, her hafta salı günleri yüzen bir çocuk, bir hafta o gün yüzmeye gidemediğinde sinirlenir).	D	Y	
3.	Otizmi olan tüm çocuklar kasıtlı olarak (bilerek) kendilerine zarar verirler.	D	Y	
4.	Otizmi olan tüm çocuklar, yetişkin olduklarında iş sahibi olurlar ve ve kendi başlarına yaşarlar (örneğin bağısmız olurlar).	D	Y	
5.	Otizm bozukluğu geçmişi olan ailelerde otizm daha yaygındır (örneğin, eğer büyükanne ve büyükbabada otizm var ise, ailede otizmli insanlara sahip olma olasılığı daha yüksektir.	D	Y	
6.	Dünyada otizmi olan çok sayıda insan yoktur. - Otizm çok nadir görülür	D	Y	
7.	Otizmi olan çocukların çoğu okulda oldukça başarılıdır.	D	Y	
8.	Otizmi olan çocuklar diğer insanların nasıl hissettiğini bilmiyor gibi görünürler (örneğin, ne zaman kızgın veya üzgün hissettiğinizi söyleyemezler)	D	Y	
9.	Otizmli olan çocuklardan, otizm "bulaşabilir" - su çiçeği hastalığı gibi bulaşıcı bir hastalıktır.	D	Y	

10.	Otizmi olan çocuklar, onlarla konuşurken gözünüze bakmakta sorun yaşarlar.	D	Y	
11.	Tüm otizmi olan çocuklar sonunda "büyür" ve hastalıktan kurtulur, yetişkin olunca otizmli olma durumları biter son bulur.	D	Y	
12.	Otizmi olan bazı çocuklar bazen farklı sesler duyunca ya da insanlar onlara dokunduklarında sinirlenirler.	D	Y	
13.	Otizmi olan tüm çocuklar iyi konuşabilir.	D	Y	
14.	Otizmi olan çocukların çoğu kendi başlarına (yalnız) oyun oynamayı tercih eder.	D	Y	
15.	Otizmli bazı çocuklar vücutlarını alışılmadık (farklı) şekillerde hareket ettirirler (örneğin, ellerini hızlı bir şekilde çırparak alkışlamak)	D	Y	
16.	Otizmi olan birçok çocuk belirli aktiviteler veya onları ilgilendiren şeyler için çok fazla zaman harcar (örneğin Ahmet, tren setiyle saatlerce ve saatlerce zaman geçirir)	D	Y	
17.	Otizmi olan birçok çocuk arkadaş edinmez.	D	Y	
18.	Otizmi olan bazı çocuklar duydukları sözcükleri veya ifadeleri tekrar ederler.	D	Y	
19.	Otizmi olan çocuklar genellikle diğer çocuklarla oyun oynamayı sever.	D	Y	
20.	Otizmi olan tüm çocuklar arkadaş edinmede iyidir.	D	Y	
21.	Otizmi olan tüm çocuklar genellikle ilgi alanlarını veya eğlenceli buldukları etkinlikleri diğer insanlarla paylaşmaktan hoşlanırlar.	D	Y	