EXPERIENCES OF MOTHERS WITH AUTISTIC CHILDREN DURING THE DIAGNOSIS PROCESS OF THEIR CHILD

A THESIS SUBMITTED TO
THE GRADUATE SCHOOL OF SOCIAL SCIENCES
OF
MIDDLE EAST TECHNICAL UNIVERSITY

BY

SEZGİ KURŞUN ÇAKIR

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR
THE DEGREE OF MASTER OF SCIENCE
IN
THE DEPARTMENT OF PSYCHOLOGY

DECEMBER 2023

Approval of the thesis:

EXPERIENCES OF MOTHERS WITH AUTISTIC CHILDREN DURING THE DIAGNOSIS PROCESS OF THEIR CHILD

submitted by **SEZGI KURŞUN ÇAKIR** in partial fulfillment of the requirements for the degree of **Master of Science in Psychology, the Graduate School of Social Sciences of Middle East Technical University** by,

Prof. Dr. Sadettin KİRAZCI
Dean
Graduate School of Social Sciences

Prof. Dr. Mine MISIRLISOY BIYIKOĞLU
Head of Department
Department of Psychology

Prof. Dr. Tülin GENÇÖZ
Supervisor
Department of Psychology

Dr. Derya ÖZBEK ŞİMŞEK
Co-Supervisor
Nevşehir Hacı Bektaş Veli Üniversitesi
Department of Psychology

Examining Committee Members:

Assoc. Prof. Dr. Bahar ÖZ (Head of the Examining Committee)
Middle East Technical University
Department of Psychology

Prof. Dr. Tülin GENÇÖZ (Supervisor)
Middle East Technical University
Department of Psychology

Assist. Prof. Dr. Ayşen MARAŞ
Muğla Sıtkı Koçman University
Department of Psychology

I hereby declare that all information in this document has been obtained and presented in accordance with academic rules and ethical conduct. I also declare that, as required by these rules and conduct, I have fully cited and referenced all material and results that are not original to this work.

Name, Last Name: Sezgi KURŞUN ÇAKIR

Signature:

ABSTRACT

EXPERIENCES OF MOTHERS WITH AUTISTIC CHILDREN DURING THE DIAGNOSIS PROCESS OF THEIR CHILD

KURŞUN ÇAKIR, Sezgi
M.S., The Department of Psychology
Supervisor: Prof. Dr. Tülin GENÇÖZ
Co-supervisor: Dr. Derya ÖZBEK ŞİMŞEK

December 2023, 123 pages

Today, the prevalence of autism continues to rise worldwide, with an increasing trend over the years. Early recognition of autism, early intervention, and adherence to educational programs are of paramount importance. Particularly, the observations of mothers, who are often the first to notice the signs and serve as primary caregivers, play a significant role in the diagnostic process. This thesis aims to explore the experiences of mothers with children on the autism spectrum during the diagnosis of their children. The study seeks to expand our understanding of these mothers' experiences throughout the diagnostic journey. The primary focus of the diagnosis process is to comprehend the mother-child interaction and gain insights into the mother's perspective. To capture the unique experiences of these mothers, a qualitative research strategy was conducted. Purposive sampling consisted of five mothers with autistic children. Semi-structured interviews were conducted with each of the participants and the interviews were analyzed through Interpretative Phenomenological Analysis. The analysis revealed four themes: 'when there is no communication: challenges in mother-child communication in the pre-diagnostic period', 'delays in the process of diagnosis', 'what happened during the diagnosis process’ and ‘acceptance after diagnosis’. The study's findings were discussed within the context of relevant literature, and implications for clinical interventions were drawn accordingly.

Keywords: Autism, Mother, Interpretative Phenomenological Analysis, Diagnosis, Experience

ÖZ

OTİZMLİ ÇOCUĞU OLAN ANNELERİN ÇOCUKLARINA TANI KONMA SÜREÇLERİNDEKİ DENEYİMLERİ

ÇAKIR KURŞUN, Sezgi
Yüksek Lisans, Psikoloji Bölümü
Tez Yöneticisi: Prof. Dr. Tülin GENÇÖZ
Ortak Tez Yöneticisi: Dr. Derya ÖZBEK ŞİMŞEK

Aralık 2023, 123 sayfa

Günümüzde otizmin görülme sıklığı hem dünyada hem ülkemizde yıllar geçtikçe artmaktadır. Otizmde erken tanı almak, erken müdahale, eğitim programlarını takip etmek açısından oldukça önemlidir. Tanıyı ilk fark edenlerden, temel bakım veren kişi annelerin gözlemleri önemli bir yere sahiptir. Bu tezin amacı, otizmli çocuğu olan annelerin çocuklarına tanı konma sürecindeki deneyimlerini incelemektir. Çalışmada, bu süreçte annelerin deneyimlerini derinlemesine anlamak amaçlanmıştır. Tanı alma sürecinde anne-çocuk etkileşiminin, annenin neler yaşadığının annenin bakış açısından anlaşılması hedeflenmiştir. Annelerin biricik deneyimlerini anlamak amacı ile nitel bir araştırma metodolojisi tercih edilmiştir. Amaca yönelik oluşturulan örneklem sonucunda beş otizmli çocuğu olan anne çalışmaya katılmıştır. Bu katılımcıların her biri ile yarı yapılandırılmış görüşmeler gerçekleştirilmiş ve görüşmeler Yorumlayıcı Fenomenolojik Analiz yöntemi ile analiz edilmiştir. Analiz sonucunda, 'iletişim eksikliği: tanı öncesi dönemde anne-çocuk iletişiminde yaşanan zorluklar', 'tanıda gecikme', 'tanı sürecinde yaşananlar' ve 'tanı sonrası kabullenme' olmak üzere dört tema tespit edilmiştir. Çalışmanın bulguları, ilgili alanyazın çerçevesinde tartışılmış ve bu doğrultuda klinik müdahaleye ilişkin çıkarımlar belirtilmiştir.

Anahtar Kelimeler: Otizm, Annelik, Yorumlayıcı Fenemenolojik Analiz, Tanı, Deneyim

To looked after children…

ACKNOWLEDGMENTS

I would like to express my gratitude to my thesis advisor, Prof. Dr. Tülin GENÇÖZ, for her unwavering support and guidance. I am thankful for the invaluable knowledge she imparted during my master's program in Lacanian Psychoanalysis. I appreciate her patience and understanding during the thesis writing process.

I extend my heartfelt thanks to my co-supervisor, Dr. Derya ÖZBEK ŞİMŞEK, for her valuable contributions and continuous support. Her detailed reviews, comments, and feedback significantly contributed to the framing and development of this thesis.

I am grateful to the esteemed members of the committee, Assist. Prof. Dr. Ayşen MARAŞ and Assoc. Prof. Dr. Bahar ÖZ, for their guidance, comments, and insightful suggestions that motivated and guided me throughout the thesis journey.

My sincere appreciation goes to my dear friends, Sevinç ŞEN and Ayça TEZERİŞİR, for their unwavering support and intellectual contributions. I also want to acknowledge Merve ÖZGER ARSLAN and Edacan KANTEKİN for their endless motivation and valuable contributions to our theoretical discussions. Both our theoretical discussions and their encouragement have been immensely valuable. I couldn't have envisioned completing this process without them.

I owe a debt of gratitude to my beloved family for their unwavering support. To my mother and father, thank you for your efforts to understand the challenges I faced. I appreciate my sister, Sıla KURŞUN, for her patient listening and encouragement of open-mindedness. My husband, Kıvanç, deserves special thanks for creating an environment conducive to my work and for his constant encouragement. His unwavering support during my moments of doubt and struggle has been indispensable. I am also grateful to our family friends, Piraye and Zarife, for their warmth and affection.

I would like to express my gratitude to all the children at my workplace for sharing their world with me. I have learned invaluable lessons from them, especially in

understanding their unique needs and characters. My thanks go to Feyza TOKAT at my workplace for her friendship, support, and willingness to share her knowledge on relevant subjects.

I extend my appreciation to my dear friend, Elçin AKÇA, for her unwavering support throughout this journey. She has been a patient and empathetic listener, always willing to lend an understanding ear during various emotional experiences.

Finally, I would like to thank all the participants in this study. Their openness, sincerity, and willingness to share their challenging experiences made this research possible. I am deeply grateful for their contribution to this work.

TABLE OF CONTENTS

CHAPTERS

LIST OF TABLES

CHAPTER 1

INTRODUCTION

1.1. The Short History of Autism

The term "autism" was initially introduced by Swiss psychiatrist Eugen Bleuler. He derived it from the Greek word "autos" meaning "self" to describe the introverted behaviors observed in schizophrenia patients (Parks, 2009). He observed that patients isolated themselves from the outside world and lacked interaction with their environment. Therefore, he defined autism as a state of pathological self-absorption and withdrawal (Houston & Frith, 2000). Leo Kanner borrowed the word "autism" from Bleuler, emphasizing the similarities between individuals with autism and patients with schizophrenia. He observed that both disorders exhibited negative symptoms like social withdrawal. Both conditions were characterized by reduced motivation for social interaction, flattened emotional expression, and deficits in social and emotional reciprocity (Woodbury-Smith et al., 2010). However, Kanner also pointed out a crucial distinction: individuals diagnosed with autism did not experience a typical developmental period before symptoms first appeared. This differentiation sets them apart from patients with schizophrenia (Gallo, 2010).

Kanner detailed the traits of 11 children in his article titled “Autistic Affective Contact Disorder." He noticed unique characteristics in these children that distinguished them from individuals with schizophrenia. These children showed social isolation, echolalia, obsession, and impressive memory abilities. Kanner also highlighted their tendency for "insistence on sameness." It refers to their strong attachment to routines, and any disruption to their routines can lead to anger and overreaction. Furthermore, he noted that these children either do not speak, or if they do, it is often not purposeful or appropriate. He referred to the challenges he observed in children as "autistic disturbances"(Kanner, 1943). Although Kanner initially suggested that autism is different from schizophrenia, autism was soon defined as childhood psychosis and widely accepted as a type of psychosis. The tendency to consider severe childhood psychiatric disorder as the same as adult schizophrenia later made it difficult to recognize autism as a separate diagnostic category. It was not considered a separate diagnosis from schizophrenia until the 1970s (Ozonoff et al., 2003).

During Kanner's research, Austrian psychiatrist Hans Asperger published an article on autism in 1944 without knowledge of Kanner's studies. Asperger's research involved studying four young boys with average intelligence and language skills. These children exhibited various traits, such as limited empathy, restricted interests, difficulties in social interaction and communication, and deficits in motor skills. Asperger highlighted that they experienced severe social isolation and struggled to participate in social groups, and their lives, along with their families, were centered around uncommon and sometimes obscure specialized interests (Asperger, 1991). In contrast to Kanner's autism definition, Asperger stressed their good verbal skills (Volkmar & McPartland, 2014). Additionally, he noted that these children had normal or high intelligence yet struggled with social skills. Although they spoke well, they tended to engage in monologues on specific subjects, faced learning difficulties, displayed weak intonation while speaking, used minimal body language, and possessed exceptional nonverbal communication skills. He referred to these children as "little professors" because of their superior intelligence. The symptoms exhibited were milder than those typically associated with autism, leading to its definition as a less severe form known as Asperger's syndrome (Parks, 2009). Asperger's article, written in German, went unnoticed by English-speaking psychiatrists. After its translation into English in 1991, years following Asperger's original work, the traits he described became diagnostic criteria for autism. Later, Asperger Syndrome was recognized in the international diagnostic systems, namely DSM-IV and ICD-10 (Volkmar & McPartland, 2014).

Following these initial studies, during the 1950s and 1960s, research aimed to uncover the underlying causes of autism. During this time, a prevailing perspective suggested a connection between autism and mothers who were rigid, unresponsive, punitive, perfectionist, and mechanical in their parenting approach. Viennese psychoanalyst Bruno Bettelheim (1967) further supported this notion. He famously used the term "refrigerator mother" to claim that a child's autistic traits were solely attributable to the behavior of their "pathological" mothers. However, by the 1970s, the psychological paradigm had lost its prominence, giving way to a focus on neurological factors as potential causes of autism. In addition, scientific methods have been applied to families with children with autism, and psychodynamic treatments such as ego enhancement and play therapy have been recommended. Then, Kolvin in 1971 and Rutter in 1972 argued that autism differed from schizophrenia and demonstrated this in their research (Volkmar & McPartland, 2014). With the contribution of these studies, a growing consensus emerged in the late 1970s on the importance of investigating autism as a separate diagnosis from schizophrenia (Ozonoff et al., 2003). Consequently, while autism was defined as childhood schizophrenia in the DSM-I (American Psychiatric Association (APA), 1952) and DSM-II (1968) in the international diagnostic system, it became a separate psychiatric diagnosis category in the DSM-III for the first time. It has been named "infantile autism" and classified under the category "pervasive developmental disorder" (APA, 1980).

Later, in the revised edition of the DSM-III (1987), autism was redefined as "autistic disorder." The change in the name of the disorder from "childhood autism" to "autistic disorder" indicates a shift towards a developmental approach. This means that the diagnosis and study of autism now encompass individuals who are not only in the early stages of childhood but also those in later stages of development (Volkmar et al., 1988). In other words, it recognizes that autism is not limited to childhood but can persist and be diagnosed in individuals as they grow older. This shift acknowledges the lifelong nature of autism and the importance of understanding its development across the lifespan (Volkmar et al., 1988).

The diagnostic criteria were further refined, requiring individuals to meet at least 8 out of the 16 specified criteria related to social interaction, communication, and limited interests or activities to be diagnosed as autistic. The requirement for autism to manifest in early childhood was removed, and a new category called Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) was introduced to accommodate individuals with similar needs but who did not meet the specific criteria for autism (Verhoeff, 2013). In DSM-IV (1994) and its revised edition, DSM-IV-R (2000), the diagnostic criteria for autistic disorder were expanded to include subtypes such as Asperger's Syndrome, autism, childhood disintegrative disorder, Rett's disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS) within the broader classification of Pervasive Developmental Disorders (Feinstein, 2010).

Today, autism has been revised as an autism spectrum disorder (ASD) with the release of DSM-5 (2013) and its updated edition DSM-5-TR (2022). This classification encompasses two main categories: consistent impairments in social communication and interaction and patterns of behavior characterized by repetition and restriction (APA, 2022). It includes impairments in social communication and interaction, deficiencies in social-emotional reciprocity, challenges in using nonverbal communication cues, and difficulties in establishing and maintaining relationships (APA, 2022). Furthermore, at least two of the following restricted and repetitive behavior patterns are involved in difficulties: stereotyped or repetitive motor movements, insistence on sameness or resistance to change, ritualistic verbal or nonverbal behaviors, and highly restricted, fixated interests or abnormal intensity and focus on specific objects or sensory aspects. In DSM-5-TR, it is accepted that these symptoms should emerge in the early developmental stages and continue throughout life (APA, 2022). Although the symptoms express their general characteristics, each autistic individual displays unique traits. Autism also has varying levels of severity. This is why autism is defined as a spectrum at present (Parks, 2009).

1.2. Developmental Features of Autism

Individuals with autism experience difficulties in social interaction and communication and repetitive, stereotypical behaviors. In the social domain, they often exhibit a lack of concern for the physical presence, desires, and needs of others, as well as a lack of empathy. When others attempt to communicate with them, they might appear unresponsive and fail to react (Bowler, 2007). They usually prefer to be alone. For instance, they only accompany a few activities their peers and family members do together, such as eating and playing games. When they play games with friends, they are unable to engage in social and symbolic games (Tohum Otizm Vakfı, 2017). Moreover, they face difficulties establishing and maintaining relationships and engaging in emotional reciprocity (Hart, 1993). When they communicate with others, they do not make eye contact and cannot maintain joint attention. They have difficulty understanding the feelings of others (Birtwell et al., 2016).

The challenges in social communication are strongly associated with their difficulties in social interaction. For instance, they may use language for instrumental purposes rather than engaging in social communication. Their conversations, therefore, tend to be one-sided, lacking the mutual characteristic of dialogue (Boucher, 2003). Moreover, their language use may involve repetitive phrases and self-centered speech patterns. Additionally, they encounter challenges in comprehending linguistic tools such as metaphors and struggle to interpret nonverbal cues like gestures and facial expressions, which are essential for effective social communication (Boucher, 2003).

In terms of behavior, autistic individuals commonly exhibit repetitive routines and atypical sensory-motor behaviors. They often adhere to specific routines and can be sensitive to disruptions in their environment (Lord et al., 2018). They may exhibit ritualistic behaviors and may want to perform their actions in a specific sequence. It's common for them to become fixated on particular objects, investing substantial time in interacting with them (Parks, 2009). They may overreact to changes in their rituals and routines, displaying a high level of intolerance towards altered situations. Moreover, they have aggressive and angry behavior, which can sometimes include self-harming situations (Birtwell et al., 2016).

1.3. Prevalence

According to a report by the Centers for Disease Control and Prevention (CDC) in the United States, the prevalence of autism spectrum disorder (ASD) is estimated to be approximately 1 in 54 children, based on their latest data from 2020. These estimates are derived from the CDC's Autism and Developmental Disability Monitoring (ADDM) Network, which monitors ASD prevalence in various communities across the country (Maenner et al., 2023).

In a more recent update from 2023, the CDC reported that the 2020 data indicates a higher prevalence of ASD, with approximately 1 in 36 children in the United States being diagnosed with the disorder. Among 8-year-olds, the estimated prevalence of ASD is approximately 4% in boys and 1% in girls. These new estimates are higher than the previous ones reported by the ADDM Network between 2000 and 2018 (Maenner et al., 2023).

A study conducted in 2022 by Zeidan and colleagues analyzed global research on the prevalence of autism. They found that the ASD diagnosis rate was about 1 in 100 children worldwide. However, prevalence estimates have shown that autism rates have increased over time and varied between different groups. These differences may result from changes in how autism is defined and the methods used in prevalence studies.

The prevalence of autism in Turkey is also increasing steadily, similar to global trends. According to the summary of the Parliamentary Research Commission Report provided by Tohum Otizm Vakfı, the reported rates were 1 in 150 in 2006, 1 in 88 in 2008, 1 in 68 in 2012, and 1 in 45 in 2014. The report includes data from the Ministry of Health, Ministry of Family and Social Services, Social Security Institution, and TUIK. The Ministry of Health announced that there were 38,661 individuals with ASD based on the data codes in the health information systems in 2019. According to the Social Security Institution's 2018 data, there are 34,589 individuals with autism in Turkey. The Ministry of Family and Social Services refers to the results of the 2011 TUIK Population and Housing Survey. This survey's results show that about 6.9% (4,876,000 people) of the population aged three and above have at least one disability. The rate is 5.9% for men and 7.9% for women. As of 2020, it's estimated that around 550,000 people in the country have been diagnosed with an autism spectrum disorder (Tohum Otizm Vakfı, 2020).

1.4. Diagnosis of Autism Spectrum Disorder

Diagnosing autism does not involve a medical test. Gathering information from adults who are familiar with the individual's developmental history is a crucial part of making an accurate diagnosis (Volkmar & McPartland, 2014). Autism symptoms typically emerge in childhood. It is often diagnosed around the age of 3 years. Early signs of autism include not responding to their name and having difficulty making eye contact

(Sauer, 2021). For the diagnosis of autism, two main classification manuals are used in the field of psychiatry: the DSM (Diagnostic and Statistical Manual of Mental Disorders) and the ICD (International Classification of Diseases). The 11th version of the ICD was prepared by the World Health Organization (WHO) in 2018, while the 5th version of the DSM was prepared by the APA in 2013. While the DSM is primarily used in scientific research, the ICD is used to improve clinical diagnoses and is employed in the healthcare domain to address diseases. Both are manuals that meet international standards and are used by clinicians for the diagnosis of autism (Sampogna et al., 2020). Moreover, clinicians use various scales to facilitate the diagnosis of autism. These include The Autism Diagnostic Interview-Revised (ADI-R), the Diagnostic Interview for Social and Communication Disorders (DISCO), the Autism Diagnostic Observation Scale (ADOS), and the Childhood Autism Rating Scale (CARS). Additionally, depending on the clinical situation, tests such as metabolic tests, electroencephalogram (EEG), and magnetic resonance (MR) tests may also be required (Susuz & Doğan, 2020).

Also, the diagnosis of autism requires collaborative efforts from a multidisciplinary team, which typically includes pediatricians, psychiatrists, neurologists, psychologists, and speech-language therapists. These experts collectively contribute their specialized knowledge and skills to assessing and diagnosing individuals with autism; parental observations and teacher observations at school are also important for diagnosis (Lord et al., 2006). The diagnostic and assessment process of ASD involves various procedures, such as conducting interviews with parents or caregivers, reviewing relevant medical, psychological, and educational records, performing cognitive and developmental evaluations, observing direct play interactions, evaluating adaptive functioning, and conducting a comprehensive medical examination (Kılınç et al., 2019). It is crucially important to make an early-yet-accurate diagnosis, as the importance of early intervention and early education programs have been and currently are being discussed all over the world. The aim of these is to increase the functionality of the autistic individual and ensure they are compatible with their environment, siblings, and friends (Sivberg, 2003). In addition to the diagnosis of autism, it should be noted that approximately 70% of individuals with ASD have at least one accompanying disorder. Furthermore, about 40% of individuals with ASD have two or more comorbid diagnoses. Comorbidities commonly found in people with ASD include intellectual disability, attention deficit hyperactivity disorder (ADHD), major depressive disorder, obsessive-compulsive disorder (OCD), bipolar disorder, phobias, anxiety disorders, psychosis, and epilepsy (Kim et al., 2023).

The situation regarding the diagnosis of autism in Turkey is as follows: The diagnosis of ASD is made by child psychiatrists together with clinical evaluations, neurological tests, and test results from other medical departments such as otolaryngology, psychology, and genetics. Moreover, families primarily request a visit to a child psychiatrist, and if there are accompanying problems, then to a child neurologist. When the families first apply for a visit to a pediatric neurology specialist, the pediatric neurologists refer patients with suspected ASD to a child psychiatrist for diagnosis after they have undergone the necessary tests. In addition, to benefit from the special education services provided by the state in Turkey, the diagnosis should be made and reported (Yiğitoğlu & Odluyurt, 2021). Diagnostic applications can display significant differences from institution to institution; the most important limitation in this field is that the number of medical specialists with knowledge and experience in autism is very limited (Tohum Otizm Vakfı, 2017).

1.5. Theoretical Explanations About Autism

Considering human psychology, establishing simple cause-and-effect relationships appears to be challenging (Moore, 2001). Despite advances in autism research, the signs and symptoms of autism remain puzzling (Frith & Hill, 2004). Whereas the exact cause of autism is still unknown, various explanations for its origins have been proposed (Chen et al., 2021).

1.5.1. Genetic, Epigenetic, and Neurological Explanation

Genetic causes related to ASD can be categorized into three groups: chromosomal anomalies detectable through cytogenetic (the study of chromosomes, carriers of genetic material within the cell nucleus) investigations (%5), copy number variations (CNVs) within the genome (%10-20), and genetic syndromes resulting from single gene mutations that encompass clinical features of autism spectrum disorder (%5), as identified through cytogenetic examinations. In most genetic studies, a focus on the 2nd, 7th, and 17th chromosome regions has been observed in relation to autism spectrum disorder (Çolak, 2016). Numerous genes have been associated with ASD through research into chromosomal abnormalities, CNVs, and individual gene studies, as evidenced by studies (Chen et al., 2021). It is believed that the contribution of 400 1000 genes is implicated in autism susceptibility (Denucci et al., 2021). In addition, there are some unusual genetic factors that add to risk factors of up to 20% to ASD (Denucci et al., 2021).

Research on the genetic factors of ASD is based on studies conducted with twin children, families, and relatives. The research in this area includes the following findings: The concordance rate in monozygotic twins is between 70-90%, which is higher compared to dizygotic twins (Sauer et al., 2021). If one of the monozygotic twins has ASD, the likelihood of the other also having it is reported to be 60-90%. Also, ASD is observed four times more frequently in males than in females. Additionally, the recurrence risk among siblings is calculated to be 4%. Due to these findings, it is considered that genetic factors play a significant role in the potential causes of ASD (Sauer et al., 2021).

Another important discipline related to autism is epigenetics (Kesli & Dosay-Akbulut, 2021). Epigenetics involves modifications to the chromosome that impact gene activity and expression without changing the DNA sequence or the genome itself. Instead, it influences the transcription of specific genes by regulating the promoter regions (Dağıdır et al., 2022). Epigenetic mechanisms are thought to play an important role in ASD as they regulate developmental genes and affect brain development. People with ASD display different patterns of epigenetic gene expression, and ASD is associated with certain mutations in genes that control epigenetic processes. Key biochemical processes involved in the regulation of epigenetics and gene expression include DNA methylation, histone modification, and non-coding RNA (Yoon, 2020).

In addition, the observation of brain abnormalities in the central nervous system and the structure and functioning of the brain, a crucial component of this system, within the genetic basis of ASD, has led to the acceptance of viewpoints that ASD stems from abnormalities in brain development and neural-chemical structures (Çolak, 2016). Children diagnosed with ASD often display pathological findings, such as being born with a smaller brain size than normal. This is followed by rapid growth, leading to a larger brain size than normal by the end of the first year. Other pathological indicators include heavier brain volume, thicker cortex and convolutions, and a larger head circumference than normal. These pathological features suggest a connection between brain structure and functions in relation to autism spectrum disorder. Comparative studies between typically developing children and those with ASD have shown that individuals with ASD have certain differences in the frontal, temporal, limbic, and cerebellar regions, which are believed to contribute to variations in emotions, social interaction, and imitation skills observed in individuals with ASD (Çolak, 2016).

1.5.2. Environmental Explanation

Research has also focused on the environmental risk factors of autism. Factors such as maternal and paternal age, fetal environment, perinatal events, medications, alcohol and tobacco use, nutrition, vaccinations, and toxic exposures have been studied as potential environmental risk factors for ASD (Bölte, 2018).

Furthermore, the psychosocial environment and maternal stress have been linked to the emergence of atypical behavior, including traits associated with autism. Numerous mechanisms have been proposed to explain how these environmental factors could lead to autistic behaviors and various clinical presentations of ASD. Moreover, inflammation and immune activation, oxidative stress, hypoxia, and disruptions in the endocrine system are considered to be some of the crucial mechanisms contributing to atypical neurodevelopment (Bölte, 2018).

There are studies indicating the relationship between different pregnancy periods and risk factors for ASD. In the early period of pregnancy, studies suggest that factors such as valproic acid, thalidomide usage, viral infections, inadequate nutrition, excessive vomiting, as well as in the second and third trimesters, bacterial infections, hospitalizations, vitamin D deficiencies, and the mother's overall emotional burden and stress can negatively impact the brain development of the fetus (Özbaran, 2014). Apart from significant risk factors during pregnancy, there are also studies mentioning the newborn period and later stages of pregnancy as crucial time frames (Özbaran, 2014).

In addition, maternal infection or inflammation during pregnancy are linked to ASD. A Danish study discovered a positive link between maternal bacterial/viral infections that need hospitalization during pregnancy and the risk of ASD in the child. Moreover, another recent Swedish research confirmed the link between the early stage of life infections and ASD risks (Nudel et al., 2022).

1.5.3. Psychoanalytic Explanation

According to contemporary psychoanalysts, it does not seem possible to understand the nature of autism with simple causality (Tarsia & Valendinova, 2021). Although there are different theories and perspectives on autism in psychoanalysis, they have essentially associated autism with the development of the child. Nevertheless, there have been numerous psychoanalysts who have made significant contributions to the psychoanalytic literature about autism.

1.5.3.1. Melanie Klein’s Contribution

One of them is Austrian-born Jewish psychoanalyst Melanie Klein, who conducted studies in the fields of child psychology and development (Rustin & Rustin, 2016). Klein first wrote a paper about autism in 1930, before Leo Kanner introduced the concept in 1943. She discussed the case of a four-year-old boy named Dick, who would likely fit the criteria to be diagnosed with autism (Hobson, 2011). She described this child who does not react to their mother or nurse, does not display emotions, and does not seem interested in what is happening around them. Klein's view of the child's development focused more on the idea that the child has a developmental inhibition rather than regression. She associated this with a structural deficiency in the ego's ability to tolerate anxiety. She also noted that symbolism did not develop in Dick, arguing that this was not due to his relationship with the objects around him but that it was an obstacle for the child to make contact (Klein, 1930).

1.5.3.2. Margaret Mahler’s Contribution

Another psychoanalyst contributing to the issue of autism is Margaret Mahler (1897-1985), of Austrian Jewish descent. She is one of the pioneers of child development, abnormal psychology, and ego psychology (Bond, 2015). She stated that there is a psychobiological harmony between mother and child in the first years of life. The empathetic care of the mother is crucial to the survival of human offspring. She defines the mother's caring for her baby in the postpartum stage as a kind of social symbiosis (Mahler, 1952).

Mahler proposed that infants go through a "normal autistic" phase in their early developmental stages, typically occurring in the first two months of life. During this period, the baby exhibits limited responsiveness to external stimuli, seemingly withdrawing into themselves. This autistic phase is followed by what Mahler termed the symbiosis stage, which typically lasts until around the sixth month (Coates, 2004). She later expanded upon these stages by introducing the concept of the "symbiotic trajectory of mother-child duality" (Gergely, 2000).

In the symbiotic phase, the child's ego remains undifferentiated. The initial step in ego differentiation occurs through the differentiation of the body image. The baby undergoes cycles of experiencing bodily discomfort and then finding satisfaction when his needs are met. They gradually realize that this satisfaction comes from something outside of themselves, like their mother. She starts to understand that there is a world beyond himself, and ego differentiation occurs. In this process, physical contact with the mother, like cuddling and touching, is crucial for the baby to distinguish his own body from the external world (Mahler, 1952).

As the child perceives their body as separate from their mother, they understands the outside world and reality. According to Mahler, the development of the sense of reality in childhood psychosis, especially the stage in which the mother is gradually excluded from the infant's omnipotent orbit, does not take place (Mahler, 1952). She states that it is difficult to determine the main cause of childhood psychosis, whether it is due to the mother's pathology and lack of empathy, the child's innate ego deviation, or a lack of interaction with the environment. However, she states that in clinical cases, mothers lack empathy and love, do not accept the child as an individual, and are highly possessive (Mahler, 1952). She saw autism as a type of childhood psychosis and named it "infantile autistic psychosis." (Mahler, 1952). The mother is not perceived emotionally by the baby, and the mother is not distinguished from inanimate objects. This condition is characterized by a lack of emotional awareness and anticipation of other people, gestures of reaching out, and behaviors that show smile responses. Parents often describe these children as unresponsive to physical contact and lacking typical social behavior. Mahler described instances where parents of autistic children mentioned that they couldn't connect with their children, the child would avoid them when they started walking, and the child's disinterest in other babies caused distress. Additionally, these babies wouldn't look back when the parent entered their room, avoided physical touch, and never sought help or assistance personally. Moreover, she emphasized that autistic children do not seem satisfied with spending time with their friends and may perceive any change in their environment as deterioration (Mahler, 1952).

1.5.3.3. Frances Tustin’s Contribution

Frances Tustin was one of the psychoanalysts (1913-1994) who conducted pioneering studies on child psychoanalysis (1913-1994), with a particular focus on children with autism (Mitrani & Mitrani, 2015). She theorized the basis for autism using concepts from the British object relations school (Brenner, 2021), claiming that autism was derived from a highly traumatic experience with the child's early separation from their mothers. She stated that this separation puts the child in a stable, depressive position that blocks or prevents the child's cognitive and emotional development (Tustin, 1972). She referred to this depressive position using the term "autistic shell," which radically isolates the child from the external world. Her argument suggested that this shell prevented the child from forming relationships with others and cut off access to their emotions and sense of self (Tustin, 1992). She observed that the child is isolated from the external world and exhibits deficiencies in both symbolization and the ability to create imaginative fantasies. In this regard, she shared the same perspectives as earlier psychoanalysts. In addition, she emphasized "non-integration" rather than "disintegration" of the autistic child. In other words, she suggested that the child may not have fully integrated or connected certain aspects of their experience or development. However, it does not necessarily mean they are falling apart or disintegrating. She argued that children interact with autistic objects and investigated how they interact (Hobson, 2011). These objects could be adjusted to create entirely personalized, comforting, and manageable shapes according to the child's preferences. Circular shapes, in particular, offered a sense of reassurance, especially to children with autism. These objects were actively held by autistic children to provide them with a feeling of security. Additionally, the softer, less-defined shapes found in autistic objects had a calming and soothing effect (Tustin, 1984). She claimed that autistic objects are employed to create the autistic shell. They are "pathological" and destructive to the child's development. She proposed that the removal of these items from the child's libidinal economy should be a component of autism treatment (Brenner, 2021).

1.5.3.4. Lacanian Psychoanalytic Contribution

Lacanian psychoanalysis is one of the schools where important studies have been carried out in psychoanalysis. It takes its name from French psychoanalyst Jacques Lacan (1901-1981), who is one of the most controversial figures in psychoanalytic literature after Freud. Lacan reinterpreted Freud's work and introduced original concepts to the literature (Nobus, 2013).

Lacanian psychoanalysts reject the notion that autism can be solely attributed to a specific brain region or a straightforward cause-and-effect relationship. Instead, Lacanian Psychoanalysis views language as the sole "reason" we have a grasp on it and, in doing so, seeks to understand the relationship of the subject with language. The theory of Lacanian psychoanalysts is that the autistic is a subject who has taken on a radical stance against the outside world as a defense against anxiety (Tarsia & Valendinova, 2021).

1.5.3.4.1. Mirror Stage and Gaze

One of the most significant concepts that Lacan contributed to psychoanalysis is the mirror stage. It clarifies the dynamics between mother and child and the formation of the subject. Lacan defined human beings as creatures born prematurely, noting that this development continues after a child is born. In contrast to other living species, a child always requires the presence of someone else, typically the primary caregiver often the mother (Kodre, 2011).

Lacan viewed the mirror stage not only as a pivotal period in the development of the child but also as a representation of a permanent structure of subjectivity (Evans, 2006). He identified the mirror stage as a significant developmental stage occurring between 6 and 18 months of age. During this stage, the child's first significant contact is often with their mother (Lacan, 1966/2006). The key point of this phenomenon is based on the premature nature of the baby. Even at six months, the baby cannot coordinate their body as they have not completed their physical development (Evans, 2006). At this stage, the baby perceives their body as fragmented. However, the child perceives themselves as a whole when the mother gazes in the mirror, points at the child and defines them as "this is you" (Gürsel and Gençöz, 2019). Even in the absence of a physical mirror, the baby sees the reflection of their own behavior while the adult imitates the baby's facial expressions and gestures. These imitative gestures of the adult serve a mirroring function and allow the child to recognize their specular image (Evans, 2006). The baby is thus identified with the specular image they see in the mirror (unified gestalt). Lacan defines the moment of the gestalt of the image as the "Aha Erlebnis" or "Aha Moment." It represents a triumph as the baby attains a sense of completeness. However, it is also a traumatic moment because it involves the destruction of the fragmented body image that the baby perceives. This moment of jubilation forms the basis of the structuring of the subject. It states that the subject's perception of themselves is a misunderstanding (méconnaissance). This process leads to the formation of the ego. Consequently, the subject becomes alienated from themselves and identifies with their image. Lacan expresses this as the “formation of I,” having formulated this stage using the L-schema using topology (Ecrits, 1966/2006).

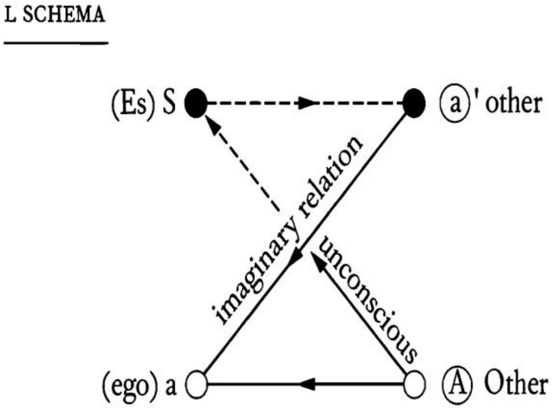


Figure 1. L Schema (Retrieved From Écrits)

It is the subject formulated with *S*; that is, it represents the baby. The mother formulated with *A*, *the Other.* The baby's identification with themselves *(a)* and the image they see in the mirror *(a')* takes place in the imaginary axis.

As can be seen in the diagram, a symbolic axis is also formed in the mirror stage. *"The symbolic order is present in the figure of the adult who is carrying or supporting the infant"* (Evans, 2006). The subject accepts their own image; they look to an adult figure, representing the Other, seemingly seeking approval for this self-identification (Evans, 2006). The person holding it in front of the mirror, which Lacan calls the Other, represents the mother or an elder; the child's first relationship with the Other is established during this period. In the mirror stage, the naming of the child is important, as well as establishing a relationship with the specular image of the child. The "vocalization" in which the child is pointed and named is very important. If the adult's gaze does not identify the child's image at this stage, the child only tries to imitate this image (Lacan 1962/2016).

Laznik emphasizes the first and important signs of autism as the absence of gaze between mother and child. Although the absence of gaze does not always indicate autism, it represents a problem in the specular relationship with the Other. As a result of this non-gaze, the relationship with the Other is either never established in autistic children or is attempted to be established through a therapeutic relationship (Laznik, 2018). In the absence of intervention, the infants face a significant risk of not fully developing or properly establishing what is known as the "mirror stage." This stage is a critical phase in an infant's development because it is when they relate to their own reflection in the mirror. This interaction with their mirror image is vital because it shapes the infant's sense of self-unity and their understanding of how they relate to objects and other people (Laznik, 2018).

1.5.3.4.2. Lacanian Structures

Now, Lacanian clinical structures will be explained, and how autism is structured will be discussed. In Lacanian psychoanalysis, there are three fundamental psychological structures: psychosis, perversion, and neurosis. These structures are based on how individuals relate to the Other. The process of developing these structures involves two main stages: alienation and separation (Dor, 1988).

Lacan states that the biological needs of the subject are immediately satisfied in the mother's womb. He then states that when these needs are not met immediately, a state of dissatisfaction occurs for the subject (Lacan, 1964/2013). In this case, the subject tries to express his needs to the Other. Nevertheless, they never fully cover the biological needs they express. There is a gap between what he lives and what he expresses. What is meant to be said in the field of the word is lacking. Lacan describes this as alienation in language (Lacan, 1964/2013).

The second crucial stage in the formation of the subject is separation. It occurs when the child's mother recognizes that she is not the sole object of interest (Fink, 1999). The father plays a role in disrupting the child's dual relationship with their mother. Lacan terms this function, which creates a separation between the mother and the child in terms of desire, as the Name-of-the-Father. Repression takes place with the function of the Name-of-the-Father (Fink, 1999).

The subject's structuring process is closely tied to its relationship with the Other, particularly in the phases of alienation and separation. Different defense mechanisms come into play during this structuring process. In cases of psychosis, the phases of alienation and separation are not realized. The subject does not experience alienation from themselves, and ego structuring does not occur (Fink, 1997). During the initial interaction with the Other in the mirror phase, the Other's act of holding and referring to themselves does not take place. The Name of the Father remains absent from the psychotic system. Foreclosure emerges as the fundamental defense mechanism in psychosis (Gürsel & Gençöz, 2019).

In the context of perversion, alienation has taken place, but the complete separation of desire from the mother has not occurred. The Name of the Father does not entirely fulfill its function. Here, the subject's ego is structured, and although the child comprehends the law of the father, full recognition remains elusive. The pervert subject acknowledges the presence of the Name of the Father but rejects it at the same time. In contrast, the neurotic subject experiences both alienation and separation phases. The subject represses their desire for the mother, aided by the function of the Name of the Father. Repression serves as the primary defense mechanism in neurosis (Fink, 1997).

In Brenner's book The Autistic Subject: On the Threshold of Language, he (2021) emphasizes that autism is a unique structure distinct from all these other structures. He expresses the purpose of his book as follows: "autism can be accounted for as a singular subjective structure that is not reducible to any of the three major subjective structures elaborated by Freud and Lacan: neurosis, perversion, and psychosis." He defines autism as a "mode of being" and states that "autism should be addressed as a singular mode of human existence" (Brenner, 2021).

Contemporary psychoanalysts state that autistic individuals use a defense mechanism called autistic foreclosure. They distinguish it from the foreclosure used by psychotics (Lefort & Lefort, 2003; Benoist, 2011; Laurent, 2012; Brenner, 2021). They have noted that the defense mechanism of autism is a radical form of that used by psychotics, referred to as the "radical form of psychotic foreclosure" (Brenner, 2021). Both autistics and psychotics reject the function of the Name of the Father. However, they point out that in psychosis, there is a minimal relationship with the symbolic realm, whereas even this minimal relationship is absent in autism (Benoist, 2011). Autistics lack the capacity to alienate themselves from the Other, remaining significantly distant from it (Lefort & Lefort, 1972). The defense mechanisms of autistics are considered an archaic form of those used by psychotics. The autistic defense lacks any signification.

Furthermore, the primary repression in which the Name of the Father becomes integrated into the subject's psychic system does not take place in psychosis and autism. Nonetheless, there is a distinction in the levels of primary repression between autism and psychosis. Primary repression involves two aspects: the negative aspect (Ausstossung) and the positive aspect (Bejahung). In autism, Ausstossung is entirely rejected. Psychotics, on the other hand, experience the initial level of signification, resulting in a limited or minimal relationship with the Other, particularly within the domain of language (Laplanche & Leclaire, 1972). Autistics radically reject the Other, preventing their entry into the realm of language.

1.5.3.4.3. Language

In order to understand the relationship between autism and language, it will first be briefly explained how babies acquire language and the concept of signifier. Then, the issue of autistic individuals and their language difficulties will be discussed.

Lacan built his theory on the relationship between the subject and language. He emphasized that language is composed of "signifiers" (Lacan, 1964/2013). He adapted the concept of the "signifier" from linguist Saussure. In Saussure's theory of signs, a linguistic sign consists of two dimensions: the signifier and the signified. The signifier is the tangible and concrete aspect (sound, writing) of the sign, while the signified is the conceptual and imaginative dimension in the mind (Acar-Logie, 2019). Lacan uniquely focused on the signifier, detached from the signified. He viewed language primarily as a system of signifiers that operate simultaneously and signification emerging only when all these connections come together. This continuous interplay of signifiers persists until a sentence is formed. Signifiers continually accumulate signified elements. The signifier imposes its structure and predetermined boundaries on the signified, thus fulfilling the function of signification (Acar-Logie, 2019).

The signifier appears in the field of the Other. It brings out the meaning of the subject. It invites the subject to fulfill the speech function (Lacan, 1964/2013). Here, the Other is perceived as the place where meaning units at the symbolic level shape the individual's spiritual reality beyond conscious control. The Other represents the place where the subject enters language before its existence. More specifically, it represents the commonplace of language based on cultural contexts (Brenner, 2023).

Furthermore, Lacan argues that the subject's relationship with the Other (mostly with their mother) emerges entirely from a process of lack (Lacan, 1964/2013). He suggests that human infants are biologically deficient and completely dependent on their caregivers for survival. While the baby's needs are met in the womb, it has needs that cannot be met after birth. For example, when the caregivers do not feed a baby when they are hungry, there appears to be a feeling of dissatisfaction. This feeling furthermore creates a deficiency in the baby's psyche, prompting them to cry. Lacan suggests that this cry functions as a message, a "call to the Other." Through crying, the baby's first demands are expressed in the mother's language. The baby calls out to the Other to relieve the tension created by unmet needs (Brenner, 2023). As the infant expresses its initial demands to the Other, there is a process of "alienation": the infant tries to translate its biological needs into a linguistic expression. However, this linguistic expression will not fully meet the baby's needs. Lacan conceptualized this as "alienation in language" (Lacan, 1964).

Now, autism and its relationship with language will be discussed. In autism, there's a radical rejection of alienation in the domain of autistic signifiers, structuring autism itself rather than being an outcome. In essence, autism involves refusing the 'call to the Other,' which begins with the absence of eye contact and a reluctance to present needs to the Other, even when hungry. Autistic individuals also struggle with indirect expressions and avoid subjective expressions (Brenner, 2023).

All of these aspects highlight that the Other, representing the source of meeting one's needs, has been excluded or pushed away. However, it's important to note that language isn't entirely rejected in autism. Instead, it's a rejection of adopting signifiers from the Other, meaning a refusal to engage with the shared field of signifiers within a culture (Brenner, 2023). This doesn't mean that autistic individuals are completely outside of language. They do use language but rely on fundamental language units, namely, signs. This can be described as “autistic sign language,” a sequence of signs consistently linking sensory forms and references (Brenner, 2023).

Autistic individuals sometimes name their language as 'factual language,' which illustrates the lack of subjectivity in speech. It can also be described as 'code language' similar to computer programming languages, which indicates the technical characteristics of language. On the one hand, the contextual and intuitive core of natural language is missing in the form of code or factual language (Brenner, 2023). On the other hand, this form of language allows for clarity and certainty when autistic individuals need to deal with ambiguities and abstract ideas in their vocabulary. While this language lacks social codes and figurative meanings, autistic individuals still use it, often through echolalia or imitation (Brenner, 2023).

Even in their early years, autistic babies may cry monotonously without varying their tone, making it challenging for parents to interpret their needs. Additionally, autistic babbling is rare and lacks social engagement (Chericoni et al., 2016). Due to their struggle with language codes, communication partners often take on the role of speech function during interactions. Consequently, these children can remain distant as they don't fully grasp language codes, hindering social connections and leading them to avoid speaking most of the time (Tarsia and Valendinova, 2021).

1.6. Having a Child with Special Needs

Caring for a child with special needs differs from typical parenting in terms of the time spent caring for and addressing their special needs (Leither et al., 2004). In particular, from the moment their children have been born, these parents may face difficulties and experience stress in dealing with their children’s well-being and health (Karadağ, 2014). Additionally, they may experience a sense of disappointment at being faced with the unexpected reality of having a child with special needs. Specifically, they are faced with an uncertain situation, which can lead to anxiety. This unexpected situation has the potential to evoke a wide range of complex emotions, such as sadness, anger, and guilt. As such, the parents of special needs children may need guidance and help dealing with both their children and their resultant emotions (İşcan & Malkoç, 2016).

However, being accepted by their social circles helps these parents to reduce their levels of anxiety and makes it easier for them to cope with the daily challenges they face (Lusting & Akey, 1999). Nevertheless, these families often face stigma—they may be seen as unwanted people in school and nursery environments, leading to their exclusion. These families may, therefore, face feelings of social isolation and loneliness, with these feelings being added to the burden of care and evoking yet another struggle in their difficult experiences (Aysever & Demirok, 2019). Therefore, families with children who have developmental disabilities typically experience more negative psychological outcomes than families with children who do not have such disabilities (Lecavalier et al., 2006). As a specific group, the parents of autistic children appear to experience greater levels of stress compared to parents of children with other disabilities (Selimoğlu et al., 2014). Also, their parents experience stress more severely and acutely than the families of those diagnosed with other developmental disorders due to the inherent uncertainty in the diagnosis and course of ASD (Gupta & Singhhal, 2005). Therefore, gaining insight into the experiences of these families is of utmost importance as it helps us understand their daily challenges and the impact of ASD on parent-child dynamics (DePape & Lindsay, 2014).

1.7. Mother-Child Relationship

The mother-child relationship is not a one-sided affair but rather a mutual exchange wherein both parties influence each other's worlds (Aoki, 2003). Explicitly, parents and children engage in a circular process whereby the mutual expression of demands and emotions limits and shapes one another (Parpal & Maccoby, 1985). For instance, an infant communicates their needs through crying, while parents impose certain limitations and encourage specific behaviors based on the child's age. Thus, it is through this interplay of demands and restrictions that a circular interaction is formed between the mother and child, thereby shaping their experiences as well as the overall relationship (Parpal & Maccoby, 1985).

Apart from the general difficulties both parents experience, mothers of children with special needs face additional difficulties in providing care to their children (Gadre & Mardhekar, 2015). The primary caregiver is the mother, who bears the responsibility of caring for the child and is the one particularly affected by stressful events associated with the well-being of their child with special needs (Sethi et al., 2007). In families with children with special needs, the majority of the daily care of the child and related responsibilities are undertaken by their mother (Marcenko & Meyers, 1991). In this regard, the mothers of special needs children tend to spend more time with their children than those children's fathers and perceive the burden of caregiving responsibilities to a greater degree (Ersoy & Çürük, 2009). Due to this burden, the mothers of children with special needs often experience high levels of frustration in their role as caregivers (Maheshwari, 2014).

When comparing the parents of children diagnosed with ASD, especially the primary caregivers, mothers are particularly negatively affected during their children's diagnostic process. Mothers of children with ASD tend to experience "increased levels of emotional distress, depressive symptoms, and anxiety compared to fathers of children with ASD or parents of children with other developmental disabilities" (Kulasinghe et al., 2022). As they try to navigate these challenges, they also go through various stages in accepting their child or children's diagnosis.

1.8. Acceptance of the Diagnosis of the Child

Accepting a child's disability takes time for parents, though this acceptance process is critical for both the parents and the child (Gordon, 2000). The stage model for the acceptance process is based on the theory of grief. In 1969, Kübler-Ross suggested that people with terminal illnesses go through stages of shock, denial, anger, bargaining, and depression (Kübler-Ross, 1969). Later, this model was also adapted to the relatives of the patients and situations where there had been any form of loss (Kübler-Ross & Kessler, 2014). In line with this, Bowlby and Parkes also described four stages of grief following loss: numbing, yearning and searching, disorganization and despair, and reorganization (Bowlby & Parkes, 1970). Similar to the grieving process, parents of children with disabilities go through certain emotional processes while accepting their child's diagnosis. Blacher defined these processes as "stages of adjustment" (Blacher, 1984). However, parents do not always follow these stages in a linear order—they might experience multiple phases simultaneously, skip certain steps, or even feel relief rather than grief (Case, 2000). Additionally, families may have different experiences. While some families completely ignore the diagnosis, others may feel inadequate, thinking that their child is not doing many of the things they can do. In addition, some families may experience deep pain and become depressed in the face of having a child affected by disability, as if they had lost a loved one (Varol, 2006). Some families may also be stuck in a certain stage (Seligman, 1989). However, overall stages that parents go through often show similarities (Howard et al., 2009).

1.9. Researches on Experiences of Parents with Autistic Child

Although qualitative research in autism has noticeably been the subject of much attention, the number of qualitative studies in autism is still well below that of quantitative studies (Bölte, 2014). In particular, the limited number of qualitative studies about autism are listed below. These examples demonstrate the different aspects of the experiences and difficulties of parents with autistic children. On the one hand, these studies enable us to understand the enriched experiences of being a parent for autistic children. On the other hand, it reveals that there is still a lack of interest in qualitative research on autism, such as is the case in Turkey.

Of the qualitative studies mentioned above, one study carried out in Canada highlighted that parents of children with autism have difficulty receiving the diagnosis. Fifty-six parents of children with autism filled out three questionnaires regarding their children's experiences during the diagnosis process. The parents reported that they waited about three years for their child to receive the diagnosis and that they had applied to an average of 4.5 specialists. This study argues that the delay in the diagnosis may be the result of the different symptoms autism exhibits, as well as a lack of appropriate assessment tools for preschool children, and problems associated with professionals (limited allotted time for diagnoses, a lack of knowledge on the part of professionals, etc.) (Siklos & Kerns, 2005).

In one qualitative study conducted in Greece, the experiences of five mothers of children with autism, as published on their personal blogs, were analyzed using the qualitative content analysis method. The mothers are between 35 and 45 years old, while their children are between 6 and 12 years old. According to the results of the content analysis, the mothers initially viewed autism as a “tragedy”, but later came to accept the diagnosis and later interpreted their child's diagnosis as “a new life experience”. They experienced feelings of anxiety, depression, and burnout as they struggled to contribute to their children's development. Moreover, while they sought to improve the quality of their children's education, they were faced with deficiencies in the education system and the ignorant or careless attitude of some educators. They also encountered challenges such as perceiving their children as "abnormal," experiencing stigmatization, and facing rejection from their social environment (Loukisas & Papoudi, 2016).

In a study conducted in Sweden, 37 families were interviewed to understand the ideas of the parents of children with autism concerning the diagnosis of their children, alongside any early suspicions the parents may have had. In this study of 66 parents, the age of the parents were between 25 and 62 years old, with a median of 43. The results of the data gleaned from the interviews, subsequently analyzed using open content analysis, indicate that some families stated that they perceived that "something went wrong" in their children from birth, and some stated that their children were born with physical disabilities. Some mothers reported that they had early communication problems with their babies, that their babies did not make eye contact, and did not like body contact while breastfeeding. Some of them stated that they noticed delays in speaking, and some of them stated that, especially after the age of 3, the aggressive behavior of their children increased and that they created problems with their teachers and friends in kindergarten. They stated that their children had problems interacting and ensuring social cohesion with other children during games and that this problem has continued. Ultimately, this study highlighted three important periods during which families could recognize their children's early behavior: birth, early speech development, and starting school (Sivberg, 2003).

Another study was conducted by mothers of children between the ages of 5 and 9 with ASD. Three themes were identified in the research using phenomenological analysis: "emotional burden, family burden, and social burden." These themes reveal that mothers feel burdened, distressed, and vulnerable when raising a child with autism (Papadopoulos, 2021).

Additionally, a recent study by Asmare et al. (2023) in Ethiopia was conducted to understand the experiences of mothers raising children with OSD. While the age of the 20 mothers participating in the study was between 30 and 57, the children were between 4 and 17, and the time of the children's diagnosis varied between 2 and 9 years of age. The themes found in the qualitative study from the interviews with the mothers are as follows: "grieving and experiencing other emotions arising from the diagnosis of their child; developing, understanding and defining autism; and developing coping strategies for accepting the diagnosis and raising their children ."The results of the study highlight that raising a child with autism is a new experience that lasts throughout the daily life of mothers, deeply changing the roles of parents and transforming their perspectives on motherhood.

Another study was conducted using a qualitative thematic analysis approach on 19 mothers with children aged 6-12 years with ASD. The mothers were asked semi-structured questions about their experiences with stress and self-compassion. When the interviews were analyzed, the following themes were found: "the impact and causes of stress, benefits of self-compassion, barriers to self-compassion, and aids to self-compassion."The mothers participating in the research described raising children with ASD as a complex experience, with their stress levels being affected by numerous factors like the diagnosis of the child, coping difficulties, and feelings of isolation. In addition, the mothers emphasized the importance of support, internal resources, and information to display more self-compassion. The mothers emphasized multiple elements that exacerbated their stress: not being understood by others, their children's suffering, and having difficulty prioritizing themselves (Bohadana et al., 2020).

In the first qualitative study investigated by Lilley et al. regarding experiences with autism and attitudes towards autism in Aboriginal and Torres Strait Islander communities in Australia, researchers interviewed 12 families with 16 autistic children residing in different parts of the country. In the interviews, which were analyzed thematically, the participants stated that they were ashamed, stigmatized, and socially isolated because of their children's atypical behaviors. They also noted that there are inclusive attitudes, which include the practice of "looking at each other" as a clear example of this growing acceptance towards individuals with autism and their unique characteristics (Lilley et al., 2020).

On the other hand, they also described inclusive attitudes, including “looking after each other” and a growing acceptance of autistic differences. This positive model of support for and acceptance of autistic children and their families may well contribute to good outcomes for autistic children and adults in Aboriginal and Torres Strait Islander communities. Nevertheless, further research is needed on cross-cultural and pluralistic understandings of autism, parental perceptions, and familial experiences.

In another qualitative study investigating the experiences of South African mothers whose children were diagnosed with autism, interviews were conducted with 12 mothers of children 7 to 9 years old. The themes obtained from the interviews include the mothers' experiences before, during, and after their children’s diagnoses. The study highlighted that the participants possessed strong cultural and religious beliefs that played a crucial role throughout the diagnosis process. Some mothers sought help from traditional healers or religious leaders to cure their children of the disorder. Some stated that after receiving the diagnosis, they felt relief because what their child went through was described. Moreover, they felt emotionally exhausted when they realized it was a lifelong diagnosis. Although they continue to pray for miracles, they have become stronger over time as their feelings of anxiety and guilt have subsided, which is due to their deeper perspective on autism (Manono & Clasquin-Johnson, 2023). In addition, looking at the qualitative studies on autism conducted in Turkey, it can be seen that there have been limited studies including parental experiences in the diagnosis process, in contrast to the international literature (Akkuş et al., 2020).

The research on the experiences of parents of children with autism during the period in which their children were diagnosed with autism was conducted with 50 parents who were the primary caregivers of children with autism aged between 2 and 12 years. The data obtained as a result of the interview were analyzed by the descriptive analysis method with four underlying themes ultimately identified: "the time difference between the time when parents first noticed the differences in their children's development and the diagnosis, the limitations of the evaluation made by the experts in the diagnosis process, the lack of support services to be provided in line with the needs of the parents, the problem of not ensuring integrity in the special education services offered to children" (Selimoğlu et al., 2013). The study revealed a delay in the diagnosis time of the children, which is attributed to both families and the diagnostic service and specialists. It takes more than a year from the initial symptom recognition to seeing a specialist. Although parents noticed developmental differences in their children at an early age, they reported that their children were typically diagnosed with autism during kindergarten or as their symptoms gradually became more pronounced.

Another study was conducted in which semi-structured interviews were conducted with 19 mothers of children with autism in the preschool period, and the data were analyzed using the thematic analysis method. The negative effects of the diagnosis of ASD on the participants' interpersonal relationships, social interactions, and professional lives were determined in the study. Additionally, the study identified the challenges experienced by both the child with ASD and their parents in their daily lives, school settings, and healthcare context. In this study, similar to the international literature, it was determined that the mothers experienced feelings such as sadness, rejection, fear, helplessness, and acceptance after their children's diagnosis of ASD. Another result of the study, again in line with the literature, was that most of the participants stated that their social life was significantly restricted due to the diagnosis. While many participants in the study stated that they had difficulty accepting the diagnosis, some participants stated that the diagnosis was not accepted by their spouses and family elders (Akkuş et al., 2020).

In a similar qualitative study conducted by Bilgin and Küçük in 2010, 43 mothers (aged between 23 and 60) of a child with autism (aged between 4 and 17) stated that they experienced stress about their children's behaviors resulting from autism symptoms, their children's care burden, their roles, and future prospects.

In addition, there are theses conducted with families with autistic children in Turkey. The thesis *"An Interpretative Phenomenological Analysis of First Time Mothers'*

Experiences on Raising Twins with One Child Diagnosed with Autism and the Other One Typically Developing" was conducted by Bilge in 2020. The study aimed to investigate the experiences of mothers who had twins in their first parenting experience, where one child was diagnosed with ASD and the other developed typically. It used qualitative research methods, conducting face-to-face interviews with six mothers. The findings revealed five main themes in the mothers' experiences: “Unknown Journey: Autism; Adapting into Unknown; Torn Apart in Two Halves; The Other Half: Healthy Child; Twins’ Bonding ."When mothers learn their child has autism, it is a stressful situation to adapt. The study found that the mothers developed their own ways of coping with the difficult situation. Over time, the mothers accepted their child's autism, especially those with older twins, but they still mourned the loss of a more independent life.

The thesis *"Discourses of Parents with Children with Autism,"* conducted by Demirbaş in 2021, investigated how parents of children with autism explained autism and identified six different interpretative repertoires they use in their explanations. These repertoires include viewing “autism as diversity," “a medical problem," “a handicap or inability," “a religious testing," “marginalization," and “a self-improvement opportunity." The parents' explanations are influenced by both societal discourses about autism and their own personal experiences. Despite the challenges of raising autistic children, the parents find support and strength in religious and self-improvement narratives (Demirbaş, 2021).

In the thesis titled *"Subjective Experiences of Women Who Have Children with Autism,"* interviews were conducted with five mothers of children over seven years old, with the IPA methodology being used. In this study, a broad framework was presented, such as the negative emotions of mothers during pregnancy, pre-diagnosis, and post-diagnosis. The findings of this thesis are discussed from a Lacanian psychoanalytic perspective. The findings of participants' experiences are multidimensional. The participants experienced intense feelings of guilt, anxiety, and anger, often adopting a self-sacrificial attitude due to a sense of inadequacy. To cope with these emotions, they employed defense mechanisms like control and projection. From a Lacanian perspective, it is significant that the mother highlights the insufficiency of the father's function. It is also evident that participants may benefit from appropriate interventions to enhance their ability to cope with these experiences (Kalaç, 2020).

1.10. Purpose of the Study and Research Question

The aim of this study is to investigate the experiences of mothers with autistic children during the diagnosis process of their children. The study focuses on exploring the mother-child relationship in the context of the diagnosis process based on the experiences of mothers. A qualitative research method was employed to gain a deep understanding of these experiences. The study was conducted using the IPA methodology.

CHAPTER 2

METHOD

2.1. Qualitative Research

Research employs two primary approaches to gather and analyze data: qualitative and quantitative. While quantitative research was traditionally more common, qualitative research has become increasingly popular in recent years. Quantitative research relies on objective and replicable methods, focusing on numerical data for analysis (Pathak et al., 2013). Qualitative research, on the other hand, generates non-numerical data and seeks to understand individuals’ attitudes, behaviors, beliefs, experiences, and interactions. Moreover, qualitative methods are widely utilized to gain a deep understanding of participants’ experiences (Pathak et al., 2013). It focuses on the meanings people attribute to these experiences (Yıldırım, 1999).

Qualitative research methods enable the collection of in-depth information from individuals with specific experiences on a particular subject (Denny & Weckesser, 2022). In qualitative research, methods such as non-standardized in-depth interviews, observation, document analysis, and discourse analysis are utilized. Furthermore, data is gathered through participants’ verbal expressions and behaviors (Taylor et al., 2016). The most commonly employed qualitative method is interviewing, which is a powerful technique for exploring individuals’ perspectives, experiences, differences, and perceptions (Yıldırım, 1999). Interviews aim to access unobservable information about the research subject, including individuals’ inner world experiences, attitudes, perceptions, and reactions (Karataş, 2015).

2.2. Interpretative Phenomenological Analysis

Interpretive phenomenological analysis (IPA) is a contemporary qualitative methodology (Miller et al., 2018). Although it has been in use since the mid-20th century, IPA is rooted in older philosophical currents of phenomenology and hermeneutics (Eatough & Smith, 2017). In the field of psychology this approach has found applications in various fields of psychology, starting with health psychology. Later, it expanded into cognitive psychology, social psychology, and clinical psychology (Ar-Karcı, 2022).

The primary goal of IPA is to gain an in-depth understanding of a phenomenon and experiences. It seeks to explore the subjective meanings of a fact or event (Pietkiewicz & Smith, 2014). Moreover, it involves collecting information about participants' emotions, motivations and desires through their verbal expressions and behaviors (Eatough & Smith, 2017). It examines how participants uniquely express an experience in their idiosyncratic terms. Furthermore, it focuses on how participants make sense of this experience (Smith & Osborn, 2003). Unlike seeking objective knowledge or generalizable findings, IPA adopts an idiographic approach, focusing extensively on an individual's subjective lived experience of a particular issue (Love et al., 2020). In addition, IPA seeks to understand psychosocial and cultural contexts. It asserts that social factors play an important role in shaping an individual's perspective. These factors influence how each individual interprets their personal experiences (Larkin et al., 2006)

IPA requires the hermeneutic process to understand experiences. First of all, participants must interpret their experience, seeking to make sense of it or them. The researcher also engages in this interpretational process, seeking to "make sense" of the participant's experience by understanding and "giving voice" to their concerns, conceptualizing them from a psychological point of view (Larkin et al., 2006). That means IPA involves a double-hermeneutic process that includes both participants' and researcher's efforts to make sense of their experiences (Smith, 2011). In this interpretational process, the researcher adopts a central position (Larkin & Thompson, 2012) and plays an active role (Smith & Osborn, 2003), including actively listening and interpreting during the investigation rather than simply being an observer (Engward & Goldspink, 2020).

In addition, IPA follows an inductive research approach, starting research with the examination of specific examples. Then, it utilizes them to develop more generalized theories. IPA does not depend on any prior hypothesis, as it is a unique approach that is not based on any theory, with its goal being to comprehend "lived experiences" rather than to verify or reject any hypothesis (Smith, 2004).

Regarding these features of IPA, it can be particularly useful for investigating topics characterized by dynamic, context-dependent, and subjective nature. Thus, this approach is well-suited for exploring themes related to identity, self, and the process of making sense of one’s experiences (Smith & Osborn, 2007). In this study, the experiences of mothers of children with autism in the diagnosis process of their children were examined. The aim was to explore the subjective experiences of mothers with autistic children and gather rich and detailed data. The goal was to gain insight into a specific experience within this particular group. Taking into account the aspects of IPA mentioned above, the IPA methodology was considered appropriate for this study.

2.3. Participants and Sampling Method

IPA aims to grasp the unique experiences of individuals who share similar life events by working with a homogeneous group with as similar characteristics as possible (Pietkiewicz & Smith, 2014; Smith, 2007). IPA uses a purposive sampling method based on the research question (Denny & Weckesser, 2022; Smith et al., 2009). The current study was conducted with mothers of children diagnosed with Autism Spectrum Disorder. In the study, the purposive sampling method was used to understand the experiences of mothers who, as primary caregivers, interact more with their children during the diagnosis process. Three inclusion criteria were used in the research. These were having a firstborn child with autism, having a male child, and the child age between 3 and 6.5. First, it focused on mothers with their firstborn child diagnosed with autism, aiming to understand what it is like to encounter a diagnosis of autism in one’s first motherhood experience. Second, the study exclusively involved mothers with autistic male children, primarily to eliminate the influence of gender variations on mother-child bonding. The other reason for choosing boys is that they are diagnosed with autism more frequently than women (Milner et al., 2019). Lastly, participants had children aged between 3 and 6.5, offering a glimpse into the experiences of mothers during the diagnostic period and insights into mother-child interactions during the preschool years.

The idiographic nature of IPA often requires the use of a small sample (Miller, 2018). Since IPA focuses on gaining deep insights into specific phenomena within specific contexts, researchers typically use small sample sizes. This approach allows them to thoroughly investigate and understand the unique details and nuances of each case they study (Smith et al., 2009). In a similar vein, Pietkiewicz and Smith (2014) recommended using small sample sizes that are fairly homogeneous, typically 5 to 10 individuals. Descriptive information about the participants is given below. Also, in order to protect anonymity, participants' names were changed, and pseudonyms were used.

Table1. Information About the Participants

Participant Number	Nickname	Child's Nickname	Child's age of diagnosis	Child's current age
Pt1	Elif	Ali	2	6
Pt2	Aynur	Berk	3.5	5
Pt3	Gül	Can	2	2.5
Pt4	Mehtap	Anıl	2.5	5
Pt5	Nuran	Alper	2.5	6.5

2.4. Procedure

Ethics Committee Approval was obtained from the Human Subject Ethics Committee of Middle East Technical University. The IPA guidelines (Pietkiewicz & Smith, 2014) were followed during the research process, which included that the study was announced to the participants and participation in the research was voluntary. The call for participation in the research was made through social media and special education centers. A signed informed consent form was obtained from the participants. They were informed that they could withdraw from the study at any time whenever they felt uncomfortable and did not want to continue. Then, two pilot interviews were conducted. Based on the insights gained from those interviews, the original interview questions were revised, and they were used in the study. The mothers of autistic children were asked questions about their experiences before, during, and after their child’s diagnosis. The participants were encouraged to speak freely and to describe their experiences in detail, with the researcher attempting to ensure that the participants could express themselves comfortably with a dynamic and conversational approach that allowed the emerging themes and important issues to be discovered (Smith & Osborn, 2003). The interviews were recorded, with two of the interviews taking place online and the other three interviews being held in special education centers. The interviews lasted between 48 and 86 minutes. To ensure confidentiality, the participants were assigned nicknames, and any personal details that could identify them or reveal their identities were changed. Five interviews were conducted, and after analyzing the data, we reached a point where no new themes or information were coming up, indicating that we had gathered enough data for the research. In other words, interviews were concluded when data saturation was reached (Smith and Osborn, 2003).

2.5. Data Analysis

The interviews were recorded using audio equipment, and each one was transcribed verbatim. Participants were given pseudonyms (Smith, 2011). The analysis of the first interview contributed significantly to shaping some of the questions for the subsequent interviews based on emerging experiences (Smith & Osborn, 2004). In this regard, notes were taken on how the participants expressed their experiences, the points they struggled with, and any points that needed to be emphasized more before moving on to the second interview. Following the idiographic approach of the IPA, the transcriptions were carried out immediately after each interview. The first interview was conducted, transcribed, and subsequently reviewed multiple times. Then, the interview was coded. This process was repeated for the second interview, and afterward, the coding of both the first and second interviews was compared. Subsequent interviews were conducted in the same manner (Smith et al., 2009; Smith, 2004). Finally, the interviews were completed, and super-ordinate themes were identified by cross-case comparison of the themes present in the interviews (Smith, 2007). A table of possible themes related to the research question was subsequently created, with connections established between themes and super-ordinate themes determined. After all the themes had been created, the research team, including the thesis advisor and co-advisor, alongside the researcher's peers, reviewed the themes, and necessary revisions were made.

The resulting themes of the analysis are as follows: *when there is no communication, challenges in mother-child communication in the pre-diagnostic period, delays in the process of diagnosis, what happened during the diagnosis process, and acceptance after diagnosis.*

2.6. Trustworthiness of the Study

Qualitative research recognizes that both the data collection and analytical processes involved are influenced by subjectivity, while quantitative research aims for objectivity. However, it is essential not to equate quantitative research solely with objectivity and qualitative research with subjectivity. Regardless of the research nature, both qualitative and quantitative studies can be influenced by researcher bias (Morrow, 2005). That means researchers must acknowledge the significance of subjectivity and bias. In this regard, qualitative researchers not only recognize the existence and benefits of subjectivity but also make efforts to explore and address biases through reflexivity (Williams & Morrow, 2009). Reflexivity, which refers to the researcher's active participation in the research process, is one characteristic of qualitative methods that are influenced by the researcher's personal story and interest in the subject matter (Harper & Thompson, 2012). According to Rennie (2004), reflexivity is described as a state of self-awareness in which the researcher engages in continuous introspection, a process that allows the researchers to discern and distinguish, as clearly as possible, the researcher's contributions from other factors within the research context. Furthermore, throughout the research process, reflexive thinking plays a crucial role in identifying potential biases and minimizing their influence through bracketing, not only during the data collection and analysis but also before initiating the study. Bracketing is a method used in phenomenological research to increase trustworthiness (Chan et al., 2013), and it was devised to identify the process of recognizing biases and to intentionally set them aside to prevent undue influence on the research (Morrow, 2005). To better explain, the purpose of bracketing is to acknowledge and make transparent the researcher's role in understanding the nature of the phenomenon under investigation rather than attempting complete objectivity (Gearing, 2004). Moreover, bracketing refers to the researcher's practice of acknowledging and consciously considering their theoretical orientation, personal experience, feelings, and cultural background related to that particular phenomenon. In addition, there are six different types of bracketing: ideal (philosophic) bracketing, descriptive (eidetic) bracketing, reflexive (cultural), pragmatic bracketing, analytical bracketing, bracketing, and existential bracketing. In this study, existential bracketing, which takes its origins from epistemological philosophy, has been used.

There are various reasons why I was interested in autism in my thesis. Since my undergraduate education, I have taken courses on children with special needs and took part in projects involving them. Then, I worked at the Special Education Center. I have always had an interest in working with children with special needs. I worked with children who perceived the world "differently" for "some reason" and had different needs. Because these groups are at a disadvantage and the people around them do not understand them, I have a desire to explain their world better.

I had ambivalent feelings about autism. It was a disabled group that I was both curious about and avoided. While working at a special education center, there was one student with autism. Although the administrators at the institution told me that it was related to my thesis and that I could take it in their class, I did not take a course together. I would practice communicating with him during breaks. I was curious about and wanted to research the fact that autistic children do not react when they are called and do not show interest in others. I wanted to connect with them, but, at the same time, the fear of not being able to do so troubled me. Although I was interested in mother-child communication in autism, I had difficulty framing my research question. While my thesis was continuing, I started working in a rehabilitation center. This institution includes individuals of different ages and disability groups. In the beginning, I was interviewing disabled children from all groups. I was interviewing just one autistic child. It was difficult to communicate in the beginning. Actually, I was having a hard time connecting. The child was communicating and bonding in his own way. I realized that the part that I had difficulty with was establishing this connection. Later, I was assigned to one of the groups with the highest number of children with autism in this organization. After I started working in this group, I accelerated my work on my thesis. After getting to know both autism and each child as unique, my "bonding" with them became stronger. In my thesis, I wanted to investigate mother-child attachment. I wanted to understand the child through the gaze of the mother-child relationship, where the child’s attachment is first structured, but mostly from the mother’s perspective. I wanted to see the point where I was having difficulty from a mother’s perspective. Therefore, I tried to understand this unique world of children with autism from a similar position to their mothers. The points where the mothers shared their intense emotional experiences during the interviews were challenging for me. It was sometimes difficult to listen to the mothers crying and blaming themselves.

Throughout my thesis journey, I actively engaged with a research team, sharing my thoughts and emotions. Forming this research team and receiving their feedback proved to be another effective strategy for reflexivity. The team included advisors, co-advisors, and peers who provided crucial insights into my responses to the research process (Morrow, 2005). We discussed alternative approaches. This was beneficial for both of us by identifying and addressing potential flaws (Shenton, 2004). After the interviews were conducted, transcripts were extracted, and feedback was received from the advisors on the notes taken. Feedback was received from the research team during the creation of super-ordinate themes. During the research process, we discussed sub-ordinate themes and possible biases that might arise as researchers in our peer group. Using qualitative methods, our peer group of clinical psychology program graduate students held regular weekly meetings where we shared our thesis process, discussed possible biases, exchanged theoretical knowledge, and shared our experiences throughout this journey. The feedback provided during these meetings significantly improved our understanding and allowed us to gain valuable new perspectives.

CHAPTER 3

RESULTS

The current study involved four super-ordinate themes based on Interpretative Phenomenological Analysis. The themes were; *when there is no communication: challenges in mother-child communication in the pre-diagnostic period, delays in the process of diagnosis, what happened during the diagnosis process, and acceptance after diagnosis* (See Table 1).

Table 2. Emerging Themes of the Current Study

1. When there is no communication: Challenges in mother-child communication in the pre-diagnostic period
    - 1.1. The Mother’s difficulty in understanding the child’s behaviors
    - 1.2. Feeling helpless as a parent to handle and calm the child

2. Delays in the process of diagnosis
    - 2.1. Ignoring the signs: Trying to find an explanation for the symptoms (rather than autism)
    - 2.2. Lack of prior knowledge about autism
    - 2.3. Symptoms overlooked by experts

3. What happened during the diagnosis process
    - 3.1. The child's autism diagnosis as a traumatic experience
    - 3.2. Getting support from psychiatry: “This is how I accepted it, I couldn't accept it”
    - 3.3. Withdrawal from the social environment after diagnosis
    - 3.4. Feeling disturbed by the other's gaze
    - 3.5. Resistance to accept the diagnosis: Denial

4. Acceptance after diagnosis
    - 4.1. Finding relief in acceptance of the diagnosis
    - 4.2. Focusing on the education and development of the child after acceptance

3.1. When there is no communication: Challenges in mother-child communication in the pre-diagnostic period

The first super-ordinate theme defined the difficulties experienced in mother-child communication during the pre-diagnosis period. The participants stated that they did not understand what their children wanted to tell. They explained that their children have some difficulties expressing themselves, communicating, and they have difficulty in understanding their children's behavior. Moreover, they described that they have difficulty managing their children's behavior because of autism symptoms. This theme showed that there was a communication problem between mother and child. It consisted of the sub-themes of *the mother's difficulty in understanding the child's behaviors* and *feeling helpless as a parent to handle and calm the child*.

3.1.1. The mother's difficulty in understanding the child's behaviors

In this sub-ordinate theme, participants stated that they could not understand their children's behavior. They were upset when they cannot understand what their children are going through.

Elif stated that when her child was about six months old, her child's body became purple, therefore they often went to the doctor. She did not notice when he wanted something, and that the bruising may be the result of this. She thought her child is trying to explain something, but she did not understand what this behavior was related to.

> *The becoming purple of my child was not connected to anything... It happened when he cried violently when he was little. And then when he grew up, he was doing something, I did not know, he was becoming purple there. For instance, when I brought him in from the outside, he wanted something, I did not notice, he was becoming purple when he cried... When he cried violently, he was becoming purple, he was getting breathless. I was worried that there was something wrong with his head because he could not breathe and was becoming purple. Then when we took him to the hospital, the doctor said that according to the results of MR, there is nothing wrong with this child's brain. His brain seems to be clean and there are no problems. I also do not understand why it happened. This situation continued until the age of two and passed after the age of two.*

> *Morarmayı hiçbir şeye bağlamadılar…Şiddetli ağlayınca öyle oluyordu küçükken. Sonra da büyüdüğünde bir şey yapıyordu, ben bilmiyordum orada morarıyordu. Mesela dışardan içeri getirdiğimde bir şey istiyordu, ben fark etmiyordum, ona ağlayınca morarıyordu…Ağlayınca da şiddetli ağlayınca da morarıyodu, nefessiz kalıyordu…Ben diyodum hani şey kafasında mı bir sorun var, hani nefes alamıyordu, mosmor oluyordu. Sonra götürünce bunun dedi beyninde bir sorun yok mr'ını çektik dedi. Beyni temiz duruyor, herhangi bir*

> *sorun yok. Artık ben de anlamadım niye oldu. İki yaşına kadar devam etti, iki yaştan sonra geçti.*

Elif also mentioned that when the becoming purple and crying ended, laughing attacks began in her child. She did not know what this behavior meant. She added that she thought her child may be going crazy and as a result, she felt upset.

> *Participant (P): Then he stopped crying and then the becoming purple as well. He was crying, crying, crying all the time. Until last year. He stopped crying after last year... He is laughing now, laughing without no reason. He is just laughing. Those crises have started. After those becoming purple crises, laughing crises now…*
> *Researcher (R): He has changed from crying to laughing now, how do you think why this is?*
> *Participant(P): I do not know. But I feel so sad, I mean, I am so sad that he is just laughing... I feel so sad that when he laughs, I wonder if something happens, he is going crazy, I feel so sad, I am worried so much like this.*

> *Katılımcı (K): Sonra ağlamaları bıraktı, o şeyi, morarmayı da. Sürekli ağlıyordu, ağlıyordu, ağlıyordu. Ta geçen seneye kadar. O geçen seneden sonra ağlamayı bırakmış…Şu an gülüyor, anlamsız anlamsız gülüyor. Sebepsiz sebepsiz gülüyor şu an. O krizlerimiz başlamış. O morarma krizlerinden sonra ağlama krizleri, ağlama krizlerinden şimdi gülme krizlerine geçtik…*
> *Araştırmacı (A): ağlamasından artık gülmeye geçmiş bu sizce nasıl niye ondan ona geçti*
> *Katılımcı(K): Bilmiyorum ki ben, onu bilmiyorum. Ama çok üzülüyorum, yani anlamsız anlamsız güldüğüne boş yere…Çok üzülüyorum o gülünce boş boş…Diyorum acaba şey mi oluyor, kafayı mı yiyor, deli mi oluyor. Çok üzülüyorum böyle kafayı yiyorum*

On the other hand, Aynur described that her child could not express himself, he was trying to explain himself with signs. Despite this, she did not understand her child and was angry with herself as a result.

> *He is a bit spoilt. He is a little spoilt, but he deserves it too, so he cannot talk, he cannot express himself, or I think it is normal for him... Sometimes I do not understand, and when I do not understand him, I get angry at myself, how I cannot understand... I say I am a mom, how I cannot understand, I have to understand. I am trying to understand him, I am trying, he is trying to explain this or that with movements. By developing sign language, I'm trying to do whatever he wants by trial and error now…*
> *Biraz şımarık bir tip. Biraz şımarıyor ama o da hak ediyor yani konuşamıyorsun işte kendini ifade edemiyor veya hırçın olması da normal diye düşünüyorum…Bazen anlamıyorum anlamayınca da kendime kızıyorum nasıl*

> *anlamazsın…Diyorum ben anneyim nasıl anlamam anlamak zorundayım. Onu anlamaya çalışıyorum, deniyorum ama şu mu, bu mu, o da hareketlerle anlatmaya çalışıyor. İşaret dili geliştir biraz, deneme yanılma ile artık ne istiyorsa onu yapmaya çalışıyorum…*

Aynur also related the understanding of the behavior of her child to her motherhood. She said that a mother has to understand her child and that the mother-child relationship requires it. She got upset when she did not understand her child.

> *I mean, I think a mother should be able to understand what her child is feeling even from a single glance. You have to understand, because you have raised him, so I think you should know what he gets upset about, what he reacts to, what he does. Of course, sometimes you may not know. Then I am sad I ask myself how you do not know, you need to try harder... The source is society, I guess. If you are a mother, every mother, and child always have a different relationship. We used to think that if you are a mother, you know the truth of everything when we were children.*

> *Yani bence anne çocuğunun bir bakışından bile neyi olduğunu anlamalı diye düşünüyorum. Anlamak zorundasın yani çünkü sen büyütmüşsün yani neye üzülür ne olur neye ne tepki verir bence bilmen lazım. Tabii insan bazen bilemeyebiliyorsun. O zaman da üzülüyorum diyorum nasıl bilmiyorsun daha çok çabalaman lazım, o zaman daha çok uğraşman lazım…Toplumun verdiği bir şey herhalde. Her anneyle çocuğun hep farklı bir ilişkisi olur yani neyse yani hani her şeyin doğrusunu bilir falan derdik küçükken…*

Gül explained that she did not understand the behavior of her child. Therefore, she was sad and burned out.

R: What did you think and how did you feel during the diagnosis process as a mother?
P: A mother's heart cannot carry this burden. There are some difficulties. I feel upset. I look at my child, sometimes I do not understand anything, I feel sad, I feel worried.

A: Siz bir anne olarak tanı sürecinde neler düşünmüştünüz, neler hissetmiştiniz?
K: Anne yüreği hiçbir şeye dayanmaz. Çok sıkıntı. Yani insan kafasına takıyor, üzülüyor. Çocuğuna bakarak bazen bir şey anlamıyor, yıpranıyor, üzülüyor.

Nuran, like the other participants, stated that her child could not express himself during the period before the diagnosis. She did not understand why her child cries. She mentioned that different emotions arose when there was no healthy communication between mother and child, and this was a sad situation. Moreover, this situation was bad because she could not understand the reactions of the child.

> *Before, I definitely did not understand what he was crying about, where he was hurting, whether he was hungry. He was just taking my hand when he wanted to ask something... Of course, I was very upset, because he was crying without no reason. For example, when he looks very happy, he started crying as if something had come to his mind. Well, of course, you do not know whether he has pain, it is too bad not to understand him... But of course, it was difficult, especially when he got sick, he just has a fever, he cries, but you know, there is also pain. It is very sad. Since you do not know what hurts him. Whether he had a sore throat or if there is an infection in his blood, you could not understand and help him due to lack of communication. ooth hurts, you know, he holds his mouth but which tooth is or how will I take this child to the dentist and how will I stop him? Of course, these are very difficult. When there is no actual interaction, I think a person feels more, and then, of course, it becomes very exhausting for the mother. It was a very exhausting period for me... Not being able to understand Ahmet makes me feel only sadness and grief...*
>
> *Önceden neye ağladığını, neresinin ağrıdığını, acıktı mı kesinlikle anlamıyordum. Sadece elimi hani götürüyordu bir şey almak istediğinde…Tabii çok üzülüyordum tabii çünkü ağlıyordu bir de durup duruken. Mesela bir anda çok mutluyken duruyordu ve bir anda sanki aklına bir şey gelmiş gibi ağlamaya başlıyordu. E tabii o zaman bir yeri mi acıdı, bir yeri mi ağrıyor, hani onu anlayamamak çok kötü…Ama tabii zordu özellikle hastalandığında hani sadece ateşi var, ağlıyor ama biliyorsun ki bir yerde bir ağrı da var. Boğazından mı ateşlendi, kanında mı enfeksiyon var ateşlendi, bunu bilememek yani onun neyi acıdığını bilememek çok üzücü oluyor. Hani dişi ağrıdığında bilememek, hani ağzını tutuyor ama hangi diş nasıl ya da ben bu çocuğu nasıl dişçiye götüreceğim nasıl durduracağım yani onlar tabii ki de çok zor oluyor. İletişimin olmadığı yerde o kopukluk olunca daha çok duygular devreye giriyor bu sefer de tabii ki anne için çok yıpratıcı oluyor yani benim için çok yıpratıcı bir dönemdi… Alper'i anlayamamak bana sadece hüzün ve keder hissettiriyor...*

3.1.2. Feeling helpless as a parent to handle and calm the child

In this sub-ordinate theme, the participants discussed that they had difficulty calming their children. Their children's behavior was different from other children's and it was difficult for mothers to manage them.

Elif explains that the care of her child is not like normal children. She says that he was born prematurely. At first, there were health problems in his care, and then there were extreme behaviors such as crying tantrums. Elif states that she often goes to the emergency room because she cannot calm her child's crying.

> *...His care and everything were very, very different, he was not like other normal babies... It was very difficult for me... He was a child who cried constantly. Constantly, constantly. He would cry and cry. We just spent those periods crying... Sometimes we went to the emergency room three times a day. The doctors were angry due to my visits again and again. I did not understand what happened to him. Only Ali's cries, crises, bursts of anger…*
>
> *…Yani bakımı falan çok çok farklıydı normal bebekler gibi değildi…Benim için çok zor geçti… Sürekli ağlayan bir çocuktu. Sürekli, sürekli. Ağlardı, ağlardı. Sadece ağlamakla geçirdik o dönemleri… Bazen günde üç defa acile gittiğim oluyordu. Artık doktorlar kızıyordu gelme diye. Neyin olduğunu bilmiyordum. Sadece Ali'nin ağlamaları, krizleri, öfke patlamaları…*

Aynur mentioned that when she goes out with her child, her child is afraid of other children. She and her husband had difficulty sliding their children in the park. They were embarrassed when they were in another place. Once, she and her husband could not calm their children down and they were crying too.

> *...He would not go to the park. What I remember, he was afraid of the other kids when I called let's go to the park. He was extremely scared. We could not have put him on a slide or anything. At first, my mom would make him sit down, and I would hold it. When he saw a child on the slide stairs, he would turn back, he was extremely afraid of other children. He could never get close to the children. These are the things I remember, every time I went somewhere I was embarrassed, I remember it very well... It was always an anxiety, a fear. We used to cry. We could not even shut up him in one of them with my husband. We both sat down and cried. The child is crying, we are crying too. It was a lot, I mean, it was bad…*
>
> *…Parka gitmezdi. Hatırladıklarım, yani park dediğim diğer çocuklardan korkuyordu. Aşırı korkardı. Kaydırağa falan biz bindiremezdik. Ben başta ıı annem oturturdu, ben de ucundan tutardım, o şekilde kayardı. Kaydırak merdivenlerinde çocuk görünce geri dönerdi, çocuklardan aşırı korkuyordu. Hiç yaklaşamazdı çocuklara. Sonra hatırladıklarım bunlar, ne zaman bir yere gitsem rezil oldum, onu çok iyi hatırlıyorum…Hep bir kaygı, korku. Ağlardık. Birinde hatta susturamadık eşimle. Oturup biz ikimiz ağladık. Çocuk ağlıyor, biz de ağlıyoruz. Çok şeydi, yani kötüydü…*

Aynur further explained that children usually calm down when they are held, but she could not calm her child. When she held her child, he became more aggressive and cried more.

> *... Everyone said what kind of kid id this. A child calms down when you hold him. On the contrary, he was nervous when I held mine. He says do not touch me, do not interfere. He wanted to put the swing, but I could never calm him down on my lap... I could never calm Berk down on my lap. He always got angry, cried more…*

> *…Herkes diyordu bu nasıl çocuk. Çocuk dediğin kucağa alınca sakinleşir ya benimki kucağa alınca geriliyordu. Diyor bana dokunmayın, hani karışmayın. Bana diyordu salıncağımı koyun sallayın, hani kucağımda hiç sakinleştiremezdim… Ben hiç Berk'i kucağıma alıp sakinleştiremedim. Hep daha sinirlendi, daha çok ağladı…*

Mehtap defined that in the period immediately after the diagnosis, her child did not stay calm and he screamed when they went out. She described that she had difficulty getting her child out of the house and there were periods when her child was aggressive.

> *… At that time, for example, we were going to school with a shuttle service, and he did not like when we went out. He was not stopping, he was shouting. He did not want, I was forcing him out of the house... Of course, there were times when our child was aggressive. We have ended those days; shouts, calls. We understood this because he could not say his wishes. He was screaming because he could not speak, he could not express his emotions, and he is going to scream. He was shouting outside…*

> *…O dönemler mesela servisle okula gidiyorduk, durmuyordu dışarı çıktığımızda. Durmuyordu, bağırıyordu. İstemiyordu, zorla çıkartıyorudum evden… Bizim çocuğumuzda da tabii agresif olduğu zamanlar vardı o günleri geçtik bağırmalar çağırmalar istekleri konuşamadığı için biz bunu anladık zaten çocuk konuşamadığı için kendini ifade edemediği için bağırıyor, bağıracak. Dışarda bağırıyordu…*

3.2. Delays in the process of diagnosis

The second super-ordinate theme was the factors that delay the diagnosis of the participants' children. Although the participants noticed some differences in their children's behavior, they did not call it "autism". They expressed that they could not associate the difference in their children with autism. This theme consisted of the sub-ordinate themes of, *"Ignoring the signs: trying to find an explanation for the symptoms (rather than autism)", "lack of prior knowledge about autism"* and *"symptoms overlooked by experts".*

3.2.1. Ignoring the signs: Trying to find an explanation for the symptoms (rather than autism)

Participants described that they noticed that their children were not developing normally and that there were some differences in their behavior, but they could not associate this with autism. They attributed these behaviors to conditions such as temperament and health problems.

Elif noticed that her child did not make eye contact, and did not react to his name. She attributed these conditions to his premature birth, connecting them to his late development, rather than associating them with his "autism."

> *P: ... My uncle's daughter was a special education teacher. She came to visit us from İstanbul. She realized that Ali had autism. I was noticing something about him, but I thought he was born prematurely, so it was the reason.*
> *R: What have you been noticing?*
> *P: The fact that he did not do what I said, did not give me anything, he was not ever making eye contact with me. And when I called his name, he did not look, he kept calm like that, he always played with things for hours. Actually I realized the situation but I was not sure. In addition, I was pregnant for the other child. I do not know, he has autism... I was saying, he was premature, maybe that's why he will develop late or not. Everything was far behind, so I thought, maybe he will continue his development late... There is a little bit of strangeness in his family, his father, his mother, I said, I wonder if he was similar to them. I wish I had not thought in this way. I would have noticed the symptoms of autism earlier. I said maybe he was similar to his father's family, he is strange like them.*

> *K: …Amcamın kızı özel eğitimciydi. İstanbul'dan bize misafirliğe gelmişti. O Ali'nin otizmli olduğunu fark etti. Ben onda bir şeyler fark ediyordum ama diyordum belki prematür doğdu, erken doğduğu için bu şekildedir.*
> *A: Neler fark ediyordunuz siz?*
> *K: Benim dediklerimi yapmaması, elime bir şey vermemesi, benimle hiç göz teması kurmuyordu. Bir de ismine çağırdığımda da bakmıyordu böyle sakin dururdu hep bir şeylerle saatlerce oynardı. Orda biraz şey yaptım aslında fark ettim de o küçük oğlanın hamilelik dönemi o şeye denk geldi. Ne bileyim ondan işte sonra otizmli…İşte ben diyordum ki prematürdür ancak ondan mıdır geç mi gelişecek. Hani her şeyi baya bir gerideydi o zaman ben de diyordum geç mi şey olacak…Biraz ailesinde de salaklık var babasında annesinde ben dedim acaba onlara mı çekti diye keşke öyle düşünmeseydim. Otizm belirtileri daha önce fark ederdim. Ben dedim belki baba tarafına çekmiştir onlar gibi salaktır.*

Aynur expressed that her child did not understand the existence of other children. She considered that the possible reason for this behavior might be his jealousy toward other children. Her child focused on an object and spent hours. For this reason, she thought that he was an introverted child. She believed her child may be timid like her she noticed his behaviors, but she did not want to accept this situation.

> *So, now when I look back, I actually understand that there were problems. When you are in the midst of it, everything seems normal... I also took him to a child psychiatrist when he was two and a half years old. Because, for example, he was watching TV so much, he was not talking, he did not have any communication. I remember my husband's sister had a son, he was a little baby. Berk was nearly two years old. He was stepping on him and crushing him as if the child did not exist there, ignoring him, not seeing him. I mean, we wondered if he was jealous of him. Maybe that's why he was doing this. The other child's presence was absent from his mind. He had been playing absurdly for hours with ropes there or on the edge of the seat. I was asking what are you doing, son. It was a rope on the edge of the seat, what are you investigating, what are you examining…We thought that he has routines, so this child is different. I thought that we did not take this child out, so this was normal... I thought that there are probably introverted temperaments or his temperament is like that. He was afraid of different people I was not a very sociable person either, I was a very timid person, I was that way when I was little. I thought he was similar to me, so I am shy, I am on my own, you always find something, we did not want to accept at first and then we took him to a child psychiatrist…*
>
> *Yani şu an eskiyi insan düşününce anlıyor aslında sıkıntıları olduğunu. Olayın içindeyken hep normal geliyor sana…Çocuk psikiyatriye de götürdüm ben iki buçuk yaşında. Çünkü çok televizyon izliyordu, konuşmuyordu, iletişimi yoktu mesela. Hatırladığım görümcemin oğlu vardı o küçük bebekti. Berk daha iki yaşında falandı. Çocuk daha yokmuş gibi üstüne basıp ezip gidiyordu, onu yok sayıyordu, görmüyordu. Yani biz acaba diyorduk kıskanyor mu ondan mı böyle yapıyor. Onun varlığı kafasında yoktu. Orada ya da koltuğun kenarında iplerle saatlerce saçma sapan oynuyordu. Ne yapıyorsun oğlum diyordum. O koltuğun kenarındaki bir ip yani hani ne araştırıyorsun ne inceliyorsun…Biz diyoduk ki bunun rutinleri var demek ki çocuk farklı ben diyordum bu çocuğu dışarı çıkartmadık o yüzden böyle oluyor…Ben hep diyodum herhalde içine kapanık mizaçlar olur ya diyodum ki demek ki onun mizacı öyle. Farklı insanlardan korkuyor açıkçası ben de çok girişken bir insan değilimdir, ben de çok çekingen bir insandım, küçükken de öyleydim..Hep diyordum bana çekmiş ben de öyle ben de çekingenim ben de kendi halimdeyim hep bir şey buluyorsun, bir kılıf derler ya sonra biz çocuk psikiyatriye götürdük…*

Gül referred that her child's lack of response to his name and walking difficulties were related to other health issues. She believed that the delays in development would improve over time.

> *R: What did you first think when he did not react to his name when he did not walk?*
> *P: Since he was not walking... Can has undergone surgery and had a liver transplant. The process of the drugs he uses, we believed to get better over time. Time passed but it was the same again. It was applied directly.*

> *A: Siz ilk neler düşünmüştünüz ismine tepki vermeyince, yürümeyince?*
> *K: Yürümediğine… Can ameliyat geçirdi, karaciğer nakli oldu. Onun süreci, o kullandığı ilaçların süreci zamanla ama olur dedik. Zamanla baktık yine aynı. Direk başvuruldu.*

Mehtap realized that her child wanted to be alone and was introverted. She had observed that he was a stagnant baby since he was born. She thought it might be related to his temperament. She did not associate these conditions with autism.

> *For example, Anıl plays alone in the park. My nephew had a son a year older than Anıl, he was coming to us. He did not want him, he was screaming. He had shouted. He did not want him, he did not want to play. He was closing on his corner. He wanted to be on his own. Just because... I mean, ignore the thing... Anıl has been a calm baby since he was born, a smart, calm baby. He always has been. Yes, he was active for a while, but he was an introverted baby. I estimated that there is something wrong, but I did not know about autism or anything. There was something in the speech or something different.*

> *Anıl parkta mesela tek başına oynuyor. Mesela benim yeğenimin Anıl'dan bir yaş büyük oğlu vardı, geliyordu bize. Onu istemiyordu, bağırıyordu. Bağırmalarımız vardı. Onu istemiyordu, oynamak istemiyordu. Kendi köşesine kapanmayı, kapanıyordu. Kendi halinde olmak istiyordu. Öyle diye diye… Yani şeyi göz ardı… Anıl doğduğundan beri bir şey bebekti, akıllı, durgun bir bebekti. Hep öyleydi. Evet bir dönem hareketliydi ama içine kapanık bir bebekti. Ben diyordum var bir şey Anıl'da ama otizm falan bilmiyordum acaba konuşmada mı var bir şey veya daha farklı bir şey mi var diyordum.*

Nuran, like the other participants, understood that there was a problem with her child's behavior, but she did not know what it was and did not associate it with autism. She considered his child was a child with his characteristics, which she understood when she saw her child's relationship with other children.

> *...If I remember his first infancy and he was three or five years old, Alper was a child who struggled more, he did a lot of the things that children with autism... I took him to psychiatry service, but of course, I understood that there was a problem. I mean, there's something wrong, but what? I thought he was acting like this because he was a little special and peculiar child. But no, of*

> *course, as time went on. When we got into the children, the children played together and Alper wanted to play alone. These were effective, so we understood after that.*

> *…İlk bebekliğine bakarsam, üç dört beş yaşına bakarsam Alper daha çırpınan hani otizmli çocukların gösterdiği şeyleri çok yapan bir çocuktu…Psikiyatriye götürdüm ama ben tabii ki yani sıkıntı olduğunu anlamıştım. Yani artık yavaş yavaş bir şey var ama ne? Bir de biraz kendine has ve özgü de bir çocuk olduğu için acaba tavır olarak mı böyle de bir çocuk diye düşünüyordum. Ama yok tabii zaman geçtikçe hani çocukların içine girdiğimizde çocukların beraber oynayıp Alper'in tek oynamak istemesi, bunlar tabii etkili* oldu yani ondan *sonra da anladık*

3.2.2. Lack of prior knowledge about autism

Participants stressed they did not know about autism. They encountered autism for the first time during the diagnosis process for their children.

Elif explains that autism is not a condition she is familiar with. She mentioned that the diagnosis of autism was challenging for her because she learned about it for the first time during her child's diagnostic process. She had no idea what her child would experience.

> *…I recognized autism with Ali for the first time in my life. If I had known it before or if this disease was in the family, maybe it would not have been so hard for me... I did not even know what it was like. Everybody was saying something different, such as he was going crazy, someone was saying this, and someone was saying he would not talk. I was researching, there was a voice coming out of every head... I was constantly sending voice mail with a voice recording. o my nephew, related to autism... I repeated constantly, autism, autism. I did not know what autism is. For the first time in my life, I learned about autism after Ali was diagnosed. And when I went to the hospital, I said, I did not know…*

> *…Hayatımda ilk defa otizmi Ali'de tanıdım. Daha önce tanısaydım veya ailede olsaydı belki bu kadar bana ağır gelmezdi…Nasıl bi şey olduğunu bile bilmiyordum. Her biri bir şey söylüyordu, diyordu biri delirecek, biri diyordu deli olacak, biri şunu diyordu, biri diyordu konuşmayacak. Araştırıyordum, her kafadan bir ses çıkıyordu…Durmadan ses kaydı sesli mesaj atıyorum. Yeğenime otizm nedir, otizm…Tekrarlıyorum otizm, otizm. Otizmin ne olduğunu bilmiyorum. Hayatımda ilk defa Ali'de karşılaştım. Hastaneye gittiğimde de söyledim, dedim bilmiyorum…*

Aynur explained that she had very limited knowledge about autism, perceiving it as a condition only in a few figures she saw in the media. The information she had was not accurate, and she truly understood what autism was like after her child received a diagnosis.

> *During that time, there was this series, a doctor, atypical autism, Asperger's syndrome, and the character's name was Ali. That's why I knew a little bit about it, just that much. That is what I knew. Then I searched on the Internet. I have never known these symptoms, honestly. I just thought that was it, I mean, he was so gifted or something. However, the probability of having Asperger's is very low anyway. In general, I guess about 3% of them are Asperger's. I only knew as much as Asperger's, I did not know the others at all. Anyway, when I went to the rehabilitation center and saw it, I was very surprised when I saw such severe cases.*
>
> *O ara hani bir şey vardı ya, bir dizi vardı. Doktordu, atipik otizm asperger sendromu, Ali doktor diye. Ondan dolayı biraz biliyordum o kadar yani. O neyse onu biliyordum. Sonra internette araştırdım. Bu ağır versiyonlarını hiç bilmiyordum açıkçası. Bir o sanıyordum hani öyle üstün zekalı falan. Halbuki asperger olma ihtimali çok düşükmüş zaten. Genel anlamda vakaların yanlış değilse yüzde üçü falan aspergermiş. Hani ben sadece asperger kadarını biliyordum, diğerlerine hiç bilmiyordum. Zaten rehabilitasyon merkezine gidip gördüm de çok şaşırmıştım ben böyle hani ağırlarını ortalarını gördükçe…*

Gül had no accurate information about what autism was, she thought it was a normal condition. She understood what autism is when she saw other children during her child's special education process. She felt sad after seeing them.

> *When autism was mentioned, I did not understand actually. The father was very upset because he knew what had happened because of working in a hospital environment. I thought autism was normal, but then I see kids with autism going to special education and I get sad. I was wondering if this would happen to Can as well…*
>
> *Otizm denildiğinde ben pek şey yapmıyordum. Baba çok üzüldü çünkü baba hastane ortamında çalıştığı için ne olduğunu biliyordu. Ben otizmi normal sanıyordum ama sonra özel eğitime gide gele otizm olan çocukları görüyorsun ve üzülüyorum. Hani olur mu öyle diye Can.*

Like the other participants, Mehtap had never heard of autism before and that she did not know a child with autism. She added that not knowing about autism during the diagnosis process wore her out.

> *... I had never heard of such a diagnosis before, it was not in my family or friends... I did not know, I did not know. It was always like this when we heard from time to time, there was not a child with autism in close friends or family, I did not know actually. It was already worn me out a lot.*

> *...Böyle bir tanıyı ben daha önce hiç duymamıştım, evet arada duyuyorduk ama yakın çevremde yoktu ...Bilmiyordum, bilmiyordum. Hep böyle işte arada bir duyduğumuzda yakın çevremde de otizmli bir çocuk yoktu, bilmiyordum açıkçası. O beni çok yıprattı zaten.*

Nuran had not heard of autism; she had only encountered someone with severe autism whom she knew when she was a child. She thought that autism was a similar condition to that of that person and that she was afraid that her child would be like that.

> *Autism is a word I have never heard in my life. I have never been around either... Actually, we had an acquaintance, but he was very hard. I mean, I said, what is going to happen, he was very severely autistic. I mean, he was a very difficult child. Of course, I was very young at the time... I was afraid that it would be like that, would my child never be able to speak. Then I was crying like that…*

> *Alper'in otizm hayatımda duymadığım bir kelime. Hiç çevremde de… Aslında bir tandığımızda vardı ama onun çok ağırdı. Yani şey dedim o bu mu yani hani öyle mi olacak çok ağır bir otistikti. Yani çok zor bir çocuktu. Ben de tabii o zaman çok küçüktüm…Öyle mi olacak diye korkuyordum benim çocuğum hiçbir zaman konuşamayacak mı o zaman öyle ağlıyordum…*

Nuran could not put autism in her mind because it was a diagnosis she did not know. She did not know the branches and degrees of autism.

> *... I could not understand the situation, because it was not a situation that I knew about before. I mean, you know, I knew a kid with autism, but he was very hard, I mean, there was a very dramatic image. I had a very different idea about him in my head because he was a completely different dimension. That's why, I did not even think about it because he was like this. Because you do not know the extent of it. When I do not know its level, because I do not know which level my child has. I do not know the branches, because I do not know anything, I have never thought about autism at work or anything.*

> *...Hiçbir şeye hiç bir şeye yani hiç bir yere koyamadım çünkü bildiğim bir durum değildi. Yani hani ben otizmli bir çocuk tanımıştım ama o çok ağır yani, çok ağır bir görüntü vardı. Onunla ilgili çok ağır bir fikir vardı kafamda çünkü o bambaşka bir boyuttu. O yüzden hani aa yok ya, bu da öyle diye hani hiç*

> *aklıma bile gelmedi. Çünkü bunun derecesini bilmiyorsun ister istemez hafif mi ağır mı. Hani hafif ağır değil de daha çok senin çocuğunda ne kadarı var onu bilemediğin için, dallarını bilmediğin için, hiçbir şeyi bilmediğin için hiç aklıma işte otizm midir falan gelmedi.*

3.2.3. Symptoms overlooked by experts

Some of the participants reported that their diagnosis was delayed due to an expert. Their children were not directly diagnosed with autism in the unit they applied to and they had to go to several different medical services. In this way, they could not be sure about the diagnoses of their children.

Aynur mentioned that when they took their children to the hospital, the doctor said that there was nothing wrong with the child. When her child communicated at that moment, the doctor thought it was due to staying at home too much. After that, they were experiencing a pandemic period.

> *He probably was not even two and a half years old, we took him. The doctor said this child has nothing. He called out "Berk". Berk was always looking. Berk was always looking back. That's why Berk was diagnosed late. He called out, Berk, Berk. Berk turned around, looked, and said a few things. Berk was not afraid. I mean, he probably liked the doctor. He communicates well with the one he likes, the one he loves. He also communicated with the doctor. He also did the things he said. He also said that he could go to kindergarten due to staying at home a lot. A pandemic happened. He said to bring him to the check-up after a month. He said I do not think there is anything.*
>
> *İki buçuk falan bile değildi herhalde, götürdük. Dedi bu çocuğun hiçbir şeyi yok. Seslendi çünkü Berk her zaman bakardı. Bir kere Berk de, her zaman döner bakardı. O yüzden Berk bizde geç kondu. Seslendi, Berk, Berk dedi. Berk döndü baktı, birkaç bir şey söyledi. Berk de o ara birazcık daha şeydi, korkmamıştı. Yani doktoru sevmişti herhalde. İstediği, sevdiğiyle iyi iletişim kurar. Onunla iletişim de kurdu. Dediği şeyleri de yaptı. O da dedi ki kreşe yazın dedi çok evde kalmış. Pandemi falan da araya girdi. Bir ay sonra kontrole getirin dedi. Bir şey olduğunu düşünmüyorum, dedi.*

Mehtap's child was not directly told that he had autism in the unit they applied to and that no definitive diagnosis was made. Then, they were experiencing a pandemic period, and then her child went to kindergarten. Her child started kindergarten, they applied to the hospital again for a diagnosis when the teacher noticed him.

> *During that time, as we went outside, Anıl started covering his ears. Cars were already passing infrequently. He was disturbed by the sound of cars and covered his ears. He started not to react to the name because he was too calm. He started not reacting to his name, we had already applied to the hospital before that pandemic, but the diagnosis had not been. Maybe or maybe not, they said. The pandemic period and the process of staying at home began. After that, he started attending daycare, and thanks to his teacher there, we were advised to seek another diagnosis for Anıl. So, we started the process again, and this time Anıl received a diagnosis.*

> *O süre zarfında biz dışarıya çıktıkça, Anıl kulaklarını kapatmaya başladı. Arabalar zaten nadir geçiyordu. O arabaların sesinden rahatsız olup kulaklarını kapatıyordu. İsmine tepki vermemeye başladı Anıl çünkü çok duruldu. İsmine tepki vermemeye başladı zaten o pandemiden önce başvurmuştuk biz tanı konmamıştı. Olabilir de olmayabilir de demişlerdi öyle kalmıştı. Sonra o işte açıldıkça, pandemi süresi bittikçe evde tıkanma süreci. Sonra kreşe başladı Anıl. İşte o kreşteki öğretmeni sağ olsun…dedi tekrardan götürün biz tekrar götürmeye başladık Anıl'ın tanısı kondu.*

Nuran went to different special education centers. She was told in these centers that her child did not have autism. When he went to kindergarten, he was told he was autistic. There were conflicting statements from experts. After her husband went to the military, her child's behavior regressed, so the expert was told that he might have a diagnosis in the form of sensory integration disorder. The mother also stated that after her husband went to the military, they were left alone with their child.

> *After his childhood and after his father went into the military, a regression began. Then we were constantly getting a diagnosis that he might have more of a sensory integration disorder, he might have withdrawn himself in this way as a result of a certain trauma. Because everyone said it is not autism. However, the eye contact stopped completely and he started walking on his fingertips, but I thought it was... I tried hard, and I took him to kindergarten. Maybe I have visited fifty special education centers. When I took him to the special education center, he was still little. At that time, when he was nearly two years old, they said this child does not have autism, there is no need. When I sent him to kindergarten, they did not accept us, saying that we cannot accept that this child has autism, we cannot deal with him here…*

> *Bebekliğinden sonra babasının askere gidişinden sonra bir gerileme başladı, bu yüzden daha çok duyu bütünleme bozukluğu olabilir, yani belirli bir travma sonucu kendini bu şekilde kapatmış olabilir diye bir tanı alıyorduk devamlı. Çünkü hiç kimse hayır otizm değil bu çocuk diyordu ama tabii sonra göz temasının iyice kesilmesi ve parmak ucunda yürümeye başlaması olduğu için ee hani ben öyle olduğuna inanıyordum…Çok da çabaladım, çok fazla kreşe*

> *de götürdüm. Yani nerelere götürmedim ki belki elli tane özel eğitim merkezi gezdim. Özel eğitim merkezine götürdüğümde işte daha ufaktı yaşı. O zaman iki iki buçuk yaşlarında hayır bu çocuk otizm değil gerek yok diyip gönderdiler. Kreşe gönderdiğimde de hayır bu çocuk otizm biz bunu burda zapt edemeyiz diyerek gönderdiler…*

3.3. What happened during the diagnosis process

Participants described that they experienced various difficulties during the diagnosis process of their children. The sub-ordinate themes of this theme were *the child's autism diagnosis as a traumatic experience*, *need for psychiatric support during the diagnosis period*, *withdrawal from the social environment after diagnosis*, *feeling disturbed by the other's gaze* and *resistance to accept the diagnosis: denial.*

3.3.1. The child's autism diagnosis as a traumatic experience

Participants expressed that when they learned that their children had been diagnosed with autism, they experienced it as shocking and devastating. Elif described the moment of hearing the diagnosis of autism as a traumatic moment. Her child was born prematurely, she took care of him with difficulties. Then her little child was born and she took care of him as well. After she overcame these challenges, learning his child has autism was terrible. She defined those times as emotionally and physically difficult and intense.

> *I hate those days, I hate myself. I do not want to remember those days at all. I have had a very intense process, extremely intense. My little boy came into the world, I have never been through such a process, but I have been through this terrible process. However, when we overcome those processes, I learned that he had autism. And then when it was all over, it was also another trauma... I learned that he had autism. That process was also terrible. I just said Ali was better, I was very happy He started walking, and he looked better now. I learned that he has autism. It was also another problem... I cried there, I cried until I came home and I cried at home. I could not feel good myself for months and days. My day was passing like this... I really wanted to be a mother, but I have experienced a lot of trauma…*

> *O günlerden nefret ediyorum, kendimden nefret ediyorum. O günleri hiç hatırlamak istemiyorum. Çok yoğun bir süreç geçirdim, aşırı aşırı yoğun. Baktım küçük çocuğum dünyaya geldi hiç öyle bir süreç atlatmadım ama bu*

> *berbat bir süreç atlattım. Ama o süreçleri atlattığımızda, sonra otizmli olduğunu duydum. Sonra her şey bittiğinde o da ayrı bir travma oldu…Otizmli olduğunu duydum. O süreç de berbat bir süreçti. Tam Ali dedim toparlandı, ele avuca sığdı biraz, çok mutlu oldum, yürümeye başladı, artık kendini toparladı. Otizmli olduğu ortaya çıktı. O da ayrı bir dertti …O zaman böyle beynime kan sıçradı sanki orda ağladım eve gelene kadar evde ağladım aylarca günlerce kafamı yerden kaldıramıyordum. Bu şekilde geçiyordu günüm… Anne olmak çok istiyordum ama yani büyük travmalar atlattım…*

Aynur also explained that the diagnosis of autism sounded scary and that she thought her child would never develop. When she heard the diagnosis, she had a shocking experience.

> *R: How did the diagnosis sound to you?*
> *P: It was scary.*
> *R: What was scary about your diagnosis?*
> *P: I mean, I do not know, he will never get better, and when he will be 18 or 20, he will not be able to talk, he will be the same, he will be subjected to peer bullying. So I was thinking that way. (Silence) Do you have any more questions?*
> *R: Well, how did you feel when you were told about the diagnosis? What did you think when you were diagnosed?*
> *P: You know, it was shocking. I did not believe…*
>
> *A: Tanı size nasıl geliyordu peki*
> *K: Korkutucu*
> *A: Neyi korkutucu geliyordu tanının?*
> *K: Yani ne bileyim hiç düzelmeyecek, 18-20 yaşına geldiğinde de konuşamayacak, olduğu yerde sayacak, sonra işte akran zorbalığına maruz kalacak gibi. Yani öyle düşünüyordum (sessizlik) başka soracağınız var mı?*
> *A: Hıhı peki tanısı söylendiğinde ne hissetmiştiniz, tanı konduğunda neler düşünmüştünüz?*
> *K: Hani böyle başımdan kaynar su dökülüyor gibi olmuştu. İnanmadım…*

Gül talked about her son's diabetes diagnosis and health problems. They went through a difficult process. She then describes her son's diagnosis of autism as a difficult experience.

> *Because Can is like this, our dreams come to naught. We dedicated ourselves to Can... His disease level was not so hard. Our only aim is for Can to be his peer and walk.*
>
> *Can da böyle olduğu için hayallerimiz suya düştü. Kendimizi Can'a adadık…Otizm hafif otizm olduğu için o daha bir ağır geldi. Valla tek hedefimiz Can'ın yaşıtlarını yakalaması ve yürümesi*

Mehtap experienced devastation when she heard that her child might have autism.

> *When Anıl was two, we had an appointment at Bilkent City Hospital. We went and the doctors said he could be autistic... I had a breakdown there. Of course, then the tests started, the comings and goings began…*
>
> *Tanı Anıl'a iki yaşına girdiği gibi, bizim Bilkent Şehir Hastanesi'nde randevumuz vardı. Gittik ve otizm olabilir dediler…orada bir yıkılma yaşadım. Tabii ki sonra tetkikler başladı gelip gitmeler başladı…*

Anıl has been examined in different hospitals during the diagnosis process. When she was told that her child may have autism, she felt sad and she started crying.

> *I took Anıl to Gata. A child development specialist at Gata examined him... Said to make him do something. Here were some of the square boxes. After that, he said you need to go to a psychiatrist. I started to cry. Why psychiatry? Then when he said my child can have autism, I did not believe it. I started crying…*
>
> *Anıl'ı GATA'ya götürdüm. GATA'da bir çocuk gelişimci muayene etti… Bir şeyler yaptırdı. İşte şöyle kare kutulardan. Ondan sonra dedi sizin psikiyatriye gitmeniz gerekiyor diyince benim gözlerden akmaya başladı. Küçücük çocuğun psikiyatride ne işi var… Sonra doktor olabilir diyince, otizm olabilir diyince, ben kafamda o kadar büyütmüşüm ki otizmi, hani ağır bir otizm, çok ağırları da var. Ben ağlamaya başladım…*

Nuran was surprised that her child had autism and considered it a terrible thing.

> *... And the fact that my child has autism... you know, how can it be possible? As if it were a very terrible thing.*
>
> *…Bir de çocuğun hani otizmli olması… Hani bir ara bunu vav nasıl oldu, otizm mi diye bakıyorduk olaya. Hani çok korkunç bir şeymiş gibi…*

3.3.2. Getting support from psychiatry: "This is how I accepted it, I couldn't accept it"

Participants could not accept when they learned that the children had autism. They had difficulty accepting the situation and could not cope with it. They described that they were affected psychologically and as a result, they received psychiatric support.

Elif reports that after learning about the diagnosis of her child, she cried constantly and could not overcome it. She found it challenging to accept the diagnosis, but eventually accepted it by going to psychiatry.

> *P: Yes, we took him to the hospital, and they asked for a test. Finally, the psychiatry service decided that my child was autistic.*
> *R: How did you feel?*
> *P: I've been very bad. I was crying constantly? All day. I was affected badly. The last time we went to psychiatry. The doctor said you need therapy. I continued for five or six months... I was just getting better myself. Acceptance was difficult. We got support from psychiatry, I accepted it like that, I could not accept it…*

> *K: Evet hastaneye götürdük işte, test istediler. Şu test, bu test derken en son psikiyatri karar verdi. Otizm dedi.*
> *A: Siz neler hissetmiştiniz?*
> *K: Çok kötü oldum. Gece gündüz ağla ağla ağla. Böyle mahvoldum. En son psikiyatriye gittik. Dedi terapi alman lazım. İşte gitti beş altı ay devam ettim…. Yeni yeni zaten kendimi toparlıyordum. Baya bir kötü o kabullenme var ya. Baya bir destek aldık psikiyatriden öyle kabullendim, kabul edemiyordum…*

Mehtap had other health problems due to the psychological effects of the diagnosis process. She did not share her experiences with anyone and she could not overcome them. As a result of this, she began to receive psychological support.

> *R: How were you affected by that process? How did you feel when you were first told about the diagnosis?*
> *P: Well, look, I have had dental treatment for clenching my teeth. I have always clenched my teeth. I could not tell anyone about my feelings. I could not react to anyone... What's going on, only I know. I made a mistake I was even late going to the doctor to get support. When such news came related to Anıl, I was more difficult. After Anıl's diagnosis, I started to get support. The medicine feels good right now, I do not cry as much as I used to.*

> *A: Siz o süreçten nasıl etkilenmiştiniz? Tanı ilk söylendiğinde neler hissetmiştiniz?*
> *K: Valla bak dişlerimi sıkmaktan, dişler damak tedavisi gördüm. Daha dişlerim, yerleri iyileşecek… Hep sıkmışım, hep dişimi sıkmışım. Kimseye duygularını anlatamıyorsun. Kimseye tepki veremiyorsun… Ne oluyor, içinde yaşıyorsun. Ben hata etmişim aslında, doktora bile gitmekte geç kalmışım destek almaya öyle… Anıl'dan böyle bir haber gelince daha çok zorlandım. Sonra Anıl işte bu tanılar falan başlayınca, ben destek almaya gittim. İlaç şu an iyi geliyor, biraz daha ağlama koşullu olmuyorum.*

Mehtap defined her child's diagnosis as a devastating situation. She could not tolerate the situation. She adds that she was receiving psychiatric support and she took medicine.

> *… It was a devastating, sad situation for us too. I barely recovered myself, I got support from psychiatry. I am currently taking my medicine under the advice of the doctor…*

> *…Bizim için de yıkıcı, üzücü bir durumdu. Ben kendimi zor toparladım, destek aldım pskiyatriden. Şu an kullanıyorum ilacımı doktor tavsiyesi altında, gözetimi altında…*

Nuran was worried about raising her child, taking care of her, and accepting her. She said her child's diagnosis has heightened these concerns. After all the challenging experiences she had a panic attack disease.

> *Having a child, taking care of him, raising him. Huh, is this my child? Because many years of my life have already been spent with anxiety. As a result, I had a panic attack disease at the end. I mean, I have a report right now. The panic attack has started when the body is blocked. But thank God I am not in the hospital. My life is always anxious. I am asking constantly myself how it happens. Alper's autism is a word I have never heard in my life...*

> *Çocuğun olması, ona bakmak, onu büyütmek… Ha bu benim mi olayları. Hayatımın uzun yılları zaten kaygı ve endişeyle geçtiği için zaten en sonunda da panik atak hastalığı oldu. Yani şu an raporlu bir şekilde. Artık vücut tıkandığı yerde de panik atak başladı. Ama o çok şükür hastanelik olmuyorum, ilaç vesaire kulanmıyorum… Hep hayatım kaygı endişe, bu böyle mi olur, şöyle olsa, böyle mi olur. Özellikle Alper'in otizm hayatımda duymadığım bir kelime...*

3.3.3.Withdrawal from the social environment after diagnosis

Some of the participants stated that after learning about their children's diagnoses, they could not cope with this situation and did not leave the house. They socially closed themselves to the outside world, and spend their time at home.

Elif reported that she did not leave the house for two years after receiving the diagnosis.

> *P: Ali, I do not know, when we learned that he had autism, it was a difficult process, extremely difficult... I did not leave the house, I remember being closed in the house for months. I have never gone out... It was a very bad, terrible feeling. I was sorry, why my child was...*
> *R: How long did you spend at home like this?*
> *P: Quite a lot, I mean, I never left the house for two years.*

> *K: Ali biraz şey oldu, otizmli olduğunu öğrenince o zor bir süreçti, aşırı zordu….Çıkmadım evden, aylarca evde kapalı kaldığımı hatırlıyorum. Hiç çıkmadım…çok kötü berbat bir duyguydu. Üzülüyordum çocuk niye böyle oldu diye…*
> *A: Ne kadar süre böyle evde geçirmiştiniz?*
> *K: Baya yani iki sene hiç evden çıkmıyordum*

Mehtap talked about how after her child was diagnosed, she withdrew and secluded herself at home, refraining from meeting her relatives.

> *After the diagnosis, of course, there were changes in our lives. As I said, I closed down a little, I closed down at home... I was seeing my sisters sometimes because they had also children.*

> *Tanı konulduktan sonra tabii hayatımızda değişiklikler oldu. Dediğim gibi hani biraz ben içime kapandım, eve kapandım… İşte ablam, ortanca ablam, gelinleri olan ablama, onların da çocukları olduğu için, onlarla kapatmıştım gidip gelmeyi…*

3.3.4. Feeling disturbed by the other's gaze

Some of the participants said that the environment did not accept the behavior of their children. They reported that society viewed them differently from their children, and families felt uncomfortable with this perception. Elif expressed that because of the different behaviors of her child, society looked at her child strangely. This was a difficult situation. She said that being asked about his child's behavior was tiring.

> *… It is hard when they look at Ali because people look at him differently. There have been many times when I have picked him up and immediately left there, gone home, and closed the doors and windows. I do not go anywhere for a while, and I do not invite... For example, if you know Ali's behavior, there are differences in his behavior. It would be difficult for me if people looked at him differently. It would have been too hard for me. Why does Ali do this, Ali do this. This situation made me tired.*

> *Ali'ye baktıklarında, farklı baktıklarında çok zoruma gidiyor. Onu alıp hemen o toplumu terk edip eve geçip kapı pencereleri kapattığım defalarca oldu. Öyle artık kimseye gitmiyorum öyle kimseyi de eve almıyorum…Mesela Ali'nin davranışları biliyorsunuz, davranışlarında farklılık var. Toplum farklı bakınca benim zoruma giderdi. Bana çok ağır gelirdi. Ali niye böyle yapıyor, Ali niye böyle, Ali şöyle yap, kimi derdi niye böyle şöyle derken beynimi yoruyorlardı…*

Because of the child's cries, Methap and her child were regarded as strange by others. She faced difficulty in determining how she could support her child, all the while others continued to view the child as strange.

> *…Screams, calls, requests, because he could not speak. We have already understood this, the child screams because he cannot speak and express himself. He was screaming outside... They were looking. Why did I expose such things to my two children? I was taking Anıl to the kindergarten. It was close to my house, to our previous house. A woman… (some voices). What happened? What happened? Why is this child like this? I said, why do you look like that? Pray at least. I have encountered similar reactions to it so much... Now we are better, thanks God. People are surprised when they do not know. Not only your own family but those people you do not recognize on the street. The crying child, the screaming child... The more I thought about it, the I felt more tired. I thought constantly about what we can do for Anıl, what we can do, and where we can go. We were investigating, they were investigating. They were telling you. We were already getting tired, and I forgot about them. Of course, it was difficult at first… but now I am used to the situation.*

> *…Bağırmalar, çağırmalar, istekleri, konuşamadığı için. Biz bunu anladık zaten, çocuk konuşamadığı için, kendini ifade edemediği için bağırıyor. Bağıracak, dışarda bağırıyordu… Bakıyorlardı, niye öyle şeyler de yaşıyordum tabii ben iki çocuğumla. Anıl'ı alıp gidiyordum kreşe. Kreş benim evime yakındı, önceki evimize. Kadının biri cık cık cık. Ne oldu, ne oldu kapalı bir teyze, ne oldu, bu çocuk niye böyle. Dedim öyle bakana kadar, garipseyene kadar teyzecim dedim dua ediver…Ona benzer tepkilerle çok karşılaştım…Şimdi daha iyiyiz şükür Allah'a. İnsanlar bilmeyince yadırgıyorlar. Tek kendi ailen değil sokakta tanımayanlar. Ağlayan çocuğa, bağıran çocuğa… Bunu düşündükçe çünkü kafam daha çok yoruluyordu. Zaten Anıl'a ne yapabiliriz ne edebiliriz nereye gidebiliriz diye yoruluyorsun, araştırıyoruz, araştırıyorlar. Sana söylüyorlar. Zaten yoruluyorduk onlarla unutuyordum artık alışmıştım. İlk zamanlar tabii zor geliyordu…*

Nuran had received reactions to her child walking on tiptoe and that she was uncomfortable with people around her asking why this was the case. Her child understood when people looked at her child and he was upset. She felt sad due to the reactions from people while she was trying to cope and improve with her child's diagnosis. While she was sensitive to her child's condition, the reactions made her more upset. She was uncomfortable with the fact that other people spoke without knowledge about the process.

> *… Tiptoe is a problem for us now, I feel very sad. Since it is obvious. You know, why is he walking on tiptoe, because I get reactions like this all the time. People say why is he walking on tiptoe, step on your foot, why cannot this boy put his foot on the ground. I understand this, my child understands it too, of course... Unfortunately, this kind of person... I get upset, and because walking on tiptoe is also a physical event. Even if the child is very normal, when people look at his feet, their minds and behaviors change directly... I cannot tell them the whole story, I just say he walks like that. I say he likes it that way… I am sad, of course, because your child is different, It does not matter if he is different, but they do not need to tell it. You are already hurt by it, you are upset in some way... People just look at what is visible from the outside, they do not look at what you are working on or how you feel about it in any way.*
>
> *For example, sometimes when he holds himself like this, he screams differently. Then everyone turns around and looks. Sometimes he mumbles a lot, for example, when he gets on the bus, he sounds different like that, hi, hi, hi. Then they turn around and look, it does not matter, we also look when we see something like that. However, I think the reaction or look is very important. Since I already believe that children feel and understand more. We have situations like that…*
>
> *…Şu an işte parmak ucu bizim için problem, ona çok üzülüyorum. Çünkü o dışardan da şey yani, belli ya. Hani neden parmak ucunda yürüyor çünkü devamlı böyle tepkiler alıyorum. Dışardan aa niye parmak ucunda yürüyor, bassana ayağını, bu çocuk niye ayağını yere basamıyor. Bunu ben anlıyorum, benim çocuğum da anlıyor tabii ki de... İşte bu tarz insanlar oluyor…İnsan üzülüyor, bir de hani parmak ucunda yürümesi de fiziksel bir olay olduğu için dışardan bakınca, hani çocuk çok normal olsa bile ayağa baktığı zaman direk insanların bakışı hareketleri değişiyor…Ben ona baştaaan sona serüveni anlat desen anlatamam, öyle yürüyor diyorum, öyle yürüyor abla, öyle hoşlanıyor diyorum.. Üzülüyorum yani tabii ki de çünkü çocuğunun farklı olduğunu ha önemli değil farklı olsun, şöyle olsun böyle olsun ama hani gözüme gözüme de sokma. Zaten o konudan yaralısın, bir şekilde bir üzlüyorsun…İnsanlar sadece dışardan görünenene bakıyor ne emek verdiğine veya ne şekilde onunla ilgili ne hissettiğine bakmıyor.*
>
> *İşte mesela bazen böyle kendini tutup sıkıp sevindiğinde böyle bir değişik bir çığlık atıyor. O zaman herkes şöyle bir dönüyor, bakıyor. Bazen de çok mırıldanıyor mesela dolmuşta giderken hıı hıı hı diye gidiyor böyle. O zaman da şöyle bir dönüp bakıyorlar, ha bakın önemli değil biz de bakıyoruz öyle bir şey gördüğümüzde ama verilen tepki veya bakış bence çok önemli. Çünkü çocukların daha fazla hissettiğine ve anladığına ben inanıyorum zaten. O tarz durumlarımız oluyor…*

3.3.5. Resistance to accept the diagnosis: Denial

Participants emphasized that they were unable to accept the children's diagnosis during the diagnosis process.

When Elif went to her family and was told that her child might have autism, she stated that she was aware of it, but she could not accept it.

> *... When I went to my family in Adana, one or two people noticed that something was not normal in Ali. My family, my brother, and my aunt told me that there is something wrong with Ali. I could not accept it there, but I had feelings... I noticed it in a year and two months, but I could not accept it. And when the others said I could not accept it... I had to accept it, I do not accept it, but I have to.*
>
> *...Adana'da babamgile gittiğimde orda bir iki kişi Ali'de normal olmayan bir şey olduğunu fark ettiler. Ailem, ağabeyim olsun, bir tane yengem olsun bana dediler ki Ali'de normal olmayan bir şey var. Ben orda kabullenemedim ama hislerim vardı… Bir yaş iki ayda tam böyle Ali'de fark ettim ama kabullenemedim. Karşımdaki diyince de ben kabullenemedim… Kabullenmek zorundaydım aslında, kabul etmiyorum ama zorundayım öyle…*

Aynur did not want to accept the diagnosis and could not relate it to her child. She had found something to feel relaxed herself and that her child did not have autism.

> *…I wanted to believe that he has sensory integration disorder so no one wants to attribute this to their child… I was saying that, If he had autism, he could not get toilet training. I was saying he got toilet training. That way we were always finding something to feel relaxed... Probably we do not want to admit it. I guess I think to not happen to me. I do not know, it always happens in movies or something, it feels like you are not... We were always saying that our son has nothing, he is fine, he is just related to sports... I did not accept it at first... His character can change and develop, the doctors said. Then we went to another doctor, then to another, and in the end, they all said he has autism anyway...*
>
> *…Ben hatta diyordum duyu bütünleme bozukluğu varmış bu şekilde hani insan kendine yakıştırmak istemiyor…Otizm olsa tuvalet eğitimi alamaz, tuvalet eğitimi aldı diyordum. O şekilde kendimizi her zaman rahatlatacak bir şey buluyorduk…Kabullenmek istemiyor herhalde insan. Her zaman başkasında olacağını düşünüyor. Ne bileyim hep filmlerde falan olur ya öyle düşünüyorsun, hani sen değilsin gibi geliyor… Biz hep diyoduk oğlumuzun hiçbir şeyi yok, bir şeyi yok hani sadece sporla ilişkili … Kabullenmedim*

> *önce… İşte bir yelpaze gibi sonradan karakteri falan dönüşebilir dedi doktorlar. Sonra başka bir doktora gittik, sonra diğerine gittik, en son zaten hep otizm dediler…*

Gül said that she could not relate the diagnosis of autism to her child. She stated that the diagnosis meant something hard for her.

> *R: So what does being diagnosed with autism mean to you?*
> *P: Well, it means something very hard because a person cannot relate to her child. Why do we pass by saying autism, but autism is also a disease. It is a distressing process, the child does not know himself…*
>
> *A: Peki otizm tanısı almak sizin için ne ifade ediyor?*
> *K: Valla almak çok ağır bir şeyi ifade ediyor çünkü insan çocuğuna yakıştıramıyor, hiçbir şeyi yakıştıramıyor. O yüzden otizm diyip de geçiyoruz ama otizm de bir hastalıktır bir sıkıntılı süreçtir çocuk kendini bilmiyor etmiyor…*

Mehtap realized that there was “something” in her child, but she could not believe it. She expressed that after the examination, her child's behavior was not related to another condition, “only autism”.

> *P: There is always something wrong, okay, it is not severe autism, but there is.*
> *A: How did you interpret it because there is something?*
> *P: When I could not believe it. Now, after going to the doctor and going to the public hospital, I have decided on private doctors, yes, there is something... When we had all the tests done, he had only autism.*
>
> *K: Hep Anıl’da bir şey var tamam ağır bir otizm değil ama var*
> *A: Siz nasıl yorumluyordunuz bir şeyi var diye*
> *K: Hani ben inanamıştım. Artık doktora da gidip geldikten sonra devlet hastanesine özel doktorlara ben artık karar vermiştim, evet var… Hani bütün tetkiklerini yaptırdığımızda evet sadece otizm çıktı…*

Although Nuran understood that her child's behavior resembles the symptoms of autism, she did not want to rely on this information. When the doctors did not say autism exactly, she said that she was hopeful.

> *A: What did you attribute to the behaviors you observed at first?*
> *P: ...I never guessed he had autism. But of course, when I searched on the internet, I thought maybe it could be. There were some of the symptoms, there were not some. Then he began to show most of the autism symptoms for some*

> *time. Then it was just a minimum and just walking on tiptoe and not making eye contact. It was increasing from period to period, it was descending. I did not want to trust the internet. The doctors we went to did not diagnose autism. So I was getting more and more hopeful, uh, yes, it is not autism. So how many doctors saw him, none of them call it autism. I was getting my hopes up.*

> *A: siz gözlemlediğiniz davranışları ilk olarak neye atfetmiştiniz*
> *K: ...Hiçbir şeyi bilmediğin hiç aklıma işte otizm midir falan gelmedi. Ama tabii internetten şöyle bir baktığımda böyle bir kaç denk geldim olabilir mi dedim. Birazı vardı, birazı yoktu. Sonra bir dönem otizm semptomlarının çoğunu taşımaya başladı, sonra sadece işte en aza ve sadece parmak ucunda yürüme ve göz teması kurmama kaldı. Böyle dönem dönem artıyordu, iniyordu. Ben internete hani güvenmek istemiyordum, gittiğimiz doktorlar da hani teşhis koymuyor, otizm koymuyor, yani hiç bir şey koymuyordu. O yüzden de daha da umutlanıyordum aa evet bak otizm değil demek ki kaç tane doktora girdi, hiçbiri buna otizm demiyor diyordum bir ümitleniyordum.*

3.4. Acceptance after diagnosis

Participants mentioned they felt more relaxed after accepting their children's autism diagnosis and that they were now focusing on their children's education and needs.

3.4.1. Finding relief in acceptance of the diagnosis

Participants talked about they felt relaxed when they accepted the diagnosis of their children.

After Elif accepted the diagnosis, after understanding what happened to her child, she expressed that she felt more relaxed.

> *... And then I accepted it. I guess when I accepted it, I got better myself... And then I fully investigated what happened. So I am a little bit better, I am fine now. I am not the same as before.*

> *...Sonra artık kabullendim. Herhalde kabullenince kendimi toparladım... Sonra işte tam araştırdım ne olduğunu falan biraz rahatladık. Yani rahatladım biraz, iyiyim şimdi. Eskisi gibi değilim.*

Previously, Aynur thought her child's diagnosis should not be autism and that she thought her child might have other diagnoses. After that, she thought it is necessary to accept it now, to stop dealing with the diagnosis, and focus on the needs of her child.

> *It has to be accepted, even a child development specialist told me at one of the special trainings, never mind what happened, why are you feeling so sad. She said your child should receive special education. After that, I gave up the diagnosis anyway…*

> *Kabullenmek lazım, hatta bir çocuk gelişimci bana demişti özel eğitimlerden birinde, ne olduğunu boş ver, niye bu kadar takılıyorsun, neyse ne dedi. Her türlü özel eğitim alması lazım senin çocuğunun. Ondan sonra ben tanıyı bıraktım zaten…*

Nuran was better after accepting her child's diagnosis. She explained that she has moved from an anxious state to a more relaxed state. She also stated that she began to react calmer to her child's crying.

> *… And then, of course, as I accepted this situation, I think it was also due to not accepting it. The more I accept it, the I am more relaxed now. Even when he falls, I can say, Son, please stand up, you are okay. If he is crying for nothing and if there is nothing important, I can say, Alper, you can cry right now because there is nothing. Son, I am saying come to me. If he prefers to cry, I either wait for him to calm down or I take him and distract him in some way. I take it and put it down immediately, I am doing something. But before, when Alper cried, my whole world was destroyed.*

> *…Sonra tabii ki de bu durumu kabul ettikçe diyeyim, bence kabul etmemekten de kaynaklıydı, kabul ettikçe şu an daha rahatım. Düştüğünde bile oğlum kalk hayır hiçbir şeyin yok diyorum. Boş yere ağlıyorsa ortada hiçbir şey yoksa ve boş yere ağlıyorsa Alper'ciğim sen şu an ağlayabilirsin çünkü ortada hiçbir şey yok oğlum ya da gel bana söyle diyorum. Hayır ağlamayı tercih ediyorsa ya sakinleşmesini bekliyorum ya da alıp dikkatini bir şekilde dağıtıyorum. Alıp hemen aşağı indiriyorum, bir şey yapıyorum. Ama önceden Alper ağladığında benim bütün dünyam duruyordu*

3.4.2.Focusing on the education and development of the child after acceptance

After the participants accepted their children's diagnoses, they were interested in their educational processes and their development and were pleased with their progress.
Elif realized that her child's autism diagnosis would not pass. After that, she was inclined to attach importance to research to contribute to her child.

> *… I know how sad I am, Ali's autism will not end totally... I have got better for him. I said Ali's education could be better. I started researching something for*

> *him. How can I help, how can I contribute to him. When I am worse, he is too, we are better together right now. I was saying that if I do not teach him something if I do not contribute to him, we will not progress at all... Now I am more interested in his education. One day I take it there, one day here.*

> *Hani ne kadar üzülsem de Ali'nin otizmliği geçmeyecek… Onun için toparlandım. Dedim Ali'nin eğitimi şey olsun, onun için bir şeyler araştırmaya başladım. Nasıl bir yardım edebilirim, nasıl ona katkı verebilirim. Hani ben bitince o da bitiyor, o benimle şu an şeydir ayaktadır. Ben diyordum ona bir şey öğretmezsem, ona bir şey katmazsam hiç ilerleyemeyiz…Şimdi daha çok onun eğitimine şu an kendisini onun eğitimine vermişim. Bir gün oraya götürüyorum bir gün buraya…*

After the diagnosis process, Aynur saw that her child was getting better. Her child's education is continuing and she was happy with the development of her child.

> *... Right now, I think we are fine, I think he will talk. They say he will talk for a year or so. The luck was good. Thanks God. Our special education teachers are really good... I feel lucky. We are getting better now. I feel like everything is getting better right now after getting the diagnosis. I see that Berk is developing, he makes me very happy.*

> *…Şu an bence iyiyiz konuşacağını düşünüyorum. Bir yıla falan konuşur diyorlar. Bizim için şey oldu, şans iyiydi. Allah iyi insanlarla karşılaştırsın, özel eğitimi gerçekten hocalarımız iyi çok şükür. …Şansım döndü benim artık daha iyiye gidiyoruz tanı aldıktan sonra her şeyin iyiye gittiğini şu an hissediyorum. Berk'in geliştiğini görüyorum o beni çok mutlu ediyor*

Gül witnessed her child's developmental progress over time and emphasized that his education was ongoing.

> *... Since we are going to special education now, we are gradually starting to improve a little, it is getting better. We go to special education, we see the benefits there very well... Looking at the past, he has got better a lot since he went to special education, and he has improved.*

> *…Şu an özel eğitime gittiğimiz için kademe kademe biraz düzelmeye başlıyoruz, iyiye gidiyor. Özel eğitime gidiyoruz, ordaki faydaları çok iyi görüyoruz… Eskiye bakarak şu özel eğitime gidip geleli kendini çok toparladı, düzelmesi oldu.*

Mehtap talked about the fact that her child's autism diagnosis was not something that would go away. Education was important and her child's development was going well.

> *Autism, as you know, there is no treatment. It is just education, education, education... My son has been talking for six months now, so we are better. After being diagnosed, we continued kindergarten and special education. Anıl is well now.*

> *Otizm de biliyorsunuz işte ne tedavisi var ne bir şeyi var. Sadece eğitim, eğitim, eğitim…Şu an bir altı aydır konuşmaya başladı oğlum, daha iyiyiz yani. Böyle sonra tanı konduktan sonra biz kreş ve özel eğitime devam ettik Anıl şu an iyi durumda…*

Nuran also described that she will struggle for her child regardless of what his diagnosis is and will focus on his education. The process after accepting his diagnosis was easier for her.

> *… And then I accepted because whether he has autism or not, whether he has sensory deficiency or stimulus excess, I mean, no matter what. I am going to struggle. I will take him to training. I will strive for him. So when I accepted, everything became easier. At least our crying, our sadness is over, so now…*

> *…Sonra da kabul ettim çünkü otizm de olsa, olmasa da, ister duyu eksikliği olsun ister uyaran fazlalığı, yani ne olursa olsun ben bu yola gireceğim. Onu eğitimlere götüreceğim. Onun için çabalayacağım. Yani kabul edince her şey daha kolay oldu en azından ağlamalarımız üzülmelerimiz bitti yani artık…*

CHAPTER 4

DISCUSSION

This study aims to explore the experiences of mothers of children with autism during the diagnostic process of their children. IPA methodology was used to gain an in-depth understanding of these experiences. Interviews were conducted with five participants, and semi-structured questions were asked to understand mothers' experiences before, during, and following their children's diagnosis. The interviews were analyzed following the IPA methodology, and according to the results of the analysis, four themes emerged: *when there is no communication: challenges in mother-child communication in the pre-diagnostic period, delays in the process of diagnosis, what happened during the diagnosis process, and acceptance after diagnosis.*

4.1. When there is no communication: challenges in mother-child communication in the pre-diagnostic period

In this theme, participants stated that they had difficulty communicating with their children before their children were diagnosed. They mentioned that their children could not express themselves, and they did not understand what kind of needs their children had. Their children were trying to convey something, but the parents could not comprehend them. The situation led to a lack of effective communication between the mothers and their children. They expressed their sadness about the situation. They also explained that they had difficulty in calming their children's behaviors resulting from autism symptoms. These behaviors could occur at any time, whether at home or outside, and they felt sad and helpless when they could not calm their children down.

Communication difficulties in autistic children can lead to challenges in their interactions with their social partners. These problems negatively affect parental stress levels and the perceived difficulty of parenting (Bianco, 2018). Understanding the needs and emotions of an autistic child can be particularly challenging for parents, which can evoke a sense of helplessness. A child's major ways of expressing their distress are through non-verbal communication, such as crying, gazing, gesturing, and movement. Parents may fail to recognize their child's needs due to the atypical development of nonverbal communication abilities. In addition, individuals with ASD struggle to coordinate with their caregivers and integrate various expressive behaviors, including gaze and gestures (Bianco, 2018). In the present study, consistent with the literature, mothers expressed their difficulties in understanding their children's attempts to communicate. Both verbal and non-verbal communication posed challenges for these mothers. Participants noted a lack of understanding regarding their children's repetitive behaviors, such as constant crying or laughing, and they found it challenging to interpret when their children needed something. The absence of effective communication often led to negative emotions and feelings of distress among the parents.

Moreover, parents with autistic children expressed that they experienced feelings of shame concerning their children's atypical behavior (Lilley et al., 2020). The most significant factor contributing to parenting stress is having a child with autism who experiences or exhibits behavioral problems (Lecavalier et al., 2006). In one qualitative study involving the mothers of children with autism, it was found that these mothers expressed feelings of fear and uncertainty when it came to managing their child's behavior. They mentioned they were often confused by their lack of understanding about how to effectively intervene in their child’s repetitive behaviors (Papadopoulos, 2021). Consistent with this information in the literature, the participants in our study stated that they had difficulty calming down their children's repetitive behaviors. They explained that they felt helpless when they could not intervene in their children's behavior.

Furthermore, some mothers who have autistic children experience sadness and depression due to their children's communicational impairment and compulsive behaviors. The situation leads them to blame themselves, which negatively impacts their mood and outlook (Manono & Clasquin-Johnson, 2023). This can also impact their communication with their child, as mother-child interaction is not one-sided: it involves the active participation of both the mother and the child (Aoki 2003). Parents and children engage in a cyclical process wherein the reciprocal expression of needs and emotions constrains and influences one another. Hence, it is within this dynamic interplay of demands and limitations that a circular interaction develops between the mother and child, ultimately shaping their individual experiences as well as their broader relationship (Parpal & Maccoby, 1985). The communication issues in this theme can be interpreted as problems experienced not only by one side but by both the mother and the child. The child is trying to express themselves, but the mother cannot understand this expression. This leads mothers to experience various emotions. Reflecting these feelings onto their children perpetuates this state of miscommunication. This communication problem is associated with the dynamics between the mother and the child.

According to the Lacanian psychoanalytic perspective, the subject's ego is constructed during the mirror stage, guided by the mother's gaze and vocalization toward the child. Laznik attributes the structuring of the autistic subject to the absence of gaze between mother and child in the mirror stage (Laznik, 2018). The absence of vocalization and gaze in the relationship with the Other in the mirror stage is related to the structure of the autistic subject (Laznik, 2013). As a result, it is accepted that the autistic subject is not in the language realm (Brenner, 2021). The explanations provided by the Lacanian Psychoanalytic perspective regarding the autistic subject align with the information shared by the participants in this study. Mothers emphasize that their children struggle to express themselves and that there is a mutual lack of understanding. Given the absence of the Other in the subject's system and their consequent exclusion from the domain of language, establishing meaningful communication with the Other is a challenge. The autistic subject fundamentally resists engaging with the Other, employing the defense mechanism of autistic foreclosure, which is not part of the Other's system (Laplanche and Leclaire, 1972). Individuals with autism exhibit distinct characteristics in their unique world. An individual with autism has unique characteristics in his or her own world. Psychoanalysis attempts to grasp autism's “world of its own” by carefully listening to overarching narratives and gaining a deep understanding of autism. The mother may have difficulty comprehending the extraordinary characteristics of her child (Tarsia and Valendinova, 2021). In our study, the mothers reported facing challenges in communicating with individuals with autism due to specific characteristics. The participants described difficulties in communicating with their autistic children, citing distinctive features of autism, such as their children alternately crying and laughing without apparent reason, struggling to express themselves, and resorting to gestures, as well as crying without cause. Additionally, they noted characteristics like temper tantrums, avoidance of interactions with other children, crying when encountering them, experiencing fear, resistance to calm, and occasional displays of aggression.

Furthermore, the psychoanalytic perspective draws attention to the place of the Other in the construction of the subject. Therefore, it discusses the structuring of the autistic subject from a relational and reciprocal perspective. The reciprocal relationship between mother and child develops in the initial years of life (Fink, 1999). Particularly during the early years of life, active verbal and non-verbal interaction between mother and child and emotional behaviors, including gestures, facial expressions, and gaze, play a pivotal role in healthy development. Between the child and the parents, there is an active communication that is dependent on the child's willingness to be social and the parent's capacity to meet the needs of socialization of a child. Factors like maternal depression, insensitivity, and the child's pathological barriers can weaken this interaction. When one of the mothers is distracted by pathological or external reasons in their life, the organic interaction between the child and the mother becomes poorer (Leclère et al., 2014). This dynamic is also evident in the relationship between the child with autism and the mother. Parents who struggle to understand their child's situation and cannot receive a reaction from them may feel disappointed. Parents who do not receive a relational response from their children may feel inadequate in their parenting skills and thus can become dull like their children.

In the current study, mothers who attempted to communicate with their children might have experienced disappointment when they did not receive a response, potentially diminishing their motivation to communicate. This could have led to a decrease in their enthusiasm. The inability to sustain reciprocal communication may have distanced them further from understanding and communicating with their children. A parent who feels increasingly distressed and disheartened when failing to comprehend may not actively engage in this communication. In response to the unresponsiveness of their mother, who represents the first Other and with whom they initially establish a connection, the child may cease their efforts to express themselves and become more withdrawn.

In addition, most of the participants in the study stated that they did not understand their children as a mother and that a mother should understand her child. They associate understanding or not understanding their children's needs, expressions, and behaviors with motherhood. Mothers stated that they could not establish a bond with their children and that not being understood as mothers deeply upset them. This situation can also be interpreted as the expectation in the mother's mind that she understands every need of the child. It can be thought that there is no separation between mother and child in the mother's mind and that she sees herself and the child as a unity. Due to the nature of language, what is intended to be expressed can never be defined exactly. There is always a gap between our inner thoughts and the way we can articulate them using words. This gap or alienation is a fundamental aspect of human language and communication. There is always a lack of what really wants to be explained (Lacan, 1964/2013). The mothers in our study might not accept this lack of the child. They may have expectations that their children will be completely understood. As a mother, they may want to fully understand their child's needs and what they want to express by thinking of themselves and their child as a unity. The emphasis on motherhood in not understanding can be interpreted as the perception of the mother-child relationship as not separated.

A summary of this perspective can be found in Aynur's statement: *"I mean, I think a mother should be able to understand what her child is feeling even from a single glance."* The sentence effectively encapsulates this perspective. The mother defines herself from an omnipotent position and knows her child's needs. In other words, the mother sees herself in a position where she wants to know everything about her child.

4.2. Delays in the process of diagnosis

This theme of the study includes factors that lead to a delay in diagnosis. Participants stated that they observed that something was wrong with their children. Nevertheless, they indicated that they did not link it to autism but rather attributed it to causes other than autism. They correlated the variations in their children's behavior to factors such as the child's disposition, premature birth, and other health issues. They lacked awareness about autism before their children received a diagnosis, preventing them from comprehending the situation they were experiencing and labeling it as autism. Additionally, they noted delays caused by specialists when they noticed the issues in their children and sought assistance at the clinic.

In a study, which was a meta-synthesis study of 31 qualitative research articles investigating the experiences of families with children with autism, parents reported that there was something unusual in their child's development. Their children lacked eye contact and delayed communication ability, but they did not initially suspect autism. Some mentioned linking the child's atypical development with physiological problems; for instance, they believed their children might be deaf (DePape & Lindsay, 2014).

Furthermore, in a qualitative study conducted with eight fathers, which explored the fatherly experiences of those with children diagnosed with autism, the fathers described their experience as a journey. They stated that they had noticed that there was something wrong with their children's behavior and had sought answers for this. However, it was a long and complex process, and some of them stated that their children had been misdiagnosed. The behaviors that parents have difficulty understanding were attributed to non-autistic causes, such as speech and hearing impairments by specialists. Participants whose children were diagnosed early stated that they initially saw autism as a “monster” that disrupted their children's behavior and prevented their normal development (Burrell et al., 2017).

For instance, in a qualitative study involving six mothers investigating their initial experiences, the participants reported observing something wrong with their child. They stated that they felt that there was something strange in their child's development, but they were faced with an unknown experience. They described that they did not know about autism previously and that they had never experienced it before (Bilge, 2020). Studies focusing on parents' knowledge about ASD are quite limited. However, there are studies investigating ASD knowledge in the general population, including parents. These studies show that the general population has limited knowledge about ASD (Benallie, 2019). Furthermore, in a qualitative study involving 50 parents discussing their experiences when their child was diagnosed with autism, families mentioned that they initially had little knowledge about autism and mistakenly believed it might be a treatable condition. However, as they gained accurate information, their understanding of autism has improved (Selimoğlu et al., 2013).

Participants in the study had limited knowledge and expressed the belief that there was only one representation of autism with which they were familiar and that no other variations existed. They did not realize that autism is a spectrum; hence, they may not have noticed that each child exhibits different symptoms and features.

The lack of knowledge about autism in our study and attributing the symptoms observed in children to causes other than autism is consistent with the literature. Diagnosis occurs after mothers first notice developmental delays, atypical behaviors, or something unusual or wrong in their children. This is of course, related to a lack of knowledge, but mothers gave different explanations for the situation they noticed at the beginning. It took time for them to take action regarding the situation they noticed and consult a specialist. When evaluated from a psychoanalytical point of view, mothers may be in a state of unconscious, ignoring this different situation they face. They may use various unconscious defenses, such as denial, to cope with this situation. In such cases, they expect to have a typically developing child, but they are disappointed when a child with different developmental characteristics is born. The mothers' experiences, expectations, and emotions related to motherhood may be quite different from what they initially imagined, as they now need to navigate the unique challenges and experiences associated with raising a child with a disability (Harvey, 2015).

The process of diagnosing autism includes parents' and teachers' opinions at school or daycare, if any, and the involvement of psychiatry. It involves interviews with parents, a review of relevant medical, psychological, and/or educational records, cognitive-developmental assessment, direct play observation, adaptive function assessment, and a comprehensive medical examination (Kılınç et al., 2019). Diagnoses of ASD can be made by observing the detailed developmental stories of children and behavioral cases and applying psychometric measurements developed for autism (Aydın & Özgen, 2018).

Additionally, this study highlighted a significant time gap between parents observing developmental concerns in their children and receiving the diagnosis. Families reported that specialists diagnosed their children within 10-15 minutes solely based on the information provided by the parents. They revealed that the evaluation was brief, and they received varied advice from other doctors. Some doctors suggested that the process arose due to their children's higher intelligence, leading to a misinterpretation of symptoms. Subsequently, they highlighted that the diagnosis might occur after the child begins kindergarten or school, prompted by teachers' observations. This scenario resulted in a delay in the diagnostic process (Selimoğlu et al., 2013).

Similarly, in a qualitative study exploring the perspectives of 15 doctors working in autism diagnosis units on the diagnosis process, the doctors reported that they allocated an average of 24 minutes for each diagnosis. They noted that families frequently lacked sufficient information and held expectations that their children could improve solely through medication. The doctors expressed negative opinions about the absence of a clear biological marker for autism diagnosis, the lack of comprehensive monitoring of the child's neuro-motor development, and the inadequacy of available special education resources (Karaarslan & Karaarslan, 2016).

Reasons for the delay in diagnosis can be attributed to various factors, including the manifestation of distinct symptoms and characteristics in each child, the utilization of different assessment tools, time constraints during the preschool period, professionals' limited awareness of mild ASD symptoms, and the scarcity of specialist physicians (Siklos & Kerns, 2005).

The information provided in the literature is consistent with the findings of the study, emphasizing that achieving an early diagnosis of autism necessitates a diagnostic process that involves collaboration between families and experts and should be conducted based on accurate information. In Turkey, diagnostic procedures can significantly differ among various institutions. A notable limitation is the lack of medical specialists with expertise in autism (Tohum Otizm Vakfı, 2017). For early diagnosis and intervention, it is thus vital to educate and better equip health personnel working in this field. Additionally, allocating sufficient time for interviews is essential in fostering comprehensive assessments and understanding the nuances of each case.

4.3. What happened during the diagnosis process

This theme reveals that participants faced several challenges during the diagnosis process. They described the moment they learned of their child's ASD diagnosis as a shocking and traumatic experience. Some participants stated that they received psychiatric support to accept this situation. Some participants indicated that they closed themselves off to the outside world during the diagnosis process, did not leave the house for a while, and withdrew from social life. They also mentioned that people around them sometimes reacted negatively to their children's atypical behavior, which was distressing for them. Throughout the diagnosis process, they struggled to accept the autism diagnosis for their child, hoping for a different outcome, but ultimately, their children were diagnosed with autism.

Parents often undergo an experience similar to the grieving process when their child receives such a diagnosis—they may go through stages of shock, denial, anger, bargaining, and depression (Blacher, 1984; Case, 2000; Howard et al., 2009). Following their child's diagnosis of ASD, they commonly experience feelings of sadness, denial, confusion, isolation, and depression (Siklos & Kerns, 2005). According to them, the most stressful time in their lives related to their child's impairment was the post-diagnostic period (Nealy et al., 2012). Following an ASD diagnosis, parents frequently suffer feelings of grief and loss, worry about the diagnosis' consequences over time, and experience a sense of mourning for life events that they believe their children could never experience (Burrell et al., 2017). Moreover, a child's autism diagnosis comes as an unexpected result for families, with their initial reaction often being one of shock. During this stage, families may experience reactions such as crying, being unresponsive, and feeling powerless and helpless (Dertli &

Başdaş, 2022). Our study aligns with the information found in the literature. Mothers expressed a range of emotions during this process, including shock, isolation, and depression. Despite receiving the diagnosis from a specialist, they found the process of acceptance to be challenging. They experienced this process as if they were going through mourning.

Moreover, parents were generally initially disappointed and did not want to accept their child's diagnosis (Broski & Dunn, 2020). Because parents who learn that their child is disabled usually do not want to believe it, and this stage is a defense mechanism that parents temporarily adopt (Dertli & Başdaş, 2022). In addition, families require educational, psychological, and social support for both themselves and their children. It highlighted that families face challenges in dealing with negative societal attitudes toward disabilities (Aslan et al., 2014). For instance, in a study, it was observed that parents of autistic children experienced a smoother diagnostic process when they received psychological support. Parents expressed that they did not receive adequate benefits from family counseling services, but they desired and required access to such support. Additionally, the study revealed a lack of well-structured mental health services specifically designed for parents of children with autism. While special education teachers and special education and rehabilitation centers attempted to address such parents' needs, it was emphasized in the narratives that education, health, and psycho-social support were generally insufficient (Köksal & Erciyes, 2015). Thus, this current study is consistent with the literature as it was revealed that the participants experienced a traumatic experience when their children were diagnosed, experiencing shock and disbelief, which led them to deny the diagnosis initially. Due to their difficulty in accepting the diagnosis, many of them sought psychological support to cope with their emotions.

Furthermore, autistic individuals around the world are frequently faced with stigma—they may be labeled because they are different, and this may cause them to be discriminated against. Internalization of this stigma may further cause autistic individuals to lose their self-confidence (Araujo et al., 2023). In a study involving mothers of children with autism, the majority of the mothers indicated having faced stigma, which led them to avoid leaving their homes, and thus, they became socially withdrawn (Papadopoulos, 2021). In another qualitative study conducted with six mothers and four fathers, which examined the challenges faced by families with autistic children in their social relationships, the participants expressed being disturbed by the social attitudes towards autism they had noted. They described feeling excluded and isolated, thereby leading them to avoid social interactions. The parents mentioned being particularly bothered by the reactions of their environment, especially when their children exhibited problematic behavior in public areas (Yüksel & Tanrıverdi, 2019). Parallel to the literature, the current study demonstrates that mothers of autistic children experience stigma and subsequently withdraw themselves from social environments. Autistic individuals often face a lack of social acceptance in their environment, with this exclusion by society becoming an even more significant challenge for mothers who are attempting to manage the behavioral problems associated with autism during the diagnosis process.

Mothers' experiences during the diagnosis process can be discussed psychoanalytically around the concept of “uncanny” and “ambivalent feelings." Freud's idea of the uncanny is rooted in the early stages of mental development, especially in the infantile ego. During this period, the developing ego has a natural inclination to project outwards what it finds unfamiliar or strange within itself. This process can lead to feelings of fear when we encounter something in others that reflects these hidden, disturbing aspects of ourselves that we repress and hide. The uncanny is, in essence, the collision of the hidden and the familiar, creating a feeling of discomfort and fear (Freud, 1919). This feeling of “strangeness” perceived from the outside is actually a feeling reflected by the ego. This is why Freud used the German terms “Heimlich” and “unheimlich” together to describe the uncanny. The familiar and homely become at the same time distant and unfamiliar (Freud, 1919). The concept of uncanny, which Freud based on the development of the ego, can be discussed as similar to the ambivalent situation that occurs in the formation of the ego in Lacan's mirror stage (Harvey, 2020). Lacan states that the subject, who perceives himself as fragmented in the mirror stage, comprehends himself through the gaze of the Other. This is a moment of both triumph and traumatic moment for the subject. The source of ambivalent feelings in the formation of the subject is in the mirror phase. Freud's concept of the uncanny and Lacan's concept of the mirror stage can be used to discuss the feelings experienced by a mother with a disabled child (Harvey, 2020). Although Freud indirectly linked the uncanny to disability and illustrated this through cases of blindness, dismembered limbs, and epilepsy, the concept of uncanny helps explain mothers' experiences and complicated feelings towards their disabled children. This uncanny thought sheds light on how these mothers balance their deep discomfort toward their disabled children with their maternal compassion and love (Harvey, 2020). If we look at the experiences of the mothers in our study during the diagnosis process of their children, all the participants state that they do not want to accept their children's diagnosis. Most of the participants express that they are disturbed by the way others look at their children. This may actually be related to the uncanny feelings mothers feel towards their children. Mothers may develop a defense that they do not want to accept the atypical behavior of their children and push it out. When they receive a comment about "strangeness" from outside, they may be disturbed by an outside "weirdness." This may describe both the mothers' own gaze and the gaze of others. When the diagnosis that mothers want to repress, do not want to accept, or deny is reflected on the mother from the other's perspective, various feelings of discomfort occur in the mother. In this sense, complex, ambivalent feelings arise in the mother towards her child. We can see the ambivalence of the participants regarding their refusal to accept their children's diagnosis in the following statements: *"I noticed it in a year and two months, but I could not accept it. And when the others said I could not accept it... I had to accept it, I do not accept it, but I have to", "Then we went to another doctor, then to another, and in the end, they all said he has autism anyway...",* *"A person cannot relate to her child," "I have decided on private doctors, yes, there is something... When we had all the tests done, he had only autism."*, *"So, many doctors saw him, but none of them called it autism. I was getting my hopes up."* Mothers actually state that they are aware of the situation, but at the same time, they have difficulty accepting it. By saying, "It is not autism," these mothers describe their own ambivalent feelings as a condition that they both know about and do not want to know about.

4.4. Acceptance after diagnosis

The participants expressed a sense of relief after accepting their child's diagnosis, mentioning that they stopped being preoccupied with the diagnosis itself and instead shifted focused on addressing their children's unique needs. This acceptance led them to become more engaged in their children's development and education.

The stages that parents with a disabled child go through during the diagnosis of their children are defined together as the acceptance model. This model, based on the theory of grief, includes the following phases: shock, denial, anger, bargaining, and depression (Kübler-Ross, 1969). Drotar et al. (1975) defined adaptation and re-organization as the final emotional process that families go through after their children have been diagnosed, with this last stage that families go through, including the processes of adapting and coping with the situation. Therefore, parents learn how to live with their child's disability and can then focus on their child's strengths, education, and future. They have more realistic expectations about their children; thus, parents who go through this stage can contribute more to their children's education (Webber & Scheuermann, 2008). In the current study, participants experienced a range of emotions and underwent various stages during their children's diagnosis process. Our findings suggest that a child's diagnosis should be viewed as a process, as over time, parents of such children appear to adapt to the circumstances. It's important to note that parents who go through this process can experience complex and varied emotions, but eventually, they become more aware of their children's unique characteristics. This process includes a wide range of experiences and emotions.

Furthermore, in a study conducted by DePape and Lindsay (2018), parents mentioned that after accepting their child’s diagnosis of autism, they experienced more typical emotions and were able to adopt a normal life. Instead of attempting to fix their children, they focused on their children's future and meeting their specific needs. This process is called “moving forward” in the study. In addition, post-traumatic growth refers to the positive changes experienced by individuals who have gone through challenging experiences as a result of the difficulties they faced. The parents of children with ASD reported experiencing post-traumatic growth, which included learning to be more patient, experiencing enriching effects in their lives from raising a child with ASD, personally feeling stronger, more patient, and having increased empathy skills (Yassıbaş, 2015). Experiencing traumatic losses, like recognizing that the child won't go through normal developmental stages, might cause parents to gain new perspectives on life as well as a stronger sense of spirituality and inner fortitude

(Zhang et al., 2013). In this study, participants stated that they were able to better understand their children's needs and abilities after going through a complicated process. They said that after the complex situation they experienced, they were able to focus on their children's development and made progress in this regard.

Mothers of children with disabilities initially encounter an unfamiliar and foreign situation in response to the challenges their children face (Harvey, 2020). In our study, mothers also confronted such situations. Experiences that are incomprehensible, foreign, and uncanny tend to generate discomfort and give rise to complex emotions (Freud, 1919). However, their child eventually diagnosed with autism might have helped them find meaning in their child's behavior by understanding its underlying cause. Receiving a diagnosis can provide “recognition” such as structuring the subject and reaching a wholeness in Lacan's mirror stage (Baltacı et al., 2023). Having their child finally receive a diagnosis of autism may have helped them make sense of their behavior in terms of understanding the cause. It could have enabled mothers to perceive their child differently and provide a framework for their experiences.

4.5. Conclusions and Contributions of the Study

The current contribution of this study is to provide an in-depth interpretive examination of the experiences of mothers of children with autism during their diagnosis period and their efforts to make sense of it. The study reveals that mothers go through various stages and experience grief during the process of diagnosing their children. Participants initially did not know what they were encountering and tried to relate it to multiple reasons. Later, when they heard the diagnosis, they experienced various emotions such as shock and denial. After experiencing multiple complex emotions, they accepted their children's diagnoses and were able to focus on their development and education. The experiences of mothers are part of a process, and the negative, complex emotions they feel are a component of this journey. It can help mothers who have autistic children and have feelings such as helplessness, anger, and sadness to make sense of this process. It may help mental health professionals working with autism deepen their understanding of these processes and emotions.

The study draws attention to the lack of communication between mother and child, especially in the pre-diagnostic period. The “lack of communication” between mother and child can be improved through mother-child interventions. It is essential to strengthen mother-child interaction with early interventions. Psychoanalytic therapies for mother-child interactions can help the mother understand the child's introverted world. This may motivate the child to get reactions from the mother and express herself (Laznik, 2000). The findings of the study highlight a communication problem between mother and child. The mother has difficulty interpreting and intervening in the child's actions, leading to feelings of helplessness. Therefore, strengthening mother-child communication through appropriate intervention programs is essential for the mental health of mothers, children, and the community.

Furthermore, participants state that they experience disruptions in services such as specialists, schools, and hospitals during the diagnosis process. In addition to the correct information received from parents, it is also essential that the specialist who makes observations and diagnoses at school has sufficient information. This situation draws attention to the importance of teamwork for early diagnosis and, therefore, early intervention.

4.6. Limitations and Future Research

The study focused on mothers of children with autism aged between 3 and 6.5. Inclusion criteria included the requirement that the child with autism was their first child and the mothers had not previously experienced the loss of a child. Three of the participating mothers had two children, and two had only one child. Choosing a more homogenous group among all participants could have provided a deeper understanding of the experiences of mothers who have multiple children. It would also have been valuable to collect information about sibling dynamics from the mother's perspective.

Another criterion in the study was that children with autism were boys. Given gender roles, autism may be more difficult to diagnose in girls than in boys. Since the symptoms of autism exhibited by autistic girls are generally associated with their temperament, such as being well-behaved, intelligent, and calm, it is more difficult to diagnose them (Hull et al., 2020). Therefore, the signs may be more challenging to identify in girls. A possible recommendation for future research is to conduct a study involving mothers of girls with autism.

Moreover, the study centered on children diagnosed with autism between the ages of 2 and 3.5 years. The literature suggests that the typical age for diagnosing autism is around 3 (Sauer, 2021). Research involving mothers of children diagnosed later than three years could explore how family dynamics are experienced, the awareness of symptoms, the mechanisms of denial, and related factors. Thus, the dynamics of delay in diagnosis might be better understood.

In addition, the study specifically involved mothers whose first child had autism. It examined the experiences of first-time mothers. Future research might focus on mothers whose first child developed typically, but their second child had autism. Such research may better explain how experiences of motherhood differ from those of recognizing a child has autism after raising a "typical" child. Experiences of mother-child interaction in two situations can be investigated.

REFERENCES

Adler, B. A., Minshawi, N. F., & Erickson, C. A. (2014). *Evolution of autism: from Kanner to the DSM-V* In J. Tarbox, D. R. Dixon, P. Sturmey, & J. L. Matson (Eds.). Handbook of Early Intervention for Autism Spectrum Disorders (pp. 3-26). Springer.

Akkök, F. (2003). *Farklı özelliğe sahip olan çocuk aileleri ve ailelerle yapılan çalışmalar.* A. Ataman (Ed.). Özel eğitime giriş. Ankara: Gündüz Eğitim Yayıncılık.

Akkuş, P., Saygan, B. B., Bahadur, E. I., Cak, T., & Özmert, E. N. (2020). Otizm spektrum bozukluğu tanısı ile yaşamak: ailelerin deneyimleri. *Türkiye Çocuk Hastalıkları Dergisi*, 1–8. https://doi.org/10.12956/tchd.731752

Alase, A. O. (2017). The interpretative phenomenological analysis (IPA): A guide to a good qualitative research approach. *International Journal of Education and Literacy Studies*, *5*(2), 9. https://doi.org/10.7575/aiac.ijels.v.5n.2p.9

American Psychiatric Association (APA). (1952). *Diagnostic and statistical manual of mental disorders, (DSM-I).* Washington, DC: American Psychiatric Press.

American Psychiatric Association (APA). (1968). *Diagnostic and statistical manual of mental disorders, 2nd edition (DSM-II).* Washington, DC: American Psychiatric Press.

American Psychiatric Association (APA). (1980*). Diagnostic and statistical manual of mental disorders, 3rd edition (DSM-III).* Washington, DC: American Psychiatric Press.

American Psychiatric Association (APA). (1987). *Diagnostic and statistical manual of mental disorders, 3rd edition revised (DSMIII-R).* Washington, DC: American Psychiatric Publishing.

American Psychiatric Association (APA). (1994). *Diagnostic and statistical manual of mental disorders, 4th edition (DSM-IV).* Washington, DC: American Psychiatric Publishing.

American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders: DSM-5-TR*. Washington, DC: American Psychiatric Press.

Aoki, K. (2003). Psychology of parent-child relationship (the Nihon Shortwave Broadcasting Co., Ltd., Trans.). *JMAJ, 46*(2): 75–79. https://www.med.or.jp/english/pdf/2003_02/075_079.pdf (Original work published 2001).

Araujo, A. G. R., Da Silva, M. A., Bandeira, P. F. R., Gillespie-Lynch, K., & Zanon, R. B. (2023). Stigma and knowledge about autism in Brazil: A psychometric and intervention study. *Autism,* 136236132311689. https://doi.org/10.1177/13623613231168917

Ar-Karcı, Y., (2022). Yorumlayıcı fenomonolojik analizin psikoterapi süreç araştırmalarında kullanımı. In S. Sarı (Ed.). *Psikoterapi Süreç Araştırmaları Nitel Araştırma Yöntemlerinin Psikoterapi Araştırmalarına Uygulanması* (pp. 53-81). Nobel.

Aslan, Y. G., Cihan, H., & Altin, D. (2014). Otizm spektrum bozukluğu tanılı çocuk sahibi annelerin deneyimleri. *Elektronik Sosyal Bilimler Dergisi*, *50*(50). https://doi.org/10.17755/esosder.41128

Asmare, R. F., Taye, F. N., Kotecho, M. G., Mishna, F., & Regehr, C. (2023). Towards a "new mothering" practice? the life experiences of mothers raising a child with autism in urban Ethiopia. *International Journal of Environmental Research and Public Health, 20*(7), 5333. https://doi.org/10.3390/ijerph20075333

Asperger, H. (1991). 'Autistic psychopathy' in childhood. In U. Frith (Ed.), *Autism and Asperger syndrome* (pp. 37-92). Cambridge: Cambridge University Press. doi:10.1017/CBO9780511526770.002

Avşaroğlu, S., & Güleş, E. (2019). Özel gereksinimli çocuğa sahip anne babaların yaşam doyumlarının öz- anlayış ve merhamet düzeyleri açısından incelenmesi *Kastamonu Eğitim Dergisi*, *27*(1), 365–376. https://doi.org/10.24106/kefdergi.2960

Awwad, A. (2020). *Experiences and knowledge of turkish siblings regarding autism spectrum disorder* [M.S. - Master thesis]. Anadolu University.

Aydin, D., & Özgen, Z. E. (2018). Çocuklarda otizm spektrum bozukluğu ve erken tanılamada hemşirenin rolü. *Gümüşhane Üniversitesi Sağlık Bilimleri Dergisi*, *7*(3),93–101. https://app.trdizin.gov.tr/makale/TXpFMU5ERTVPUT09/cocuklarda-otizm-spektrum-bozuklugu-ve-erken-tanilamada-hemsirenin-rolu

Aysever, H., & Demirok, M. S. (2019). Özel gereksinimli çocuğa sahip ebeveynlerin sosyal destek algılarının ve yılmazlık düzeylerinin incelenmesi. *Ankara Üniversitesi Eğitim Bilimleri Fakültesi Özel Eğitim Dergisi, 20*(3), 561–595. https://doi.org/10.21565/ozelegitimdergisi.467417

Baltacı, S., Gençöz, T., & Sarı, S. (2023). Diagnosis, Stigmatization or Legitimization? A Discussion within the Medicalization Discourse and Lacanian Psychoanalytic Theory. *Ayna Klinik Psikoloji Dergisi*, *10*(3), 413–427. https://doi.org/10.31682/ayna.1351575

Benallie, K. J., "Parent Knowledge of Autism Spectrum Disorder" (2019). *All Graduate Theses and Dissertations*. 7693. https://digitalcommons.usu.edu/etd/7693

Benoist, V. (2011). L'Autre dans L'Autisme. *International Psychology, Practice and Research, (2),* 1–13.

Bilge, E., İ., (2020). *An ınterpretative phenomenological analysis of first time mothers' experiences on raising twins with one child diagnosed with autism and the other one typically developing* [M.S. - Master thesis]. Bahçeşehir University.

Bilgin, H., & Kucuk, R. L. (2010). Raising an autistic child: perspectives from Turkish mothers. *Journal of Child and Adolescent Psychiatric Nursing*, *23*(2), 92–99. https://doi.org/10.1111/j.1744-6171.2010.00228.x

Birtwell, K. B., Willoughby, B., Nowinski, L. (2016). Social, cognitive, and behavioral development of children and adolescents with autism spectrum disorder. In C. J. McDougle (Ed.), *Autism spectrum disorder.* (pp. 19-30). Oxford University Press.

Bohadana, G., Morrissey, S. A., & Paynter, J. (2020). Self-compassion in mothers of children with autism spectrum disorder: A qualitative analysis. *Journal of Autism and Developmental Disorders,* *51*(4), 1290–1303. https://doi.org/10.1007/s10803-020-04612-2

Bond, A. H. (2015). *Margaret Mahler: A biography of the psychoanalyst*. McFarland.

Boucher, J. (2003). Language development in autism. *International Congress Series, 1254*, 247–253. https://doi.org/10.1016/s0531-5131(03)00976-2

Bowlby, J. (1961). Processes of mourning. *International Journal of Psychoanalysis,* 42.

Bowlby, J. (1980). *Attachment and loss III: Loss, sadness and depression*. New York: Basic Books.

Bowlby, J. and Parkes, C. (1970) *Separation and loss within the family*. In Anthony, E.J. (ed.) The Child in His Family. New York: Whiley.

Bowler, D. M., (2007). *Autism spectrum disorders: psychological theory and research* John Wiley & Sons.

Bölte, S. (2014). The power of words: Is qualitative research as important as quantitative research in the study of autism? *Autism*, *18*(2), 67–68. https://doi.org/10.1177/1362361313517367

Bölte, S., Girdler, S., & Marschik, P. B. (2018). The contribution of environmental exposure to the etiology of autism spectrum disorder. *Cellular and Molecular Life Sciences*, *76*(7), 1275–1297. https://doi.org/10.1007/s00018-018-2988-4

Brenner, L. S. (2021). *The autistic subject: on the threshold of language*. Palgrave Macmillan.

Broski, J., & Dunn, W. (2020). Parent mental models of transition related to their child's developmental diagnosis. *Journal of Child and Family Studies*, *29*(9), 2377–2389. https://doi.org/10.1007/s10826-020-01735-z
Bulletin Freudienne,34,1-16

Burrell, A., Ives, J., & Unwin, G. (2017). The Experiences of Fathers Who Have Offspring with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *47*(4), 1135–1147. https://doi.org/10.1007/s10803-017-3035-2

Centers for Disease Control and Prevention. (2020). *Data & statistics on autism spectrum disorder*. Retrieved from https://www.cdc.gov/ncbddd/autism/data.html

Chan, Z. C., Fung, Y., & Chien, W. (2013). Bracketing in phenomenology: only undertaken in the data collection and analysis process. *The Qualitative Report*, *18*(30), 1-9. https://doi.org/10.46743/2160-3715/2013.1486

Chen, W., Zhang, Z., Wang, H., Tseng, T., Ma, P., & Chen, L. (2021). Perceptions of autism spectrum disorder (ASD) etiology among parents of children with ASD. *International Journal of Environmental Research and Public Health*, *18*(13), 6774. https://doi.org/10.3390/ijerph18136774

Chericoni, N., De Brito Wanderley, D., Costanzo, V., Diniz-Gonçalves, A., Gille, M. L., Parlato, E. M., Cohen, D., Apicella, F., Calderoni, S., & Muratori, F. (2016). Pre-linguistic vocal trajectories at 6–18 months of age as early markers of autism. *Frontiers in Psychology*, *7*. https://doi.org/10.3389/fpsyg.2016.01595

Coates, S. (2004). John Bowlby and Margaret S. Mahler: Their lives and theories. *Journal of the American Psychoanalytic Association*, *52*(2), 571–601. https://doi.org/10.1177/00030651040520020601

Çolak, A. (2016). Otizm spektrum bozukluğunu anlamak. In A. Cavyaktar (Ed.). *Otizm spektrum bozukluğu* (2nd ed., pp. 21-58). Aile ve Sosyal Hizmetler Bakanlığı. Grafiker.

Dağıdır, H. G., Bukan, N., Bahçelioğlu, M., (2022). Otizmin etiyolojisi. *FBB 4*(2):49-57

Del Bianco, T., Ozturk, Y., Basadonne, I., Mazzoni, N., & Venuti, P. (2018). The thorn in the dyad: A vision on parent-child relationship in autism spectrum disorder. *Europe's Journal of Psychology*, *14*(3), 695–709. https://doi.org/10.5964/ejop.v14i3.1453

Demirbaş, D. (2021). *Otizmli çocuğu olan ebeveynlerin otizme yönelik söylemleri* [M.S. - Master thesis]. İstanbul Arel University.

Denny, E., & Weckesser, A. (2022). How to do qualitative research? *BJOG: An International Journal of Obstetrics and Gynaecology*, *129*(7), 1166–1167. https://doi.org/10.1111/1471-0528.17150

Denucci, B. L., De Lima, L. S., Mota, I. F. L., Azevedo, J. R. M., Veras, L. G., Bicca, J. V. M. L., De Miranda Santana, B., Pinheiro, G. B., Coelho, G. G., & Mortari, M. R. (2021). Current knowledge, challenges, new perspectives of the study, and treatments of Autism Spectrum Disorder. *Reproductive Toxicology*, 106, 82–93. https://doi.org/10.1016/j.reprotox.2021.10.010

DePape, A., & Lindsay, S. (2014). Parents' experiences of caring for a child with autism spectrum disorder. *Qualitative Health Research*, *25*(4), 569–583. https://doi.org/10.1177/1049732314552455

Dertli, S., & Başdaş, Ö. (2022). In the Adaptation Process of Parents with a Child Diagnosed with Autism Using the Human-to-Human Relationship Model. *Arsiv Kaynak Tarama Dergisi*, *31*(3), 237–242. https://doi.org/10.17827/aktd.1078456

Dietert, R. R., Dietert, J., & DeWitt, J. C. (2011). Environmental risk factors for autism. *Emerging Health Threats Journal*, *4*(1), 7111. https://doi.org/10.3402/ehtj.v4i0.7111
DOI:
https://doi.org/10.36255/exonpublications.autismspectrumdisorders.2021

Dor, J. (1998). *Clinical Lacan*. Other Press, LLC.

Down Sedromu, Otizm ve Diğer Gelişim Bozukluklarının Yaygınlığının Tespiti ile İlgili Bireylerin ve Ailelerinin Sorunlarının Çözümü İçin Alınması Gereken Tedbirlerin Belirlenmesi Amacıyla Kurulan Meclis Araştırması Komisyon Raporu. Otizm Spektrum Bozukluğu Özelinde Rapor Özeti. (2020). Retrived July 8, 2023, from https://tohumotizm.org.tr/wp-content/uploads/2021/02/TBMM_Komisyon_Raporu_yonetici-ozeti.pdf

Drotar, D., Baskiewicz, A., Irvin, N., Kennell, J. H., & Klaus, M. H. (1975). The adaptation of parents to the birth of an infant with a congenital malformation: a hypothetical model. *Pediatrics*, *56*(5), 710–717. https://doi.org/10.1542/peds.56.5.710

Dur, Ş., & Mutlu, B. (2018). Autism spectrum disorder and nursing approach. *Koç Üniversitesi Hemşirelikte Eğitim Ve Araştırma Dergisi*. https://doi.org/10.5222/head.2018.045

Eatough, V., & Smith, J. A., (2017). The SAGE Handbook of Qualitative Research in Psychology. In C. Willig, & W. Steinton-Rogers, (Eds.). *SAGE Publications Ltd eBooks*. (pp. 193-211). SAGE Publishing. https://doi.org/10.4135/9781526405555

Engward, H., & Goldspink, S. (2020). Lodgers in the house: living with the data in interpretive phenomenological analysis research. *Reflective Practice*, *21*(1), 41–53. https://doi.org/10.1080/14623943.2019.1708305

Ersoy, Y. D. D. R., & Çürük, A. (2009). Özel gereksinimli çocuğa sahip annelerde sosyal desteğin önemi. *Sosyal Politika Çalışmaları Dergisi*, *17*(17), 104–110. https://doi.org/10.21560/spcd.73242

Evans, D. (2006). *An introductory dictionary of Lacanian psychonalysis*. Routledge.

Feinstein, A. (2010). *A history of autism: conversations with the pioneers*. Wiley-Blackwell.

Fink, B. (1997). *The Lacanian subject: Between language and jouissance*. Princeton University Press.

Fink, B. (1999). *A clinical introduction to Lacanian psychoanalysis: Theory and Technique*. Harvard University Press.

Freud, S. (1919). The uncanny. *The standard edition of the complete psychological works of Sigmund Freud, Volume XVII (1917–1919):* An infantile neurosis and other works. London, UK: Hogarth Press.

Frith, U. (1992). Autism and Asperger syndrome. *Focus on Autistic Behavior*, *7*(3), 13–15. https://doi.org/10.1177/108835769200700302

Gadre, V. & Mardhekar, V. (2015). Does having a normal child benefit mothers psychologically over those mothers with only special child?, *Journal of Psychosocial Research, 10*(2), 393-399.

Gallo, D. P. (2010). *Diagnosing autism spectrum disorders: A lifespan perspective*. Oxford:Wiley-Blackwell.

Gearing, R. E. (2004). Bracketing in Research: A typology. *Qualitative Health Research*, *14*(10), 1429–1452. https://doi.org/10.1177/1049732304270394

Gordon, T. F. (2000). *Parent effectiveness training: the proven program for raising responsible children.* Three Rivers Press. http://ci.nii.ac.jp/ncid/BA52597238

Gunawan, J. (2015). Ensuring trustworthiness in qualitative research. *Belitung Nursing Journal*, *1*(1), 10–11. https://doi.org/10.33546/bnj.4

Gupta, A., & Singhal, N. (2005). Psychosocial support for families of children with autism. *Asia Pacific Disability Rehabilitation Journal*, *16*, 62-83.

Gürsel, M. D., & Gençöz, T. (2019). Psikoz. Gençöz T, (Ed.). Lacanyen Psikanaliz. 1. Baskı. Ankara: Türkiye Klinikleri; p.1-8.

Harper, D., & Thompson, A. R. (2012). *Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners*. John Wiley & Sons.

Harvey, C. (2015). Maternal subjectivity in mothering a child with a disability: A psychoanalytical perspective. *Agenda (Durban)*, *29*(2), 89–100. https://doi.org/10.1080/10130950.2015.1039871

Harvey, C. (2020). The uncanny effect of disability: uncomfortable maternal love for a disabled child. *Contemporary Psychoanalysis*, *56*(1), 1–28. https://doi.org/10.1080/00107530.2020.1717218

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

Hobson, R. P. (2011). On the relations between autism and psychoanalytic thought and practice. *Psychoanalytic Psychotherapy*. https://doi.org/10.1080/02668734.2011.604205

Houston, R., & Frith U., (2000). *Autism in history: the case of hugh blair of borgue*. Wiley-Blackwell.

Howard, V. F., Williams, B. F., & Lepper, C. (2009). *Very young children with special needs: a foundation for educators, families, and service providers.* Pearson. https://openlibrary.org/books/OL29401476M/Very_Young_Children_with_Special_Needs
http://doi.org/10.48086/ASD0042

Hull, L., Petrides, K. V., & Mandy, W. (2020). The Female Autism Phenotype and Camouflaging: a Narrative Review. *Review Journal of Autism and Developmental Disorders*, *7*(4), 306–317. https://doi.org/10.1007/s40489-020-00197-9

İşcan, G. Ç., & Malkoç, A. (2016). Özel gereksinimli çocuğa sahip ailelerin umut düzeylerinin başa çıkma yeterliği ve yılmazlık açısından incelenmesi. *Trakya Üniversitesi Eğitim Fakültesi Dergisi,* *7*(1), 120-127. https://app.trdizin.gov.tr/makale/TWpRMk5UWTJOZz09/ozel-gereksinimli-cocuga-sahip-ailelerin-umut-duzeylerinin-basa-cikma-yeterligi-ve-yilmazlik-acisindan-incelenmesi

Jones, L., Goddard, L., Hill, E. L., Henry, L. A., & Crane, L. (2014). Experiences of receiving a diagnosis of autism spectrum disorder: a survey of adults in the United Kingdom. *Journal of Autism and Developmental Disorders, 44*(12), 3033–3044. https://doi.org/10.1007/s10803-014-2161-3

Kalaç, Z. (2020). *Subjective experiences of women who have children with autism* [M.S. - Master of Science]. Middle East Technical University.

Kanner, L. (1943). Autistic disturbances of affective contact. *The Nervous Child, 2*(2), 217–250.

Karaaslan, Ö., & Karaaslan, D. (2016). Otizmli çocukların tıbbi tanılama sürecinde yer alan uzman doktorların tanılamaya ilişkin görüşlerinin incelenmesi. *Trakya Üniversitesi Sosyal Bilimler Dergisi, 18* (2). https://dergipark.org.tr/tr/pub/trakyasobed/issue/30207/326008

Karadağ, G. (2014). Özel gereksinimi olan çocuğa sahip ebeveynlerin yaşadığı zorluklar ve çözüm önerileri. *TSK Koruyucu Hekimlik Bülteni*, *13*(6), 491–494. https://app.trdizin.gov.tr/makale/TVRjME5qRTJOZz09/ozel-gereksinimi-olan-cocuga-sahip-ebeveynlerin-yasadigi-zorluklar-ve-cozum-onerileri

Karataş, Z., (2015). Sosyal bilimlerde nitel araştırma yönetemleri. *Manevi Temelli Sosyal Hizmet Araştırmaları Dergisi, 1 (1),* 62-80.

Kesli, R., & Dosay-Akbulut, M. (2021). Autism Spectrum Disorder with the perspective of etio-pathogenesis; enviremantal, genetic, and epigenetic factors. *Journal of Contemporary Medicine*, *11*(5), 745–746. https://doi.org/10.16899/jcm.932499

Kılınç, C., Bağlama, B. ve Akçamete, G. (2019). Erken çocukluk döneminde otizm spektrum bozukluğunun tanısında ve değerlendirilmesinde kullanılan ölçme araçların incelenmesi. *Kıbrıs Türk Psikiyatri Ve Psikoloji Dergisi, 1*(3). https://doi.org/10.35365/ctjpp.19.1.26

Kim, Y. R., Song, D., Bong, G., Han, J. H., Kim, J., & Yoo, H. J. (2023). Clinical characteristics of comorbid tic disorders in autism spectrum disorder: exploratory analysis. *Child and Adolescent Psychiatry and Mental Health*, *17*(1). https://doi.org/10.1186/s13034-023-00625-8

Klein, M. (1930). The importance of symbol-formation in the development of the ego. *The International Journal of Psychoanalysis.* https://psycnet.apa.org/record/1930-02320-001

Kodre, L. (2011). Psychoanalysis for anthropology: An introduction to Lacanian anthropology. Anthropological notebooks, 17(1). 53–72.

Kuhn, R., (2004). Eugen Bleuler's concepts of psychopathology (C. Cahn, Trans.). *History of Psychiatry*, *15*(3), 361–366. https://doi.org/10.1177/0957154x04044603

Kulasinghe, K., Whittingham, K., Mitchell, A. E., & Boyd, R. N. (2022). Psychological interventions targeting mental health and the mother–child relationship in autism: Systematic review and meta-analysis. *Developmental Medicine & Child Neurology*, *65*(3), 329–345. https://doi.org/10.1111/dmcn.15432

Kübler-Ross, E. (1969). *On death and dying: What the dying have to teach doctors, nurses, clergy and their own families.* New York, NY: Macmillan.

Kübler-Ross, E., & Kessler, D. (2005). *On grief and grieving: finding the meaning of grief through the five stages of loss.* Scribner.

Lacan, J. (1991). *Freud's papers on technique.* (J. Forrester, Trans.). W. W. Norton & Company. (Original work published 1953-1954)

Lacan, J. (2006). *Écrits.* (B. Fink, Trans.). New York: Norton & Company. (Original work published 1966)

Lacan, J. (2013). *Psikanalizin dört temel kavramı.* (N. Erdem Trans.). Metis. (Original work published 1964).

Lacan, J. (2016). *Anxiety: The seminar of Jacques Lacan.* (A. Price, Trans.). Polity. (Original work published 1962)

Lacan, J. (2021). *The object relation: The seminar of Jacques Lacan, Book IV*. (A. Price, Trans.). Polity. (Original work published 1956-1957)

Laplanche, J., & Leclaire, S. (1972). The unconscious: A psychoanalytic study. *Yale French Studies, (48),* 118–175.

Larkin, M., & Thompson, A. R. (2012). Interpretative phenomenological analysis in mental health and psychotherapy research. In D. Harper & A. R. Thompson (Eds.), *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners* (pp. 99–116). Hoboken, NJ: Wiley-Blackwell.

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology, 3*(2), 102–120. https://doi.org/10.1191/1478088706qp062oa

Laznik, M. C. (2013). The invocatory drive in babies at risk of autism. *Cahiers de PreAut*, 10(1), 23-78

Laznik, M. C. (2018). Lacan and autism. In *The New Klein-Lacan Dialogues* (pp. 217-229). Routledge.

Laznik, M.C. (2009). The Lacanian theory of the drive: an examination of possible gains for research on autism » In: *JCFAR The Journal of the Centre for Freudian analysis and research.* Gillian Clayton (Edited by), n. 19, London

Laznik, M-C. (2000). Des psychanalystes qui travaillent en santé publique. *Le*

Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, *50*(3), 172–183. https://doi.org/10.1111/j.1365-2788.2005.00732.x

Leclère, C., Viaux, S., Avril, M., Achard, C., Chétouani, M., Missonnier, S., & Cohen, D. (2014). Why Synchrony Matters during Mother-Child Interactions: A Systematic Review. *PLOS ONE*, *9*(12), e113571. https://doi.org/10.1371/journal.pone.0113571

Lefort, R., & Lefort, R. (2003). *La Distinction de L'Autisme.* Paris: Seuil.

Leiter, V., Krauss, M. W., Anderson, B., & Wells, N. (2004). The consequences of caring effects of mothering a child with special needs. *Journal Of Famıly Issues, 25* (3). 379-403 DOI: 10.1177/0192513X03257415

Lilley, R., Sedgwick, M., & Pellicano, L. (2020). Inclusion, acceptance, shame and isolation: Attitudes to autism in Aboriginal and Torres Strait Islander communities in Australia. *Autism*, *24*(7), 1860–1873. https://doi.org/10.1177/1362361320928830

Lord, C., Brugha, T. S., Charman, T., Cusack, J. C., Dumas, G., Frazier, T. W., Jones, E., Jones, R., Pickles, A., State, M. W., Taylor, J., & Veenstra-VanderWeele, J. (2020). *Autism spectrum disorder.* Nature Reviews Disease Primers, 6(1). https://doi.org/10.1038/s41572-019-0138-4

Lord, C., Elsabbagh, M., Baird, G., & Veenstra-VanderWeele, J. (2018). Autism spectrum disorder. *The Lancet*, *392*(10146), 508–520. https://doi.org/10.1016/s0140-6736(18)31129-2

Lord, C., Risi, S., DiLavore, P. S., Shulman, C., Thurm, A., & Pickles, A. (2006). Autism from 2 to 9 years of age. *Archives of General Psychiatry, 63*(6), 694-701.

Loukisas, T. D., & Papoudi, D. (2016). Mothers' experiences of children in the autistic spectrum in greece: narratives of development, education and disability across their blogs. *International Journal of Disability Development and Education*, *63*(1), 64–78. https://doi.org/10.1080/1034912x.2015.1111304

Love, B., Vetere, A., & Davis, P. (2020). Should interpretative phenomenological analysis (IPA) be used with focus groups? navigating the bumpy road of "iterative loops," idiographic journeys, and "phenomenological bridges." *International Journal of Qualitative Methods, 19.* https://doi.org/10.1177/1609406920921600

Lusting, D. C. and Akey, T. (1999). Adaptation in families with adult children with mental retardation: impact of family strengths an appraisal. *Education and Training in Mental Retardatıon and Developmental. 34* (3) pp: 260-270.

Maenner, M. J., Warren, Z., Williams, A. R., Amoakohene, E., Bakian, A. V., Bilder, D. A., Durkin, M. S., Fitzgerald, R. T., Furnier, S. M., Hughes, M. M., Ladd-Acosta, C. M., McArthur, D., Pas, E. T., Salinas, A., Vehorn, A., Williams, S., Esler, A., Grzybowski, A., Hall-Lande, J., . . . Shaw, K. A. (2023). Prevalence and characteristics of autism spectrum disorder among children aged 8 years

— autism and developmental disabilities monitoring network, 11 sites, United States, 2020. *Morbidity and Mortality Weekly Report*, *72*(2), 1–14. https://doi.org/10.15585/mmwr.ss7202a1

Maheshwari, K. (2014). Burden of care givers of mentally retarded children. *IOSR Journal of Humanities and Social Science, 19*(7), 6-12.

Mahler, M. S. (1952). On child psychosis and schizophrenia. *Psychoanalytic Study of the Child*, *7*(1), 286–305. https://doi.org/10.1080/00797308.1952.11823164

Manono, M. N., & Clasquin-Johnson, M. G. (2023). Yebo, it was a great relief': How mothers experience their children's autism diagnoses. *African Journal of Disability*, *12*. https://doi.org/10.4102/ajod.v12i0.1101

Manouilenko, I., & Bejerot, S. (2015). Sukhareva—Prior to Asperger and Kanner. *Nordic Journal of Psychiatry*, *69*(6), 1761–1764. https://doi.org/10.3109/08039488.2015.1005022

Marcenko, M. O., & Meyers, J. C. (1991). Mothers of children with developmental disabilities: who Shares the burden? *Family Relations, (40)*, 186-190.

Metin, E. N. (2012). Özel gereksinimli çocuğun aileye katılımı. E. N.Metin (Ed.) *Özel gereksinimli çocuklar içinde.* Ankara: Maya Akademi.

Miller, R., Chan, C. S., & Farmer, L. B. (2018). Interpretative phenomenological analysis: a contemporary qualitative approach. *Counselor Education and Supervision*, *57*(4), 240–254. https://doi.org/10.1002/ceas.12114

Milner, V. S., McIntosh, H., Colvert, E., & Happé, F. (2019). A qualitative exploration of the female experience of autism spectrum disorder (ASD). *Journal of Autism and Developmental Disorders,* *49*(6), 2389–2402. https://doi.org/10.1007/s10803-019-03906-4

Mitrani, J. L., & Mitrani, T. (2015). *Frances Tustin today*. Routledge.

Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology, 52,* 250-260.

Morrow, S. L., & Smith, M. L. (2000). Qualitative research for counseling.

Nealy, C. E., O'Hare, L., Powers, J. D., & Swick, D. C. (2012). The Impact of autism spectrum Disorders on the family: A Qualitative Study of Mothers' Perspectives. *Journal of Family Social Work*, *15*(3), 187–201. https://doi.org/10.1080/10522158.2012.675624

Nizza, I. E., Farr, J., & Smith, J. D. (2021). Achieving excellence in interpretative phenomenological analysis (IPA): Four markers of high quality. *Qualitative Research in Psychology*, *18*(3), 369–386. https://doi.org/10.1080/14780887.2020.1854404

Nobus, D. (2013). Jacques Lacan and the Freudian practice of psychoanalysis. In *Routledge eBooks*. https://doi.org/10.4324/9780203130094

Nudel, R., Thompson, W. K., Børglum, A. D., Hougaard, D. M., Mortensen, P. B., Werge, T., Nordentoft, M., & Benros, M. E. (2022). Maternal pregnancy-related infections and autism spectrum disorder—the genetic perspective. *Translational Psychiatry*, *12*(1). https://doi.org/10.1038/s41398-022-02068-9

Ozonoff, S. J., Rogers, S. J., & Hendren, R. L. (2003). *Autism Spectrum Disorders: A Research Review for Practitioners*. http://ci.nii.ac.jp/ncid/BA65021837

Özbaran, B. (2014). Do environmental factors have influence on autism spectrum disorder? *Journal of Pediatric Research*, *1*(4), 170–173. https://doi.org/10.4274/jpr.44153

Papadopoulos, D. (2021). Mothers' Experiences and Challenges Raising a Child with Autism Spectrum Disorder: A Qualitative Study. *Brain Sciences*, *11*(3), 309. https://doi.org/10.3390/brainsci11030309

Parks, P. J. (2009). *Autism.* Referencepoint Press.

Parpal, M., & Maccoby, E. E. (1985). Maternal responsiveness and subsequent child compliance. *Child Development*, *56*(5), 1326. https://doi.org/10.2307/1130247

Pathak, V., Jena, B., & Kalra, S. (2013). Qualitative research. *Perspectives in Clinical Research*, *4*(3), 192. https://doi.org/10.4103/2229-3485.115389

Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Psychological Journal, 20*, 7–14. doi:10.14691/ CPPJ.20.1.7

Posar, A., & Visconti, P. (2017). Tribute to Grunya Efimovna Sukhareva, the woman who first described infantile autism. *Journal of Pediatric Neurosciences*, *12*(3), 300. https://doi.org/10.4103/jpn.jpn_46_17

Qiu, S., Qiu, Y., Li, Y., & Cong, X. (2022). Genetics of autism spectrum disorder: an umbrella review of systematic reviews and meta-analyses. *Translational Psychiatry*, *12*(1). https://doi.org/10.1038/s41398-022-02009-6

Rennie, D. L. (2004). Reflexivity and personcentered counseling. *Journal of Humanistic Psychology*, *44*(2), 182–203. https://doi.org/10.1177/0022167804263066

Rosen, N., Lord, C., & Volkmar, F. R. (2021). The Diagnosis of Autism: From Kanner to DSM-III to DSM-5 and Beyond. *Journal of Autism and Developmental Disorders*, *51*(12), 4253–4270. https://doi.org/10.1007/s10803-021-04904-1

Rustin, M., & Rustin, M. (2016). *Reading Klein*. Taylor & Francis.

Sampogna, G., Del Vecchio, V., Giallonardo, V., Luciano, M., Perris, F., Saviano, P., Zinno, F., & Fiorillo, A. (2020). [The revision process of diagnostic systems in psychiatry: differences between ICD-11 and DSM-5]. *Rivista Di Psichiatria*, *55*(6), 323–330. https://doi.org/10.1708/3503.34889

Sauer, A. K., Stanton, J. E., Hans, S., Grabrucker, A. M. (2021). Autism spectrum disorders: etiology and pathology. In A. M. Grabrucke (Ed.). *Autism spectrum disorders.* Exon Publications.
schizophrenia and diagnostic confusion. *Journal of Psychiatry and Neuroscience*, *35*(5), 360.

Seligman, M. (1989). *Ordinary Families Special Children; Becoming The Parent Of A Disabled Children, Reaction To Frist Information.* New York: The Guilford Pres.

Selimoğlu, Ö. G., Özdemir, S., Töret, G., & Özkubat, U. (2013). An examination of the views of parents of children with autism about their experiences at the Post-Diagnosis Period of autism. *International Journal of Early Childhood Special Education*, *5*(8646). https://doi.org/10.20489/intjecse.107930

Sethi, S., Bhargava, S.C., and Dhiman, V. (2007). Study of level of stress and burden in the caregivers of children with mental retardation. *Eastern Journal of Medicine*, *12*, 21-24.

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, *22*(2), 63–75. https://doi.org/10.3233/efi-2004-22201

Siklos, S., & Kerns, K. A. (2005). Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. *Research in Developmental Disabilities*, *28*(1), 9–22. https://doi.org/10.1016/j.ridd.2005.09.003

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. doi:10.1177/136236130-2006004-006

Sivberg, B. (2003). Parents' detection of early signs in their children having an autistic spectrum disorder. *Journal of Pediatric Nursing*, *18*(6), 433–439. https://doi.org/10.1016/s0882-5963(03)00139-8

Sivberg, B. (2003). Parents' detection of early signs in their children having an autistic spectrum disorder. *Journal of Pediatric Nursing*, *18*(6), 433–439. https://doi.org/10.1016/s0882-5963(03)00139-8

Smith, J. A. & Osborn, M. (2004). Interpretative phenomenological analysis. In G. M. Breakwell (Ed.), *Doing social psychology research.* (pp. 229-254). Blackwell Publishing; British Psychological Society.

Smith, J. A. (2007). Hermeneutics, human sciences and health: Linking theory and practice. *International Journal of Qualitative Studies on Health and Well-Being*, *2*(1), 3–11. doi:10.1080/17482620601016120

Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 51–80). Sage Publications, Inc.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method, and research.* Thousand Oaks, CA: Sage.

Smith, J. D. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review*, *5*(1), 9–27. https://doi.org/10.1080/17437199.2010.510659

Smith, J. D. (2017). Interpretative phenomenological analysis: Getting at lived experience. *The Journal of Positive Psychology*, 12(3), 303–304. https://doi.org/10.1080/17439760.2016.1262622

Smith, J. D., & Osborn, M. (2007). Pain as an assault on the self: An interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. *Psychology & Health*, *22*(5), 517–534. https://doi.org/10.1080/14768320600941756

Smith, J.A. (2004). Reflecting on the development of Interpretative Phenomenological Analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, *1*(1), 39–54.

Smith, J.A. and Eatough, V. (2006) ‘Interpretative phenomenological analysis’, in G. Breakwell, C. Fife-Schaw, S. Hammond and J.A. Smith (Eds.), *Research Methods in Psychology*, (3rd edn). London: Sage.

Susuz, Ç., & Doğan, B. (2020). Halk sağlığı bakışıyla otizm spektrum bozukluğu. *Eskişehir Türk Dünyası Uygulama Ve Araştırma Merkezi Halk Sağlığı Dergisi*, *5*(2), 297–310. https://doi.org/10.35232/estudamhsd.684075

Tarsia, L., & Valendinova, K. (2021). *Treating autism today: Lacanian perspectives*. Routledge.

Taylor, S. J., Bogdan, R., & DeVault, M. (2016). *Introduction to Qualitative Research Methods: A Guidebook and Resource*. John Wiley & Sons.

Tohum Otizm Vakfı. (2017). *Türkiyede otizm spektrum bozukluğu ve özel eğitim.* https://www.tohumotizm.org.tr/wp-content/uploads/2018/10/tosboe2017.pdf

Tustin, F. (1972). *Autism and child psychosis*. London: Hogarth Press.

Tustin, F. (1984). Autistic shapes. *International Review of Psycho-Analysis*, *11*(3), 279–290.

Tustin, F. (1992). *The protective shell in children and adults.* London: Karnac Books.

Verhoeff, B. (2013). Autism in flux: a history of the concept from Leo Kanner to DSM-5. *History of Psychiatry*, *24*(4), 442–458. https://doi.org/10.1177/0957154x13500584

Volkmar, F. R., & McPartland, J. C. (2014). From Kanner to DSM-5: Autism as an Evolving Diagnostic Concept. *Annual Review of Clinical Psychology*, *10*(1), 193–212. https://doi.org/10.1146/annurev-clinpsy-032813-153710

Volkmar, F. R., Bregman, J. N., Cohen, D. J., & Cicchetti, D. V. (1988). DSM-III and DSM-III-R diagnoses of autism. *American Journal of Psychiatry*, *145*(11), 1404–1408. https://doi.org/10.1176/ajp.145.11.1404

Webber, J., & Scheuermann, B. (2008). *Educating Students with Autism: A Quick Start Manual*. Pro-Ed.

Williams, E. D., & Morrow, S. L. (2009). Achieving trustworthiness in qualitative research: A pan-paradigmatic perspective. *Psychotherapy Research*, *19*(4–5), 576–582. https://doi.org/10.1080/10503300802702113

Wolff, S. (2004). The history of autism. *European Child & Adolescent Psychiatry*, *13*(4). https://doi.org/10.1007/s00787-004-0363-5

Woodbury-Smith, M., Boyd, K., & Szatmari, P. (2010). Autism spectrum disorders, schizophrenia and diagnostic confusion. *Journal of Psychiatry & Neuroscience, 35*(5), 360. https://doi.org/10.1503/jpm.100130

Woodgate, R. L., Ateah, C. A., & Secco, L. (2008). Living in a world of our own: the experience of parents who have a child with autism. *Qualitative Health Research*, *18*(8), 1075–1083. https://doi.org/10.1177/1049732308320112

World Health Organization. (2018, May 24). *The top 10 causes of death.* https://www.who.int/news-room/factsheets/detail/the-top-10-causes-of-death
Yenilikçi biyokimya ve biyobilim, *4*(2), 49–57. https://doi.org/10.48086/asd0042

Yıldırım, A. (1999). Nitel Araştırma Yöntemlerinin Temel Özellikleri ve Eğitim Araştırmalarındaki Yeri ve Önemi. *Egitim ve Bilim-Education and Science*, 7–17. https://hdl.handle.net/11511/80803

Yiğitoğlu, E., & Odluyurt, S. (2021). Otizm spektrum bozukluğu tanısı koyan doktorların tıbbi tanılama sürecine ilişkin görüşlerinin incelenmesi. *Ankara Üniversitesi Eğitim Bilimleri Fakültesi Özel Eğitim Dergisi, 22*(1), 1-29. doi: 10.21565/ozelegitimdergisi.635435)

Yoon, S. H., Choi, J., Lee, W. J., & Tae, J. (2020). Genetic and epigenetic etiology underlying autism spectrum disorder. *Journal of Clinical Medicine, 9*(4), 966. https://doi.org/10.3390/jcm9040966

Yosunkaya, E. (2013). Otizm etyolojisinde genetik ve guncel perspektif. *İstanbul Tıp Fakültesi Dergisi,* 76, 84-88.

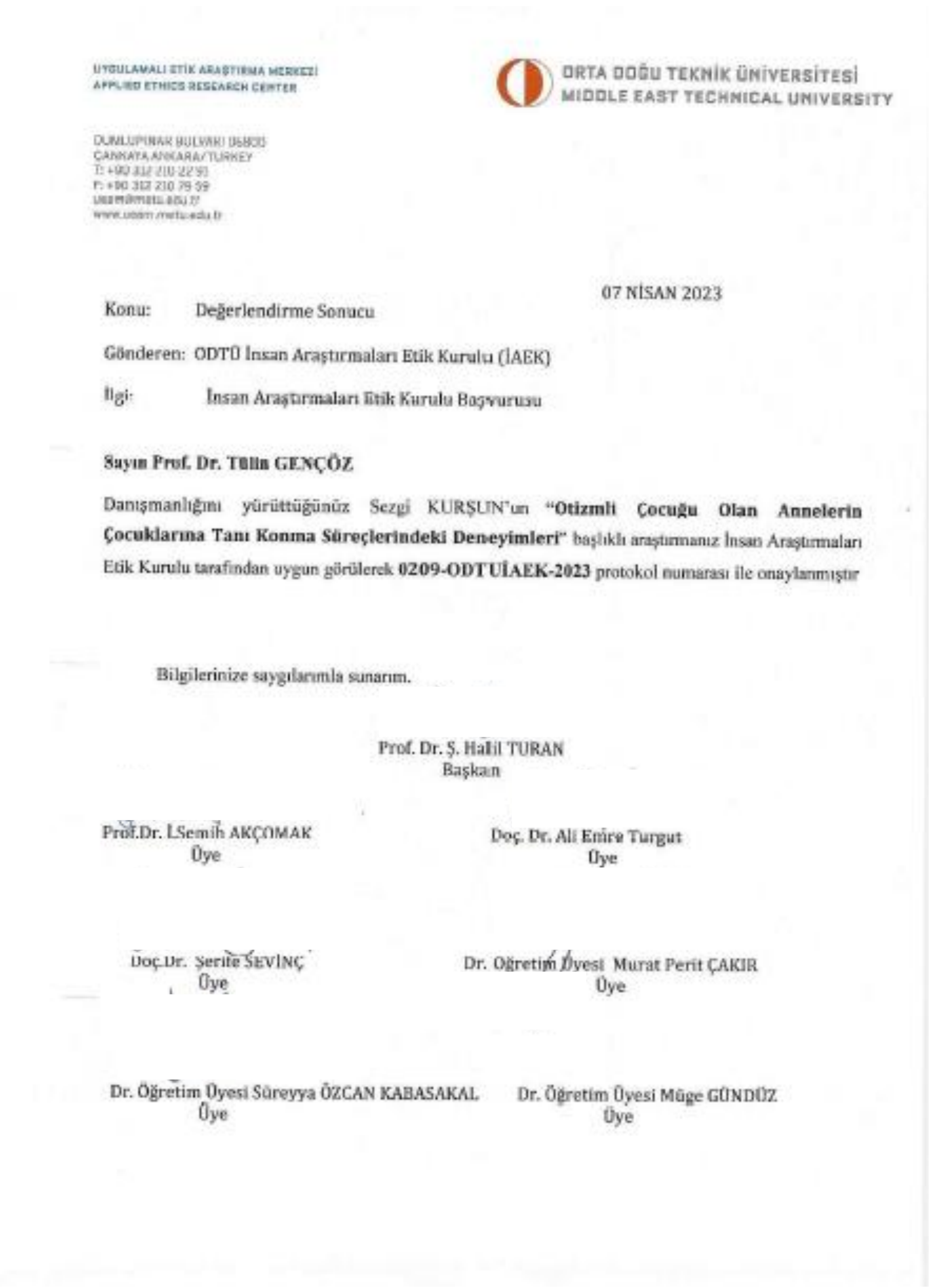
Yüksel, H., & Tanrıverdi, A. (2019). Özel gereksinimli çocuğa sahip olan ailelerin yaşadıkları sosyal sorunlar ve baş etme yolları. *Ankara Üniversitesi Eğitim Bilimleri Fakültesi Özel Eğitim Dergisi, 20*(3), 535-559. doi: 10.21565/ozelegitimdergisi.493089

Zeidan, J., Fombonne, E., Scorah, J., Ibrahim, A. I., Durkin, M. S., Saxena, S., Yusuf, A., Shih, A. Y., & Elsabbagh, M. (2022). Global prevalence of autism: A systematic review update. *Autism Research*, *15*(5), 778–790. https://doi.org/10.1002/aur.2696

Zhang, W., Yan, T., Barriball, L., While, A., & Liu, X. H. (2013). Post-traumatic growth in mothers of children with autism: A phenomenological study. *Autism*, *19*(1), 29–37. https://doi.org/10.1177/1362361313509732

APPENDICES

A. APPROVAL OF THE METU HUMAN SUBJECTS ETHICS COMMITTEE



UYGULAMALI ETİK ARAŞTIRMA MERKEZİ
APPLIED ETHICS RESEARCH CENTER

ORTA DOĞU TEKNİK ÜNİVERSİTESİ
MIDDLE EAST TECHNICAL UNIVERSITY

DUMLUPINAR BULVARI 06800
ÇANKAYA ANKARA/TURKEY
T: +90 312 210 22 91
F: +90 312 210 79 59
ueam@metu.edu.tr
www.ueam.metu.edu.tr

07 NİSAN 2023

Konu: Değerlendirme Sonucu

Gönderen: ODTÜ İnsan Araştırmaları Etik Kurulu (İAEK)

İlgi: İnsan Araştırmaları Etik Kurulu Başvurusu

Sayın Prof. Dr. Tülin GENÇÖZ

Danışmanlığını yürüttüğünüz Sezgi KURŞUN'un **"Otizmli Çocuğu Olan Annelerin Çocuklarına Tanı Konma Süreçlerindeki Deneyimleri"** başlıklı araştırmanız İnsan Araştırmaları Etik Kurulu tarafından uygun görülerek **0209-ODTUİAEK-2023** protokol numarası ile onaylanmıştır

Bilgilerinize saygılarımla sunarım.

Prof. Dr. Ş. Halil TURAN
Başkan

Prof.Dr. I.Semih AKÇOMAK
Üye

Doç. Dr. Ali Emre Turgut
Üye

Doç.Dr. Şerife SEVİNÇ
Üye

Dr. Öğretim Üyesi Murat Perit ÇAKIR
Üye

Dr. Öğretim Üyesi Süreyya ÖZCAN KABASAKAL
Üye

Dr. Öğretim Üyesi Müge GÜNDÜZ
Üye

B. SEMI-STRUCTURED INTERVIEW QUESTIONS

1. Kendinizi tanıtır mısınız?
2. Eşinizle ilişkiniz nasıl?
3. Evlenmeden önce çocuk sahibi olmak hakkında ne düşünüyordunuz? Nasıl hayalleriniz, beklentileriniz vardı? Eşinizle beraber çocuk sahibi olmaya nasıl karar verdiniz?
4. Hamile olduğunuzu öğrendiğinizde neler hissettiniz? Planlı gebelik(ler) miydi?
5. Otizm tanısı almış çocuğunuzun hamilelik süreci nasıldı?
6. Doğum sürecinizin ve doğum sonrası süreciniz nasıl geçmişti?
7. Çocuğunuzun gelişimi nasıldı? Çocuğunuzun davranışlarında neler gözlemlemiştiniz? Sizce farklılıklar var mıydı?
8. Ne zaman tanı kondu? Tanı alma süreciniz nasıl gelişmişti? Tanı alma sürecinde neler yaşamıştınız, neler hissetmiştiniz?
9. Otizm hakkında nasıl bir bilgiye sahiptiniz? Bu bildikleriniz süreç içerisinde değişti mi? Siz otizmi nasıl tanımlarsınız?
10. Çocuğunuz otizm tanısı aldıktan sonra hayatınızda değişiklikler oldu mu? Aile içindeki ilişkilerinizde değişiklikler oldu mu?
11. Çocuğunuz sizinle nasıl iletişim kuruyor?
12. Eşiniz çocuğunuzla nasıl ilgilenir? Eşiniz çocuğunuz ve siz nasıl vakit geçirirsiniz?
13. Otizm tanısı alan çocuğunuzun diğer aile bireyleri ile ilişkisi nasıl?
14. Çocuğunuz hakkında gelecekle ilgili planlarınız, beklentileriniz neler? Neler hissediyorsunuz? Neler düşünüyorsunuz?
15. Paylaşmak istedikleriniz, eklemek istedikleriniz var mı?

C. TURKISH SUMMARY / TÜRKÇE ÖZET

BÖLÜM 1

GİRİŞ

1.1. Otizmin Kısa Tarihi

Otizm terimi ilk olarak İsviçreli psikiyatrist Eugen Bleuler tarafından kullanılmıştır. Bleuler, bu terimi Yunanca "autos" kelimesinden türetmiş ve şizofreni hastalarında gözlemlenen içe dönük davranışları tanımlamak için kullanmıştır (Parks, 2009). Daha sonra Kanner, "Autistic Affective Contact Disorder" makalesinde 11 çocuğun şizofreni hastalarından farklı olan sosyal izolasyon, ekolali, takıntı, ve rutinlere bağlılık gibi özelliklerini belirtti. Bu özellikleri "otistik bozukluklar" olarak adlandırdı (Kanner, 1943). Avusturyalı psikiyatrist Hans Asperger, dört genç erkek çocuğu üzerine yaptığı çalışmada, bu çocukların sınırlı empati, kısıtlı ilgi alanları, sosyal etkileşim ve iletişimde zorluklar ve motor becerilerde eksiklik gibi çeşitli özellikler sergilediklerini belirtti (Asperger, 1991).

1950'li ve 1960'lı yıllarda yapılan araştırmalar otizmin altında yatan nedenleri ortaya çıkarmayı amaçladı (Volkmar ve McPartland, 2014). Ancak 1970'li yıllarda otizmin potansiyel nedenleri olarak nörolojik faktörlere odaklanılmaya başlandı (Ozonoff ve ark. 2003). Uluslararası tanı sisteminde DSM-I Amerikan Psikiyatri Birliği (APA), (1952) ve DSM-II (1968)'de çocukluk çağı şizofrenisi olarak tanımlanırken, DSM-III'te ilk defa ayrı bir psikiyatrik tanı kategorisi haline gelmiştir. "Çocukluk otizmi" olarak adlandırılmış ve "yaygın gelişimsel bozukluk" kategorisi altında sınıflandırılmıştır (APA, 1980). DSM-IV (1994) ve DSM-IV-R (2000)'te, otistik bozukluk, Asperger Sendromu, otizm, çocuklukta dezintegratif bozukluk, Rett bozukluğu ve yaygın gelişimsel bozukluk gibi alt tipleri içerecek şekilde genişletilerek, Yaygın Gelişimsel Bozukluk kategorisinde toplanmıştır (Feinstein, 2010). Günümüzde otizm, DSM-5 (2013) ve DSM-5-TR (2022)'nin otizm spektrum bozukluğu (ASD) olarak revize edilmiştir (APA, 2022).

1.2. Otizmin Gelişimsel Özellikleri

Otizm, sosyal etkileşim ve iletişimde zorluklar, tekrarlayıcı davranışlar ve duyusal-motor davranışlar gibi çeşitli özelliklerle tanımlanır. Otizmli bireyler genellikle sosyal alanda diğer insanların ihtiyaçlarına ve duygularına ilgi göstermezler, duygusal karşılıklılıkta güçlük yaşarlar (Bowler, 2007) ve genellikle yalnız kalmayı tercih ederler. (Tohum Otizm Vakfı, 2017). Ayrıca, dilsel iletişimlerinde eksiklikler vardır, genellikle tekrarlayıcı dil kullanırlar ve sözel olmayan ipuçlarını yorumlamakta güçlük çekerler (Boucher, 2003). Davranış açısından, tekrarlayan rutinlere bağlı kalma, aşırı tepki verme ve atipik duyusal-motor davranışlar yaygındır, bu da otizmin belirgin özelliklerindendir (Lord ve ark., 2018).

1.3.Yaygınlık

Amerika Birleşik Devletleri'ndeki Hastalık Kontrol ve Önleme Merkezleri (CDC) tarafından hazırlanan bir rapora göre, 2020 yılına ait en son verilere göre otizm spektrum bozukluğunun yaygınlığının yaklaşık 54 çocukta 1 olduğu tahmin edilmektedir. 2023'teki daha yeni bir güncellemede CDC, 2020 verilerinin daha yüksek OSB prevalansına işaret ettiğini ve Amerika Birleşik Devletleri'nde yaklaşık 36 çocuktan 1'ine bu bozukluk tanısı konulduğunu bildirdi (Maenner ve ark, 2023).

Otizmin yaygınlığı küresel eğilimlere benzer şekilde Türkiye'de de giderek artmaktadır. Tohum Otizm Vakfı'nın sunduğu Meclis Araştırma Komisyonu Raporu'nun özetine göre, bildirilen oranlar 2006'da 150'de 1, 2008'de 88'de 1, 2012'de 68'de 1, 2014'te ise 45'te 1 olarak gerçekleşti. 2020 yılı itibarıyla ülkede yaklaşık 550.000 kişiye otizm spektrum bozukluğu tanısı konulduğu tahmin edilmektedir (Tohum Otizm Vakfı, 2020).

1.4. Otizm Tanısı

Otizm spektrum bozukluğu (OSB) tanısı, tıbbi testler yerine bireyin gelişim geçmişi hakkında bilgi toplamayı içerir ve genellikle çocukluk döneminde teşhis edilir (Volkmar & McPartland, 2014). Tanı için yaygın olarak kullanılan sınıflandırma kılavuzları DSM (Zihinsel Bozuklukların Tanısal ve İstatistiksel El Kitabı) ve ICD (Uluslararası Hastalık Sınıflandırması) olup, bu tanılar uzman bir ekibin multidisipliner çalışmasını gerektirir (Sampogna ve ark., 2020). Otizm tanısının yanı sıra, bu bireylerin yaklaşık %70'inde en az bir eşlik eden bozukluğun olduğu ve %40'ında iki veya daha fazla komorbid tanının bulunduğu unutulmamalıdır (Kim ve ark., 2023). Türkiye'de otizm tanısı, çocuk psikiyatristleri ve çocuk nörologları tarafından klinik değerlendirmeler ve tıbbi testlerle birlikte konulur, ayrıca bu tanı devletin sunduğu özel eğitim hizmetlerine erişim için önemlidir (Yiğitoğlu & Odluyurt, 2021). Ancak bu alandaki bilgi ve deneyime sahip uzman sayısı sınırlıdır ve uygulamalar kurumdan kuruma farklılık gösterebilir (Tohum Otizm Vakfı, 2017).

1.5. Otizme İlişkin Teorik Açıklamalar

1.5.1. Genetik, Epigenetik ve Nörolojik Açıklama

Otizmin genetik nedenleri sitogenetik, genom içindeki kopya sayısı varyasyonları (CNV'ler) ve tek gen mutasyonlarına dayanmaktadır ve bu nedenle çok sayıda gen OSB ile ilişkilendirilmektedir (Çolak, 2016). Ayrıca ikiz ve aile çalışmaları, genetik faktörlerin OSB'nin potansiyel nedenlerinin önemli bir bileşeni olduğunu göstermektedir (Sauer ve ark., 2021). Epigenetik mekanizmalar, gen ekspresyonunun düzenlenmesinde önemli bir rol oynar ve OSB'li bireyler farklı epigenetik gen ekspresyonu modelleri sergilerler (Dağıdır ve ark., 2022). Genetik temel ve nörolojik anormallikler, beyin yapısı ve işlevlerindeki farklılıkların OSB ile bağlantılı olduğunu göstermektedir. OSB'li bireylerin beyinlerinde anormal büyüklük, şekil ve işlev ile ilgili bulgular vardır, bu da duygusal, sosyal ve taklit yeteneklerindeki farklılıklara katkıda bulunabilir (Yoon, 2020).

1.5.2. Çevresel Açıklama

OSB’de Anne ve baba yaşı, fetal çevre, perinatal olaylar, ilaçlar, alkol ve tütün kullanımı, beslenme, aşılar ve toksik maruziyetler gibi faktörler potansiyel çevresel risk faktörleri olarak incelenmiştir (Bölte, 2018). Gebeliğin erken döneminde valproik asit, talidomid kullanımı, viral enfeksiyonlar, yetersiz beslenme, aşırı kusma gibi faktörlerin yanı sıra ikinci ve üçüncü trimesterde bakteriyel enfeksiyonlar, hastaneye yatışlar, D vitamini eksiklikleri ve annenin sağlık sorunlarının olduğu yapılan araştırmalarda öne sürülmektedir (Özbaran, 2014). Ayrıca hamilelik sırasındaki anne enfeksiyonu ve/veya inflamasyon da OSB ile bağlantılıdır. Danimarka'da yapılan bir araştırma, hamilelik sırasında hastaneye yatırılması gereken annedeki bakteriyel/viral enfeksiyonlar ile çocukta OSB riski arasında pozitif bir bağlantı olduğunu ortaya çıkarmıştır (Nudel ve ark., 2022).

1.5.3. Psikanalitik Açıklama

Melanie Klein, 1930'da otizm hakkında bir makale yazarak, otistik davranışları bir çocuğun gelişimsel engellenme olarak tanımladı (Klein,1930). Margaret Mahler, çocuk gelişimi ve simbiyotik ilişkiler konusunda çalışmalar yaparak, otistik dönemlerin bebeğin ego farklılaşmasının yavaş olduğu dönemler olduğunu öne sürdü (Mahler, 1952). Frances Tustin, otizmi erken ayrılıkla bağdaştırarak, bu ayrılığın çocuğun duygusal gelişimini bloke ettiğini ve otistik davranışları tetiklediğini iddia etti. Tustin ayrıca “otistik nesne” kavramını tanıttı, bu nesnelerin çocuğun otistik kabuğunu oluşturduğunu ve tedavi edilmesi gerektiğini öne sürdü (Tustin, 1984).

Lacanyen psikanaliz, otizmin basit bir neden-sonuç ilişkisine indirgenemeyeceğini ve otistiğin dil ile işkisine odaklanır (Tarsia & Valendinova, 2021). Lacanyen Psikanalitik kuram açısından ayna evresi, Lacanyen yapılar ve dil oluşumu açıklanacaktır. Lacan, ayna evresini, Büyük Başka’nın çocuğa bakışı ile çocuğu tanımlamasıyla (Gürsel & Gençöz, 2019) 6 ila 18 aylar arasında bebeğin aynadaki yansıması olan speküler imajıyla özdeşleşmesi ve egonun oluşmasını sağlayan bir evre olarak açıklar (Lacan, 1966/2006). Laznik, otizmin ilk ve önemli belirtisinin anne ile çocuk arasında bu bakışın olmaması olduğunu vurgulamaktadır. Bu bakış yokluğu sonucunda otizmli çocuklarda Başka ile ilişki ya hiç kurulamaz ya da terapötik ilişki yoluyla kurulmaya çalışılır (Laznik, 2018).

Lacanyen psikanalizde üç temel psikoz, sapkınlık ve nevroz olmak üzere üç temel yapı vardır. Bu yapıların oluşum süreci yabancılaşma ve ayrışma aşamalarını içerir (Lacan, 1964/2013). Otizm ise bu yapıların dışında kendine özel bir yapı olarak kabul edilmektedir (Brenner, 2021). Otistikler "otistik hesaptan düşme" adı verilen savunma mekanizmasını kullanırlar ve Baba Adının işlevini reddederler. Psikozdan farklı bir yapı olarak otizmde, simgesel alanla minimal bir ilişki bile kurulmaz (Brenner, 2021). Lacan teorisini özne ve dil arasındaki ilişki üzerine kurmuştur. Dilin "gösterenlerden" oluştuğunu vurgulamıştır (Lacan, 1964/2013).

Ayrıca Lacan, öznenin Başka ile (çoğunlukla annesiyle) ilişkisinin tamamen bir eksiklik sürecinden ortaya çıktığını savunur (Lacan, 1964/2013). Bebek, karşılanmayan ihtiyaçların yarattığı gerilimi azaltmak için Başka'ya seslenir (Brenner, 2023). Otizmde, otistik gösterenler alanında yabancılaşmanın radikal bir reddi vardır. Özünde otizm, göz temasının olmaması ve aç olsa bile ihtiyaçlarını Başka'ya sunma konusundaki isteksizlikle başlayan Başka'ya çağrıyı reddetmeyi içerir. Otistikler aynı zamanda dolaylı ifadeleri anlayamamakta ve öznel ifadelerden kaçınmaktadır (Brenner, 2023).

Otistik bebekler, ilk yıllarında bile ses tonlarını değiştirmeden monoton bir şekilde ağlayabilirler ve bu da ebeveynlerin ihtiyaçlarını yorumlamasını zorlaştırır. Ek olarak, otistik bebek pek babıldamaz ve sosyal etkileşimden yoksundur (Chericoni ve ark, 2016). Sonuç olarak bu çocuklar dil kodlarını tam olarak kavrayamadıkları için mesafeli kalabilmekte, sosyal bağlantıları engellemekte ve çoğu zaman konuşmaktan kaçınmalarına yol açabilmektedir (Tarsia & Valendinova, 2021).

1.6. Özel Gereksinimli Çocuğa Sahip Olmak

Özel ihtiyaçları olan bir çocuğa sahip olmak, ebeveynler için tipik ebeveynlikten farklılık gösterir (Leither ve ark, 2004) ve çeşitli zorluklar ve duygusal karmaşıklıklarla karşılaşmalarına neden olabilir (İşcan & Malkoç, 2016). Bu ebeveynler, beklenmedik durumlarla baş etme konusunda rehberlik ve destek arayışında olabilirler (Aysever & Demirok, 2019).

Özel gereksinimli çocukların aileleri, psikolojik stres açısından daha fazla risk altında olabilirler ve diğer engelli çocukların ailelerine göre daha fazla stres yaşayabilirler. Bu ailelerin deneyimlerinin anlaşılması, bu zorlu süreçlerle başa çıkmalarına yardımcı olmak açısından önemlidir (DePape & Lindsay, 2014).

1.7. Anne-Çocuk İlişkisi

Anne-çocuk ilişkisi iki tarafında katılımını içeren, her iki taraf da taleplerin ve duyguların karşılıklı ifadesiyle birbirlerinin dünyalarını etkilediği karşılıklı bir ilişkidir (Aoki, 2003). Özel gereksinimli çocukların anneleri, çocuklarının bakımı konusundaki sorumlulukları daha fazla üstlenirler (Gadre & Mardhekar, 2015) ve bu, genellikle annelerin olumsuz duygusal etkilenme riskini artırırken babalarda daha az etkilenme görülür (Ersoy & Çürük, 2009). Otistik çocukların anneleri, özellikle tanı sürecinde, yüksek düzeyde duygusal sıkıntı, depresif belirtiler ve kaygı yaşama eğilimindedirler. Bu zorlukların üstesinden gelirken, teşhislerini kabul etme süreci de anneler için birçok aşamayı içerir (Kulasinghe ve ark, 2022).

1.8. Kabul Süreci

Çocuğun engelini kabul etmek ebeveynler için zaman alır (Gordon, 2000) ve bir dizi duygusal aşama içerir. Bu aşama modeli, ölümcül hastalıkları olan kişilerin yas sürecini tanımlayan Kübler-Ross modeline dayanmaktadır (Kübler-Ross, 1969). Ebeveynler, tanıyı kabul etme sürecinde inkar, öfke, pazarlık, depresyon ve kabullenme gibi çeşitli duygusal aşamalardan geçerler ve bu aşamaları farklı sıralarda, bazen aynı anda veya atlayarak deneyimleyebilirler (Blacher, 1984). Engelli çocukların ebeveynleri bu kabul sürecini farklı şekillerde deneyimleyebilir ve bazıları bu durumla başa çıkmak için yardım ararken diğerleri çocuklarının yeteneklerine odaklanabilirler (Varol, 2006).

1.9. Otizmli Çocuğa Sahip Ebeveynlerin Deneyimleri Üzerine Araştırmalar

Otizmle ilgili yapılan nitel araştırmalar, otizmli çocuğa sahip ebeveynlerin deneyimlerini ve yaşadıkları zorlukları anlamamıza olanak sağlamaktadır. Bu araştırmalar, otizmin tanısının konmasından sonraki süreçten, çocuğun gelişimindeki farklılıkları ilk fark etmeye kadar farklı aşamalardaki ebeveyn deneyimlerini aydınlatmaktadır. Ebeveynlerin, tanı sürecinde bekleyiş, stres ve çocuklarına yönelik duygusal reaksiyonları incelemektedir. Ayrıca otizm tanısı almış çocuk yetiştiren annelerin yaşadığı suçluluk, kaygı, öfke ve kabullenme duyguları öne çıkmaktadır. Bu araştırmalar, otizmli çocukların ebeveynlerinin yaşadığı farklı duygusal ve sosyal deneyimleri göstererek bu konuda daha fazla farkındalık yaratmaktadır ve ailelerin ihtiyaçlarına odaklanılmasının önemini vurgulamaktadır.

1.10. Çalışmanın Amacı ve Araştırma Sorusu

Bu çalışmanın amacı otizmli çocuğa sahip annelerin, çocuklarının tanı sürecindeki deneyimlerini araştırmaktır. Bu deneyimlerin derinlemesine anlaşılması için nitel bir araştırma yöntemi kullanılmıştır. Çalışma YFA metodolojisi kullanılarak gerçekleştirilmiştir.

BÖLÜM 2

YÖNTEM

2.1. Nitel Araştırma

Nitel araştırma, nicel araştırmadan farklı olarak daha çok insanların deneyimlerini ve görüşlerini anlamak için kullanılır (Denny & Weckesser, 2022). Bu yöntem, bireylerin içsel dünyalarını ve bakış açılarını daha iyi anlamak için görüşmeler, gözlemler, doküman analizleri gibi teknikler kullanır (Taylor ve ark., 2016). Nicel araştırmalar sayısal verilere odaklanırken, nitel araştırmalar insanların deneyimlerini ve düşüncelerini daha derinlemesine inceler (Pathak ve ark., 2013).

2.2. Yorumlayıcı Fenomenolojik Analiz

Yorumlayıcı Fenomenolojik Analiz (YFA), çağdaş bir nitel araştırma metodolojisi olup, deneyimleri derinlemesine anlamak için kullanılır (Miller ve ark., 2018). YFA katılımcıların sözlü ifadeleri ve yorumlarını odaklanır. YFA, belirli bir konu veya olayın öznel anlamlarını keşfetmeyi amaçlar ve nesnel bilgi arayışının aksine bireyin kendi deneyimine odaklanır (Pietkiewicz & Smith, 2014). Araştırmacı ve katılımcılar, deneyimleri yorumlamada aktif rol oynarlar (Smith & Osborn, 2003). YFA, tümevarımsal bir yaklaşımı benimser ve önce örneklerin incelenmesiyle başlar, daha sonra genelleştirilmiş teoriler geliştirmek için kullanılır (Smith, 2004). Bu metodoloji, özellikle kimlik, benlik ve öznel konuların araştırılmasında faydalıdır ve öznel deneyimleri anlamak için idealdir (Smith & Osborn, 2007). Bu çalışmada otizmli çocuğa sahip annelerin çocuklarının tanı sürecindeki deneyimleri incelenmiştir. YFA'nın yukarıda belirtilen yönleri dikkate alındığında, YFA metodolojisi bu çalışma için uygun bulunmuştur.

2.3. Katılımcılar ve Örnekleme Yöntemi

YFA benzer yaşam deneyimlerine sahip homojen bir grupla çalışarak bu grup üyelerinin biricik deneyimlerini anlamayı hedefler (Pietkiewicz & Smith, 2014; Smith, 2007). Araştırma sorusuna dayalı olarak amaçlı örnekleme yöntemi kullanır (Denny & Weckesser, 2022; Smith vd., 2009). Küçük örneklem boyutları tercih edilir; çünkü her vakanın benzersiz ayrıntılarına derinlemesine odaklanmak amaçlanır (Smith ve ark., 2009). Çalışmada üç kriter uygulanmıştır: otizm tanısı alan ilk doğan çocuğa sahip olmak, erkek çocuğa sahip olmak ve çocuğun yaşının 3 ile 6,5 arasında olması.

2.4. Süreç

Araştırmada, Orta Doğu Teknik Üniversitesi İnsan Araştırmaları Etik Kurulu'ndan onay alınmıştır ve YFA yönergelerine uygun olarak gerçekleştirilmiştir. Katılımcılar araştırmaya gönüllü olarak katılmış ve bilgilendirilmiş onam formları alınmıştır. Görüşmeler öncesi pilot görüşmeler yapılarak görüşme soruları revize edilmiş ve otizmli çocukların annelerine tanı öncesi, tanı sırası ve sonrası deneyimlerine ilişkin sorular yöneltilmiştir. Katılımcıların kendilerini rahat ve özgürce ifade edebilmeleri konusunda teşvik edilmiştir. Görüşmeler kayıt altına alınmıştır. Veri doygunluğuna ulaşıldığında görüşmeler sonlandırılmıştır, toplam beş görüşme yapılmıştır. Katılımcıların gizliliği korunmuş ve kişisel bilgiler değiştirilmiştir.

2.5. Veri Analizi

Veri analizi, görüşmelerin kaydedilip kelime kelime yazıya geçirilmesiyle başladı. Katılımcılara takma adlar verilerek gizlilik korundu (Smith, 2011). İlk görüşmenin analizi, sonraki görüşmeleri şekillendiren bazı soruların oluşturulmasına katkıda bulundu. Transkripsiyonlar her görüşme sonrası yapıldı ve ardından görüşmeler kodlandı. Her görüşme, kodlama ve analiz süreçleriyle birlikte tekrarlandı. Temaların çapraz karşılaştırması sonucunda üst temalar belirlendi (Smith, 2007). Bu temalar daha sonra bir tabloya döküldü, aralarındaki bağlantılar kuruldu ve düzeltmeler yapılarak gözden geçirildi. Analiz sonucunda dört ana tema belirlendi: *'iletişim eksikliği: tanı öncesi dönemde anne-çocuk iletişiminde yaşanan zorluklar', 'tanıda gecikme', 'tanı sürecinde yaşananlar' ve 'tanı sonrası kabullenme'.*

2.6. Araştırmanın Güvenilirliği

Nitel araştırmalar araştırmacının aktif olarak araştırma sürecine katıldığı, araştırmacının fikirlerinin, öznelliğinin araştırma sürecini etkilediği çalışmalardır (Harper & Thompson, 2012). Nitel çalışmalarda araştırmanın güvenirliği için kullanılan refleksivite kavramı araştırmacının sürekli iç gözlemle meşgul olduğu bir öz farkındalık durumu olarak tanımlanmaktadır; bu, araştırmacıların, araştırmacının araştırma içindeki diğer faktörlerden yaptığı katkıları mümkün olduğunca açık bir şekilde ayırt etmesine ve ayırt etmesine olanak tanıyan bir süreçtir (Rennie, 2004).

Araştırmanın güvenilirliğini artırmak için bir araştırma ekibinin oluşturulmasının önemlidir. Tez danışmanı, yardımcı danışman ve klinik psikoloji alanında master yapan akran grubu ile işbirliği yapmanın, araştırmacının refleksivite açısından etkili bir stratejidir. Akran gruplarının düzenli toplantılarının da araştırmacının bakış açısını geliştirdiği ve yeni bakış açıları kazanmasına yardımcı olmaktadır (Shenton, 2004). Bu stratejiler araştırma süreci boyunca kullanılmıştır. Araştırmacının otizme ilgisi ve deneyimi süreci hem zenginleştirmiş hem de olası yanlılıklar tartışılmıştır.

BÖLÜM 3

BULGULAR

Bu çalışma, Yorumlayıcı Fenomenolojik Analiz'e dayanan dört üst temayı içermektedir. Temalar şunlardır: 'iletişim eksikliği: tanı öncesi dönemde anne-çocuk iletişiminde yaşanan zorlukla', 'tanıda gecikme', 'tanı sürecinde yaşananlar', 'tanı sonrası kabullenme'.

3.1. İletişim Eksikliği: Tanı Öncesi Dönemde Anne-Çocuk İletişiminde Yaşanan Zorluklar

Bu tema, tanı öncesi dönemde anne-çocuk iletişiminde yaşanan zorlukları tanımlamaktadır. Katılımcılar çocuklarının anlatmak istediklerini anlamadıklarını belirtmişlerdir. Çocuklarının kendilerini ifade etmede ve iletişimde bazı zorluklar yaşadıklarını, çocuklarının davranışlarını anlamakta zorlandıklarını anlatmışlardır. Ayrıca otizm belirtileri nedeniyle çocuklarının davranışlarını yönetmekte zorlandıklarını ifade etmişlerdir. Bu tema anne ile çocuk arasında iletişim sorunu olduğunu göstermektedir. "annenin çocuğun davranışlarını anlamakta zorlanması" ve "ebeveyn olarak çocuğu idare etme ve sakinleştirme konusunda çaresiz hissetme" alt temalarından oluşmuştur.

3.2. Tanıda Gecikme

Araştırma kapsamında, ikinci ana tema, katılımcıların çocuklarının otizm tanısının gecikmesine katkıda bulunan etkenlere odaklanmaktadır. Katılımcılar, çocuklarının davranışlarında belirgin farklılıklar fark etmelerine rağmen bu farklılıkları otizm ile ilişkilendirmekte zorlanmışlardır. Bu temanın altında üç önemli alt tema bulunmaktadır: işaretleri görmezden gelmek: (otizm yerine) belirtilere açıklama bulmaya çalışmak, otizm hakkında bilgi eksikliği ve uzmanların gözden kaçırdığı belirtiler.

Katılımcılar, çocuklarının davranış farklılıklarını otizm yerine başka faktörlere bağlamaya çalıştıklarını ifade etmiştir. Bu, çocukların olağandışı davranışlarını, örneğin mizaç veya sağlık sorunları gibi daha yaygın nedenlerle açıklamaya çalıştıklarını ifade etmişlerdir. Birçok katılımcı, çocukları tanı almadan önce otizm hakkında yeterli bilgiye sahip olmadığını vurgulamıştır. Otizmin, çocuklarına tanı konulduğunda ilk kez karşılaştıkları bir kavram olduğunu ifade etmişlerdir. Bu bilgi eksikliği, otizmi tanımada ve anlamada gecikmelere yol açmıştır. Bazı katılımcılar, çocuklarının otizm tanısının gecikmesinin nedeninin uzmanların belirtileri doğru bir şekilde tanıyamamış olması olduğunu bildirmiştir. İlk başvurdukları sağlık birimlerinde otizm tanısı koymak yerine çeşitli faktörleri göz önünde bulundurmak zorunda kalmışlardır. Bu durum, çocuklarının gerçek durumunu anlamak ve kesin bir tanı almak konusunda belirsizlik yaşamalarına yol açmıştır. Birkaç uzmana görünmeleri gerekmiştir. Bu süre zarfında da çocuklarında otizm tanısı olup olmadığına dair bir belirsizlik durumu içinde kalmışlardır.

3.3. Tanı Sürecinde Yaşananlar

Bu tema katılımcıların tanı sürecinde yaşadıkları zorlukları açıklamaktadır. Çocuğun otizm tanısı almasının travmatik bir deneyim olması, tanı sürecinde psikiyatrik destek ihtiyacı, tanı sonrası sosyal ortamdan uzaklaşma, başkasının bakışından rahatsız olma ve tanıyı kabul etme direnci: inkar alt temalarından oluşmaktadır.

Katılımcılar, çocuklarına otizm tanısı konulduğunda bu deneyimi travmatik bir olay olarak yaşadıklarını belirtmişlerdir. Tanı aldıkları andan itibaren hayatlarının büyük bir değişiklikle karşı karşıya olduğunu hissetmişlerdir. Otizm tanısını duyduklarında büyük bir şok yaşadıklarını, korkunç bir an olduğunu ifade etmişlerdir. Otizm tanısı almak, bazı katılımcılar için büyük bir psikolojik etkiye yol açmıştır. Bu durumu kabullenmekte zorlanan katılımcılar, psikiyatrik destek almaları gerektiğini ifade etmişlerdir. Tanı aldıktan sonra yaşadıkları stres ve kaygı, profesyonel yardım gereksinimini ortaya çıkarmıştır. Bazı katılımcılar, çocuklarına otizm tanısı konulduktan sonra toplumdan uzaklaştıklarını, içe kapandıklarını ifade etmişlerdir. Bu durumu kabullenme ve başkalarının bakış açısından kaçınma nedeniyle, evde daha fazla zaman geçirmeye başlamışlardır. Evden çıkmama, kimseyi görmek istememe gibi durumların bir süre devam ettiğini ifade etmişlerdir. Ek olarak, katılımcılar toplumun ve diğer ailelerin çocuklarının otizmli olduğu gerçeğine farklı bir şekilde baktığını ifade etmişlerdir. Başkalarının çocuklarının davranışlarını anlamadığını ve bu nedenle dışlanma yaşadıklarını düşünmüşlerdir. Bu algı, katılımcıları rahatsız etmiştir. Ayrıca, bir grup katılımcı çocuklarının otizm tanısını kabul etmekte zorlandıklarını vurgulamışlardr. Bu durumu kabullenmek yerine, başlangıçta tanıyı inkar etme eğiliminde olmuşlardır. Bu, otizm tanısının getirdiği değişiklikleri kabul etme sürecinde yaşadıkları direnci yansıtmıştır. Bu alt temalar, otizm tanısı almanın aileler üzerindeki karmaşıklığını ve duygusal etkisini daha ayrıntılı bir şekilde açıklamaktadır. Ailelerin bu zorluklarla başa çıkmaları ve çocuklarının tanılarına uyum sağlamaları genellikle zaman ve destek gerektirmiştir.

3.4. Tanı Sonrası Kabullenme

Bu temada katılımcıların otizm teşhisini kabul etmeleri sonrasındaki deneyimlerini açıklamaktadır. Tanının kabul edilmesinden sonra rahatlama ve tanının kabulünden sonra çocuğun eğitimine ve gelişimine odaklanmak alt temalarından oluşmaktadır.

Katılımcılar, çocuklarının otizm teşhisini kabul ettikten sonra önemli bir duygusal rahatlama yaşamışlardır. Teşhisin kabul edilmesi, çoğu katılımcı için başlangıçta yaşadıkları şok, inkar ve karmaşıklıktan uzaklaşmalarına yardımcı olmuştur. Artık çocuklarının durumuyla yüzleşme aşamasına gelmişlerdir. Katılımcılar, otizm teşhisini kabul ettikten sonra çocuklarının eğitimine odaklandıklarını belirtmişlerdir. Bu dönemde, çocuklarının özel eğitim ihtiyaçlarını anlamaya ve bu ihtiyaçları karşılamaya yönelik çaba harcamışlardır. Özellikle özel eğitim programlarını aktif bir şekilde takip etmişlerdir. Çocuklarının gelişimini daha yakından izlemeye başlamışladır. Çocuklarının kaydettikleri ilerlemeleri görmek, aileler için büyük bir memnuniyet kaynağı olmuştur. Aileler çocuklarının potansiyelini daha iyi anlamışlar ve onlara daha iyi destek olmuşlardır. Katılımcıların otizm tanısını kabul etme süreci, başlangıçta yaşanan zorluklardan duygusal rahatlama ve çocuklarının ihtiyaçlarına odaklanma aşamasına geçişle karakterize edilmiştir. Bu süreç, ailelerin çocuklarının gelişimine daha aktif bir şekilde katkıda bulunmalarını ve onlar için uygun destek ve eğitim kaynaklarını araştırmalarını sağlamıştır.

BÖLÜM 4

TARTIŞMA

Bu çalışma, otizmli çocuğa sahip annelerin, çocuklarına tanı koyma sürecindeki deneyimlerini ortaya çıkarmayı amaçlamaktadır. Bu deneyimlerin derinlemesine anlaşılması için IPA metodolojisi kullanıldı. Beş katılımcıyla görüşmeler yapıldı ve annelerin çocuklarına tanı konulması öncesinde, sırasında ve sonrasındaki deneyimlerini anlamak için yarı yapılandırılmış sorular soruldu. Görüşmeler IPA metodolojisine göre analiz edilmiş ve analiz sonuçlarına göre dört tema ortaya çıkmıştır: ‘iletişim eksikliği: tanı öncesi dönemde anne-çocuk iletişiminde yaşanan zorlukla’, ‘tanıda gecikme’, ‘tanı sürecinde yaşananlar’, ‘tanı sonrası kabullenme’.

4.1. İletişim Eksikliği: Tanı Öncesi Dönemde Anne-Çocuk İletişiminde Yaşanan Zorluklar

Otizmli çocuklarda yaşanan iletişim güçlükleri, ebeveynlerin stres seviyelerini artırabilir ve ebeveynlik deneyimini daha zorlu hale getirebilir (Bianco, 2018). Ayrıca, otistik çocukların duygusal ihtiyaçlarını ve ifadelerini anlamak ebeveynler için özellikle zor olabilir ve bu, çaresizlik hissi yaratabilir. Ebeveynler, çocuklarıyla sözsüz iletişim yoluyla zorluk yaşayabilirler. Otizmli çocukların bakıcılarıyla koordinasyon sağlamakta ve çeşitli ifade biçimlerini bütünleştirmekte zorlandıkları görülmüştür (Bianco, 2018). Çalışmanızdaki katılımcılar da çocuklarının iletişim çabalarını anlamakta zorlandıklarını ifade etmişlerdir. Hem sözlü hem de sözsüz iletişim bu anneler için zorluklar yaratmıştır. Bu eksik iletişim, olumsuz duygulara ve sıkıntı hislerine yol açmıştır.

Ayrıca, otizmli çocuğu olan ebeveynler, çocuklarının atipik davranışları nedeniyle utanç duygusu yaşadıklarını ifade etmişlerdir (Lilley ve ark., 2020). Ebeveynlik stresine katkıda bulunan en önemli faktör, otizmli bir çocuğa sahip olmaktır. Otizmli çocukların anneleri, çocuklarının davranışlarını yönetmekte korku ve belirsizlik hissetmektedirler (Papadopoulos, 2021). Literatürdeki bilgilerle uyumlu olarak, çalışmanızdaki katılımcılar da çocuklarının tekrarlayan davranışlarını sakinleştirmekte zorlandıklarını dile getirmişlerdir.

Ek olarak, çocukları otizmli olan bazı anneler, çocuklarının iletişim zorlukları ve tekrarlayıcı davranışları nedeniyle üzüntü ve depresyon yaşadıklarını ifade etmişlerdir. Bu durum, ebeveynlerin kendilerini suçlamalarına ve ruh hallerini olumsuz etkilemelerine neden olabilir (Manono & Clasquin-Johnson, 2023). Anne-çocuk etkileşimi, hem annenin hem de çocuğun aktif katılımını içerir (Aoki, 2003) ve bu durum iletişimlerini etkileyebilir. Bu temadaki iletişim sorunları, hem annenin hem de çocuğun yaşadığı karşılıklı sorunlar olarak yorumlanabilir. Çocuk kendini ifade etmeye çalışır ancak anne bu ifadeyi anlayamaz. Bu nedenle anneler, çocuklarının farklı davranışlarını anlamakta zorluk yaşarlar.

Laznik, otistik öznenin yapılanmasını ayna aşamasında anne ile çocuk arasındaki bakışın olmamasına bağlamaktadır (Laznik, 2018). Ayna evresinde Başka ile ilişkide seslendirme ve bakışın olmayışı otistik öznenin yapısıyla ilgilidir (Laznik, 2013). Sonuç olarak otistik öznenin dil alanında olmadığı kabul edilmektedir (Brenner, 2021). Öznenin sisteminde Başka'nın yokluğu ve bunun sonucunda dil alanından dışlanmaları göz önüne alındığında, Başka ile anlamlı bir iletişim kuramamaktadır (Laplanche & Leclaire, 1972). Otizmli bir bireyin kendi dünyasında, içe çekilmiş kendine özgü özellikleri vardır. Anne, çocuğunun olağanüstü özelliklerini kavramakta zorluk yaşayabilir (Tarsia ve Valendinova, 2021). Araştırmamızda anneler otizmli bireylerle iletişim kurmada belirli özelliklerden dolayı zorluklarla karşılaştıklarını belirtmişlerdir. Katılımcılar, otistik çocuklarıyla iletişim kurmakta zorlandıklarını, çocuklarının görünürde bir sebep olmadan sürekli olarak ağlaması ve gülmesi, kendilerini ifade etmede zorluk yaşaması ve jestlere başvurması, ayrıca sebepsiz ağlaması gibi otizmin ayırt edici özelliklerinden bahsettiler.

Çocuğundan ilişkisel bir yanıt alamayan ebeveynler, ebeveynlik becerilerinde kendilerini yetersiz hissederek çocukları gibi donuklaşabilirler. Mevcut çalışmada çocuklarıyla iletişim kurmaya çalışan anneler, yanıt alamadıklarında hayal kırıklığı yaşıyor ve bu durum iletişim motivasyonlarını düşürüyor olabilir. Bu onların heyecanlarının azalmasına neden olmuş olabilir. Karşılıklı iletişimin sürdürülememesi onları çocuklarını anlamaktan ve onlarla iletişim kurmaktan daha da uzaklaştırmış olabilir. Anlamayı başaramadığında giderek daha fazla sıkıntı çeken ve cesareti kırılan bir ebeveyn, bu iletişime aktif olarak katılamayabilir. Çocuk, ilk Başka'yı temsil eden ve başlangıçta bağ kurduğu annesinin tepkisizliğine tepki olarak, kendini ifade etme çabalarını bırakıp daha da içine kapanabilir. Ayrıca, araştırmaya katılanların çoğu bir anne olarak çocuklarını anlamadıklarını, bir annenin çocuğunu anlaması gerektiğini ifade etmişlerdir. Çocuklarının ihtiyaçlarını, ifadelerini, davranışlarını anlamayı ya da anlamamayı annelikle ilişkilendirmişlerdir. Bu durum aynı zamanda annenin zihninde çocuğun her ihtiyacını anlayacağı beklentisi olarak da yorumlanabilir. Annenin zihninde anne çocuk ayrımının olmadığı, kendisini ve çocuğunu bir bütün olarak gördüğü düşünülebilir. Dilin doğası gereği anlatılmak istenen hiçbir zaman tam olarak ifade edilemez. Gerçekten açıklanmak istenen şey her zaman eksiktir (Lacan, 1964/2013). Çalışmadaki anneler kendisini çocuğuyla ilgili her şeyi bilmek isteyecek, tümgüçlü bir konumda görmektedir.

4.2. Tanıda Gecikme

Otizmli çocuğa sahip altı annenin ilk deneyimlerini araştıran nitel bir çalışmada, katılımcılar çocuklarında bir sorun gözlemlediklerini bildirdiler. Çocuklarının gelişiminde bir tuhaflık olduğunu hissettiklerini ancak bilinmeyen bir deneyimle karşı karşıya kaldıklarını belirttiler. Daha önce otizm hakkında bilgi sahibi olmadıklarını ve daha önce hiç yaşamadıklarını ifade etmişlerdir (Bilge, 2020). Başka bir nitel çalışma, ebeveynlerin çocuklarının davranışlarında bir terslik olduğunu fark ettiklerini ve buna yanıt aradıklarını ifade ettiklerini belirtmektedir. Çocuklarına erken tanı konulan katılımcılar, otizmi başlangıçta çocuklarının davranışlarını bozan, normal gelişimlerini engelleyen bir "canavar" olarak gördüklerini belirtmişlerdir (Burrell ve ark., 2017). 50 ebeveynin katıldığı ve çocuklarına otizm tanısı konulduğunda yaşadıkları deneyimlerin tartışıldığı nitel bir araştırmada, aileler başlangıçta otizm hakkında çok az bilgiye sahip olduklarını ve yanlışlıkla bunun tedavi edilebilir bir durum olabileceğine inandıklarını belirtmişlerdir. Ancak doğru bilgi edindikçe otizme ilişkin anlayışları gelişmiştir (Selimoğlu ve ark., 2013).

Çalışmamızda otizm konusunda bilgi eksikliği olması ve çocuklarda görülen belirtilerin otizm dışındaki nedenlere atfedilmesi literatürle tutarlıdır. Teşhis, annelerin çocuklarında gelişimsel gecikmeleri, atipik davranışları veya olağandışı veya yanlış bir şeyi ilk kez fark etmesinden sonra konur. Bu elbette bilgi eksikliğiyle alakalı ama anneler ilk başta fark ettikleri duruma farklı açıklamalar getirmişler. Fark ettikleri durumla ilgili harekete geçmeleri ve bir uzmana başvurmaları zaman aldı. Psikanalitik açıdan değerlendirildiğinde anneler karşılaştıkları bu farklı durumu bilinçsizce görmezden gelme durumunda olabilirler. Bu durumla baş edebilmek için inkar gibi çeşitli bilinçdışı savunmalara başvurabilirler. Bu gibi durumlarda normal gelişim gösteren bir çocuğa sahip olmayı beklerler ancak farklı gelişimsel özelliklere sahip bir çocuk doğduğunda hayal kırıklığına uğrarlar. Annelerin annelikle ilgili deneyimleri, beklentileri ve duyguları, başlangıçta hayal ettiklerinden oldukça farklı olabilir; çünkü artık engelli bir çocuk yetiştirmenin getirdiği benzersiz zorluklar ve deneyimler arasında yol almaları gerekmektedir (Harvey, 2015).

Görülen gelişimsel gecikmelere rağmen ailelerin reddedilmesi çocuklarında etkili tarama programları kapsamındaki sağlık profesyonellerinin yetersizlikleri tanı sürecini zorlaştıran veya geciktiren durumlardır (Aydın & Özgen, 2018; Dur & Mutlu, 2018). Tanıda bu kadar gecikmenin nedenleri; her çocukta farklı belirti ve özelliklerin sergilenmesi, okul öncesi dönemde değerlendirme araçlarının farklı olması ve zaman kısıtlılığı, hafif düzeydeki OSB belirtileri konusunda profesyonellerin bilgi eksikliği ve uzman hekim eksikliği olarak açıklanabilir. hizmetler (Siklos ve Kerns, 2005). Araştırmanın bulguları şu bilgilerle tutarlıdır: Katılımcılar gittikleri uzmandan dolayı tanıda gecikme yaşandığını ve söz konusu uzmanın otizm konusunda doğru bilgiye sahip olmadığını belirtmişlerdir. Sınırlı bilgiye sahip olanlar, otizmin aşina oldukları tek bir temsili olduğuna ve başka bir varyasyonun bulunmadığına inandıklarını ifade ettiler. Katılımcılar otizmin bir spektrum olduğunu bilmiyorlardı ve bu nedenle her çocuğun farklı semptom ve özellikler sergilediğini fark etmemiş olabilirler.

4.3.Tanı Sürecinde Yaşananlar

Bu çalışma, çocuklarının OSB teşhisi almasının, ebeveynler için zorlu bir süreç olduğunu açıklamaktadır. Ebeveynler, teşhis sürecinde çeşitli zorluklar yaşarlar ve bu süreci travmatik olarak deneyimlerler. Teşhis sonrası, ebeveynler genellikle şok, inkar, öfke, pazarlık ve depresyon aşamalarından geçerler (Blacher, 1984; Case, 2000; Howard ve ark., 2009). Aynı zamanda, toplumun bazen olumsuz tepkiler verdiği ve ebeveynleri üzdüğü belirtilmiştir. Ebeveynler, teşhisi kabul etmekte zorlanırlar ve başlangıçta çocuklarının engelli olduğunu kabul etmek istemezler (Broski & Dunn, 2020). Bu süreç, ebeveynlerin duygusal destek aramalarına neden olabilir. Ebeveynler ayrıca toplumsal damgalanma ve dışlanma ile karşı karşıya kaldıklarını, bu nedenle sosyal ilişkilerde zorluklar yaşadıklarını ifade etmişlerdir. Aynı zamanda, annelerin deneyimlerinin psikanalitik açıdan "tekinsiz" ve "ikircikli duygular" kavramlarına benzer olduğu ve çocuklarının otizm teşhisini kabul etmekte ikircikli duygular yaşadıkları vurgulanmıştır (Harvey, 2020). Bu duygusal karmaşıklık, annelerin teşhisle başa çıkma sürecini yansıtmaktadır.

4.4. Tanı Sonrası Kabullenme

Çalışmaya katılan ebeveynler, çocuklarının otizm tanısını kabullendikten sonra sonra içerisinde bulundukları duruma daha fazla uyum sağladıklarını ve bu sürecin sonunda daha fazla rahatladıklarını ifade etmişlerdir. Tanı sonrası bu ebeveynler, çocuklarının benzersiz ihtiyaçlarına odaklanarak daha olumlu bir yaklaşım benimsemişlerdir. Ebeveynler, tanı aşamalarının yanı sıra, çocuklarının gelişimine daha fazla dikkat etmek ve destek olmak için daha iyi hazırlandıklarını belirtmişlerdir. Bu süreç, ebeveynlerin olumsuz duyguları aşarak çocuklarının gereksinimlerine daha iyi yanıt verme yeteneğini arttrmıştır. Tanı almanın bir süreç olarak yaşandığını ve çeşitli aşamalardan geçildiğini göstermektedir (Kübler-Ross, 1969; Drotar ve ark., 1975). Aynı zamanda, bu travmatik deneyimlerin ardından ebeveynler, çocuklarının olumlu değişimlerini ve kişisel büyümeyi deneyimlediklerini ifade etmişlerdir.

4.5. Araştırmanın Sonuçları ve Katkıları

Bu çalışmanın katkısı, otizmli çocuğa sahip annelerin tanı sürecinde yaşadıkları deneyimleri ve bu deneyimleri anlamlandırma çabalarını detaylı bir şekilde incelemesidir. Araştırma, annelerin tanı sürecinde çeşitli duygusal aşamalardan geçtiğini ve yas yaşadığını göstermektedir. Anneler, tanı konulmadan önce karmaşık duygular yaşamış ve bunları anlamlandırmaya çalışmışlardır. Daha sonra tanı alındığında şok, inkar gibi duygusal tepkiler yaşamışlardır. Ancak zaman içinde bu duygusal zorlukları aşmış ve çocuklarının tanısını kabul etmişlerdir, bu da onların çocuklarının gelişimine ve eğitimine daha fazla odaklanabilmelerine yardımcı olmuştur. Bu bulgular, otizmli çocuğa sahip annelerin karmaşık duygusal deneyimlerini anlamlandırma süreçlerine ışık tutmaktadır. Ayrıca, araştırma tanı öncesi dönemde anne-çocuk iletişim eksikliğine vurgu yapmaktadır. Bu eksiklik, erken müdahale programları ile giderilebileceği belirtilmektedir. Anne-çocuk etkileşiminin güçlendirilmesi, annenin çocuğun iç dünyasını daha iyi anlamasına yardımcı olabilir. Bu, çocuğun anneden daha fazla destek ve anlayış almasına katkı sağlayabilir. Son olarak, ebeveynlerin teşhis sürecinde sağlık ve eğitim hizmetlerinde yaşadığı aksaklıkların vurgulanması, erken teşhis ve müdahale için ekip çalışmasının önemini öne çıkarmaktadır.

4.6. Araştırmanın Sınırlılıkları ve Gelecek Çalışmalar İçin Öneriler

Katılımcılar 3 ila 6,5 yaşları arasındaki otizmli çocukların anneleridir, bu nedenle daha homojen bir grup seçimi daha iyi bir anlayış sağlayabilirdi. Ayrıca, katılımcı annelerin çoğunluğunun birden fazla çocuğu vardı, bu nedenle kardeş dinamiklerini daha fazla incelemek önemlidir. Araştırmada yer alan otizmli çocukların tamamı erkek olarak seçilmiştir ve kızlarda otizmin teşhisi zor olabileceğinden, gelecekte otizmli kız çocuklarının annelerini içeren çalışmalara ihtiyaç olduğu düşünülmketedir. Çalışma, 2 ila 6,5 yaşları arasındaki çocuklarla sınırlıydı ve gelecekte, 3 yaşından sonra teşhis alan çocuklar ve aileler üzerine daha fazla araştırma yapılabilir. Son olarak, araştırmada ilk çocuğu otizmli olan katılımcılarla, ilk annelik deneyimlerinde otizmli çocuğa sahip annelerle çalışılmıştır. Bu nedenle ileride normal gelişim gösteren bir çocuğun ardından otizmli bir çocuğa sahip olan annelerin deneyimlerine odaklanan çalışmalara ihtiyaç vardır. Bu tür araştırmalar, annelik deneyimlerinin farklı durumlarda nasıl değişebileceğini daha iyi açıklayabilir.

D. THESIS PERMISSION FORM / TEZ İZİN FORMU

(Please fill out this form on computer. Double click on the boxes to fill them)

ENSTİTÜ / INSTITUTE

Fen Bilimleri Enstitüsü / Graduate School of Natural and Applied Sciences ☐

Sosyal Bilimler Enstitüsü / Graduate School of Social Sciences ☒

Uygulamalı Matematik Enstitüsü / Graduate School of Applied Mathematics ☐

Enformatik Enstitüsü / Graduate School of Informatics ☐

Deniz Bilimleri Enstitüsü / Graduate School of Marine Sciences ☐

YAZARIN / AUTHOR

Soyadı / Surname : Kurşun Çakır
Adı / Name : Sezgi
Bölümü / Department : Psikoloji / Psychology

TEZİN ADI / TITLE OF THE THESIS (**İngilizce** / English): EXPERIENCES OF MOTHERS WITH AUTISTIC CHILDREN DURING THE DIAGNOSIS PROCESS OF THEIR CHILD

TEZİN TÜRÜ / DEGREE: **Yüksek Lisans** / Master ☒ **Doktora** / PhD ☐

1. **Tezin tamamı dünya çapında erişime açılacaktır. /** Release the entire work immediately for access worldwide. ☒
2. **Tez iki yıl süreyle erişime kapalı olacaktır.** / Secure the entire work for patent and/or proprietary purposes for a period of **two years**. * ☐
3. **Tez altı ay süreyle erişime kapalı olacaktır.** / Secure the entire work for period of **six months**. * ☐

***** *Enstitü Yönetim Kurulu kararının basılı kopyası tezle birlikte kütüphaneye teslim edilecektir. / A copy of the decision of the Institute Administrative Committee will be delivered to the library together with the printed thesis.*

Yazarın imzası / Signature .... **Tarih** / Date ....
(Kütüphaneye teslim ettiğiniz tarih. Elle doldurulacaktır.)
(Library submission date. Please fill out by hand.)

Tezin son sayfasıdır. / This is the last page of the thesis/dissertation.