SUBJECTIVE EXPERIENCES OF WOMEN WHO HAVE CHILDREN WITH AUTISM

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ABSTRACT

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The current thesis aims to gain an in-depth understanding of participants' experiences of having a child with autism. This research study had two main research questions; (1) how does autistic structure come to develop and (2) how do mothers experience raising a child with autism. Five individuals who have children diagnosed with autism were interviewed. Information gathered through these interviews was analyzed using interpretative phenomenological analysis. Seven super-ordinate themes are emerged, which are (1) challenges during pregnancy and child birth, (2) pre -diagnostic stance of mothers about raising their child, (3) experiencing negative emotions after diagnosis, (4) efforts to compensate for their child's shortcomings, (5) idealizing their place in their child's life, (6) conflicting attributions regarding the child's father (7) projections towards others varying by social proximity. Findings of the current study are discussed according the prevailing literature.

Keywords: Autism, Motherhood, Interpretative Phenomenological Analysis, Lacan, Psychoanalysis

ÖZ

OTİZMLİ ÇOCUĞU OLAN KADINLARIN ÖZNEL DENEYİMLERİ

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Bu çalışmanın amacı katılımcıların otizmli bir çocuk sahibi olmaya dair deneyimlerinin derinlemesine anlaşılmasını amaçlamaktadır. Bu çalışmada iki araştırma sorusu bulunmaktadır; (1) otistik yapı nasıl gelişir ve (2) anneler otismli bir çocuğu yetiştirmeyi nasıl deneyimlerler. Çocuğu otizm tanısı almış beş birey ile görüşmeler yapılmıştır. Görüşmelerden elde edilen bilgiler yorumlayıcı fenomenolojik analiz kullanılarak analiz edilmiştir. Bu analizin sonucunda, yedi üst tema ortaya çıkmıştır. Bunlar, (1) hamilelikte ve doğumda yaşanan güçlükler, (2) tanı once annenin çocuk yetiştirmeye dair duruşu, (3) tanı sonrası deneyimlenen olumsuz duygular (3) çocuğun eksiklerini telafi etmeye yönelik çabalar, (4) çocuğun hayatındaki rolünü idealize etme, (6) çocuğun babasına dair çelişkili atıflar yapma, (7) ötekilere olan yakınlığa gore değişiklik gösteren yansıtmalar. Mevcut çalışmanın bulguları, güncel literature gore tartışılmıştır.

Anahtar Kelimler: Otizm, Annelik, Yorumlayıcı Fenomenolojik Analiz, Lacan, Psikanaliz

To my dearest father,

Yusuf Kalaç

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CHAPTER 1

INTRODUCTION

1.1 An Overview to Autism

Autism is a condition that causes impairments in social interaction, communication and speech and also involves repetitive and stereotypical behaviors and interests. And it is a long journey starting from parents recognizing the first symptoms to diagnosis and management and treatment of the disability after. According to a study the mean age of the child which the parents see the first signs are 2 years and 6 months. Average age which the child is diagnosed with autism is 4 years and 5 months. The word autism is first expressed as infantile autism by Kanner in 1943. Mahler (1968) also used the term symbiotic psychosis for this type of children's condition. Autism is initially viewed as a type of childhood schizophrenia but later this view is abandoned. In 1980 autism is stated under the title Pervasive Developmental Disorder in American Psychiatry classification. Autism is characterized by differences in verbal and nonverbal communication and in relation to the outside world, with behaviors limited to strict patterns. It manifests itself in the first three years of life. Epidemiological studies show that autism is seen 1 in every 68 live births, 3.8 / 1 male to female ratio, and eighty percent are accompanied by mental disability. Socio-cultural conditions are regarded to be not important in the development of autism (Wollf, 2004)

Deterioration in mutual social interaction is one of the main features of autism. There is no response to the voice of the mother and father when his or her name is being called. He is indifferent to other people and has limited facial expressions. In terms of language, it can be said that autistic person's relationship with language is radically and categorically different than his peers. He can make up his own words, speak repetitive, and confuse pronouns. The autist has troubles understanding humor, since it is linked to the presence of an unconscious (Freud, 1905a). There are differences in tone, rhythm, and accent. There are no gestures, signs and greetings. The imaginary game is not usually seen (Mostert, 2001).

The autistic does not try to attract the attention of adults. It does not show joy or anxiety to the presence of others. He is afraid of eye contact. His interests are obsessively directed towards non living things. They can get deeply attached to some objects. They have stereotypical behaviors and insist on uniformity. They may also have problems with their diet and toilet habits (Erickson, 2005). Regarding the treatment of autism it can be said that belief in the psychogenic paradigm decreased especially in the 1970s and the biological foundations of autism began to be emphasized and associated with mental disability. Research has increased as to whether there is an underlying medical or genetic disorder. Medical diagnosis of autism is made by child psychiatrists and neurologists. There are evaluation tools developed by researchers to be used in the screening and diagnosis process in our country and abroad. Following the medical diagnostic process, the therapeutic evaluation process begins (Howlin, 1997).

1.2 Psychoanalytic perspective to autism

When we look at the explanations regarding the origins of autism, we can encounter two groups: Organists and psychoanalysts (Melman, 2004). While it is worthwhile to examine the mechanisms responsible for this disorder by researchers, there is also the fact that neural plasticity cannot be specific in such an early age. Neurohormonal pathologies are worth researching, but it is difficult to defend genetic causality propositions. However, the thesis of psychoanalysis is much simpler. It is based on the fact that the child who is likely to be autistic cannot connect his mother with his product for reasons that may be structural or situational. The word of the mother seems to be divorced from her relationship with the phallic object or a personal reference to her related to the birth of the child. This makes the child deaf, does not care about anything he hears and it makes him mute, he cannot find anything to do in the world where he is not represented. The clinicians have met mothers who are in a withdrawn position as characters or temporarily due to mourning, divorce, unemployment or depression. In such cases, the child cannot make sense of what he is. On the other hand, researchers continue to try to catch autistic features in infants at the age of three months. Those seeking organic origin are trying to perfect their research and bring out behavioral explanations with medical imaging devices and genetic studies. Organic-minded people say that human behavior is caused by predetermined but scientifically controllable physico-chemical factors. On the other hand the Lacanian view says that giving a voice to the child is related to assigning a place for him or her in the language (Melman, 2009). In other words, it is not enough to breathe to be born, but also to breathe in language. This includes raising the child with love, not with the logic of duty. With the proper intervention of the therapist, the baby's attention awakens, the eye contact of the baby is formed, and mobility begins in the limbs and activates the vocal cords that have not worked before. This intervention is related to the formation of primary narcicism. (Freud, 1914). Melman (2009) says that today it is understandable that families unite on the internet and rebel against this interpretation. They are charged with the perception that they have a sick baby and have a microbe and now they spread it. What is certain is that the behavioral method can make these children a math prodigy, but it does not register it with a lineage, and it does not awaken its efforts in that child, that is, it does not awaken its own desire.

1.2.1 Preaut initiative and role of the maternal Other

Melman’s project involves detecting autistic symptoms as early as four months old and preventing an autistic structure to hold (2014). Signs can be seen early in life affecting structures necessary to start the psychic apparatus. And because clinicians and researchers are working against the clock with autism, it is helpful to implement Lacanian metapsychology into autism research. This communication between psychoanalysts and medical doctors can help us gain time when we know that working with children later after 2 or 3 years amounts a greatly lost time. Prevention involves modifying the relationship between the child and the parent. Whether there is a need to intervene can be decided by the presence of two signs: if there is no exchange of gaze between the child and the parent and if the third stage of the oral drive circuit has failed. The lack of gaze can also be an indicator of the mirror stage not holding up and the jubilation not occurring. Ego formation is important and body unity must be experienced through a spectator. If the baby can identify with the mirror image, it can be as a result of the gaze of the Other. And then the child tries to register its absence. During the formation of the psychic structure, this presence and absence and the time in between is important. But an initial gaze has to be installed first. So if the pediatrician goes beyond the physical and motor examination and takes into account relationship with the gaze of the Other, early signals can be caught on more quickly. Libidinal investment of the Other helps to phallicize the child as object, only in front of the mirror while catching the gaze of the Other, the child perceives his lack. In order for that lack to be recognized, the mother must be a lacking, castrated subject as well. Without the lack, the libidinal investment that will allow the phallicization does not occur either. In this situation, the family doctor should act in a way to revive the phallicization of the baby. By observing the doctor, parents can take on that role too.

According to Melman, infantile autism happens when the mother cannot register the child to envy of the penis, when she cannot give her the phallic medal (2014). In this process, he expresses surprise towards his colleagues who are interested in infantile autism, and radically treat autism independent from sexuality. He says that this is precisely why the child is autistic, although the situation does not have a direct relationship with sex for the mother. If we do not want the child to be autistic, the child must be involved in sexual dialectics. The autistic refuses to enter in the language of the big Other because he escapes alienation from being the object of desire of the maternal other. The autistic subject chooses to stay in a hallucinatory universe with his own mental representations. It does not engage in this complex and alienating relationship of the Other's desire, and the countless norms, ideals, and prohibitions that the Other would ask him to obey. All children enter the language through the language of their mother. This system is a system governed by law that determines the relationships of places, objects, things and people. Before the child enters the system of these places ordered by language, his mother tells him the name of these places and gives him access to these places so that the child can build a spatial plane they can share. But before that, the child must face the main feature of the mother tongue. This is the voice of the mother's desire and should create a relationship with this voice. What constitutes the child's own existence is precisely related to the desire in the voice of this maternal other. The autistic child rejects this.

Symptoms of autism become more evident after the first 2 years of life (Larrson, Eaton and Madsen, 2005). These symptoms are shown to be fewer responses to their name, less gazing at others, weaker eye contact in both quality and quantity, less facial expression and interactive behaviors like shared attention. Since a diagnosis can usually be made between 2 and 3 years of age, it is crucial to improve knowledge regarding early manifestation of signs and how they develop into autism in infants. Early signs are found to be present during the initial 6 months of life involving less social attention, less pointing comprehension and attuning behaviors. In the first year of life infants has shown to lack social interest and interacted poorly and looked at others less presenting signs in autistic domains like socialization, communication, intersubjectivity and affect. It is important to note that looking, paying attention and vocalizing had significant differences between objects and people. Signs of autism specifically targeted communicative exchange with people whereas non-social attention, vocalization to objects and gazing at non-living things could still be present among these children. These vocalizations were also found to be more stereotyped and less in response to caregiver vocalizations. So it can be said that an disinterest in relating to people is displayed while having an inadequacy to show appropriate affect and facial expression as well as communicative gestures were present (Warlamount et al, 2014)

Quality of affect and eye contact were shown to be the most prominent predictors of later development of autism in small infants. As they moved on to their second year of life, these initial signs become more evident. Lack of interest in people also demonstrated many consequences regarding motor development. These infants showed impaired activity, hypotonia and unusual postures (Lloyd et al, 2013). One of the most important aspects of autistic disposition is also lack of functional and symbolic play as well as a lack of interest in playing with their peers. Infants who will later be diagnosed with autism showed affective disturbances and irritability from six months old increasing gradually with age. While early signs of autistic traits were present among many infants, it is discovered that late onset autism is also an existing phenomenon in the etiology of autism. Infants who showed appropriate affect, babbling, communicative gesturing and pretend playing showed autistic regression around 12 months, displaying withdrawal becoming both silent and engaging in repetitive behavior and play from 22 months onward. Infants who responded to parentese with vocalizations or body language stopped these communicative behaviors after 22 months (Larsson,2005). This indicated that early signs may not always be present among all infants who will later develop autism. In early onset autism while being not completely absent, a lower rate of social and communicative activity is present from the first year making an early diagnosis more difficult to make by professionals. It is suggested that rare use of communicative behaviors turn in to aversion and avoidance in the second year and previous behaviors are lost. Thus a diagnosis becomes easier to make in the second and third year of life in infants. The French prospective "Preaut" aims to detect these signs as early as 4 months old and it suggests the role of desire to invoke pleasure in others plays a key role in developing reciprocal relationships. By detecting the presence of absence of such a desire and pleasure, a sooner diagnosis and a better management and treatment of autism can be made possible (Olliac, Crespin and Laznik,2017).

Laznik and colleagues founded an association called Préaut (Autism prevention) in order to prevent the occurrence of autism in babies less than four months old (2017). If an early diagnosis is made possible with adequate assessment, treatment of autism can take place. That's why intervening early when the psychic device is not done being structured can help us buy a great deal of time. This kind of intervention involves intervening in the relationship of the infant with the other. And it is known that autism is characterized by a disturbance in establishing social relationships with people. There are two signs in autistic structure that needs to be assessed by doctors that can easily be noticed. First one is the lack of a gaze between mother and the baby and it correlates to the failure of the scopic drive (Lacan, 1977). The second sign is the failure of the completion of the oral drive circuit that takes place in the third stage. During the mirror stage, the moment of jubilation is essential for the construction of the ego. Jubilation happens when the baby comes to see his own reflected image not only in the mirror but also on the face of his mother. That also helps child with his understanding of body unity and without the functioning of the mirror stage we can end up with an ego-free child. The baby's body is constituted with what comes from the Other and not the baby himself. The look represents the parents' investment and attention and it is a link to the Other and the mirror stage can only hold on top of an existence of an original gaze. In this gaze there is a libidinal investment. And it is the lack in the Other and her libidinal investment that allows the phallcization of the baby. Instead a very depressed mother, who is incapable of acknowledging her lack, may not be able to invest into her baby libidinally (Melman,2014) The second sign seen among babies who develop autism is the failing of the feedback loop in the drive circuit. Drives are different than needs and drive satisfaction can take place by completing the drive circuit making a loop. A drive circuit happens in three stages and it is the third stage that does not emerge in autistic babies (Lacan, 1962-1963). First stage can be seen as the babies taking hold of the breast or the bottle by grabbing it. Second stage is an autoerotic stage where the baby is sucking and calming himself. The autistic children are well capable of these stages stating that they are capable of staying alive. Doctors are keenly interested in these stages while the third stage can be vital to take into account. In the third step, by getting hooked at the enjoyment of the Other, the subject of drive appears. The enjoyment can present itself during a pretend play after the feeding time is over. The mother pretends to eat the baby’s food and comments on how delicious it is. Through the gaze, the baby becomes aware of her mother’s smile and enjoyment. When that foundation is implemented, the hallucinatory pole of desire might take place during the absence of the mother, enabling the representation of desire to emerge in the psychic apparatus. These representations are related to the unconscious thought. When that does not take place, the language may not flow because the subject lacks the metaphor and metonymy. The prosodic peek that is planted with the mother’s joy and pleasure seems to mark the difference between drive and need in the child. The mother who usually holds the space for the primordial Other is an opening with a lack and subjugating to the mother’s surprise and astonishment makes the baby a subject of drive. This subject has a certain appetite for the maternal enjoyment of the Other even before he meets his needs and their satisfaction (Laznik 2013).

1.2.2 Lacan’s theory of drives

According to the drive theory of Lacan (1962-63), drive is different than instinct in the sense that drive has no object and it does not aim satisfaction. Drive can be thought as a circle that continuously wants to go around its object. What drives the subject to its object of satisfaction is its lack of that object. This object occupies only a void and is hollow. It is the lost object. Thus drive circuit is repetitive and making that circle is an enjoyment in itself. It is explained that the drive has a source, an aim, an object and pressure. The source of this enjoyment is the desire that can only be found in the barred subject and desire is what keeps us going this repetitive circle. Lacan added scopic and invocatory drives in addition to the oral and anal drives that Freud (1908) mainly named. These erogenous zones plays an important role in how the subject and the Other relate to one another and only eventually can be perceived as separate from one another. This relation creates the subject's personal relation to jouissance. With this alienation from the breast the primary object is lost and can only be reconstructed in the field of the Other. This happens to be the field of demand. It is about what is left with the subject after food satisfies hunger but it does not satisfy the oral drive because its object is eternally lacking. Lacan's theory of drives includes scopic and invocatory drives in addition to objects of drive described as breast, penis and feces. In the study of a family with an autistic child it is found out that his mother lacked the prosody in her voice that would constitute as motherese (Laznik et al. 2005). She showed no peaks in her voice analysis .This can be an important founding since prosody can be a reflection of enjoyment of the maternal other. Production of motherese and the baby's active contribution to this exchange is a mutual experience. A study found that baby's reactions have an improving effect on the prosody curves of mother's speech. The more the surprise and the amazement is the higher and more exaggerated the prosody becomes. A child's response to infant directed speech and adult directed speech can be explicitly observed. The same child who were non responsive to his mother that lacked the prosody for motherese responded very enthusiastically to his uncle and can act like a normal baby who smiles, vocalizes and looks. This means that babies are equipped to respond to a relationship with an Other. Neuroscience research shows us that in autistic people neuronal activation to humans voice did not differ from any other kind of sound. Thus autistic children show no preference towards human voice or face (Fernald and Kulh,1987). In typically developed children, they become well equipped with distinguishing their caregivers voice and face from other people whereas autistic children show disinterest. This voice and the face of the caregiver can be served as a hallucinatory experience later to be dreamt of by the child when the mother is away. Without this dreaming of the Other, an autistic state can be talked about.

While defining autism in psychoanalytical terms, it is essential to talk about aspects in psychical mechanism which is constituted by an ego and a subject of an unconscious. According to Lacan, ego is formed as a specular image, the ego is a product of alienation and the baby experiences this mirror image that is actually outside of himself as a moment of jubilation. The mirror image is essentially linked to a relationship with the big Other and the autistic retreat is about a total lack of this specular relationship with the mother who usually holds up the space for the big Other. The apparent lack of gaze to a human fact is a prominent sign in these babies and they just seem to be uninterested in human face and voice. This disinterest leads to a fail in primary identification that is going to pave the way for symbolization. Lacan introduces scopic and invoculatory aspects to Freud's drive theory. And these drives form a link to the big Other in the field of desire. Lacan (1977) distinguishes drive from satisfaction by stating that satisfying the need does not satisfy or diminish the drive Desire is what remains after the satisfaction of need. This libidinal investment in erogenous zones of the body is related to a relationship with the Other. Autistics lacking that relationship, show saliva flow uncontrollably from their mouths indicating indifference. Thus it can be said that according to the Lacanian perspective, autistics do not have an unconscious organization. A drive is related to a signifier overwriting the body. So in order for a subject of the unconscious to merge, the drive circuit should function to be able to reach the big Other. Lacan says that *The subject is subject only to being subjugated to the field of the Other* . By subjugating to the big Other through the loop of drives, the subject enters alienation and gains a body similar to the specular image. This adds an imaginary dimension to the forming of the subject and constitutes the ego. These steps in becoming a subject of desire are crucial to take place and make early intervention essential. Even though psychoanalytic views are abandoned for cognitivist models and interventions, research focusing on the relationship between the baby and his parents present important data for prevention. Laznik(1995) proposed to take advantage of Lacanian concepts in autism research for better knowledge and insight. She proposed that autistic retreat occurs because the child fails to complete the full drive circuit in order to become engaged with the Other. Referring to the Lacanian theory of drives, she states that autism is about a defect in the drive link to the Other. This defect can take place anywhere in three drive circuits: scopic, invocutory and oral.

According to Laznik(2017), clinicians' role is to restore this broken link. Lacan says that drive is a constant force and it is supposed to complete a certain route. Unlike the satisfaction of need, a drive requires no object. Here Lacan introduces his concept of *object a*, the cause of desire, where no object of need can satisfy the drive. Coming to contact with the mother who is kissing the baby after she feeds him may cause a response and an enjoyment by the baby. This indicates the completion of the drive circuit. However this does not occur in autistic babies, the contact is perceived as an intrusion. And the Other's pleasure is unwarranted. The excitement the baby gets by watching his mother's enjoyment is what is missing in an autistic baby. It is not clearly known whether the baby fails to arouse this enjoyment or the mother is unable to answer the baby's search for enjoyment in the other. By subjugating to this enjoyment of the Other, representation of desire will emerge in the hallucinatory pole of satisfaction (Lacan, 2014). This investment will help the baby refresh his dreams and fantasies when he is alone with his pacifier. Through this hallucinatory pole of satisfaction, system of representations forms and by representations we can talk about an unconscious with metaphor, metonymy, condensation and displacement processes.

1.2.3 Motherese

The key to this enjoyment lies in a preference babies have for a certain type of speech called the motherese. (Saint-Georges et al, 2013). Motherese has a certain prosodic quality involving punctuation and scansion and contains grammatical characteristics specific to this type of speech. Babies' preference to this type of talk presents itself even before the need satisfaction like feeding happens with very small one day old new born babies. This shows that the attention paid to motherese exceed need satisfaction and implies a drive looking for a different kind of satisfaction. The language of motherese is a language of amazement and pleasure. This Other filled with amazement and pleasure because of her baby indicates lack in the big Other making the third round in the drive circuit. This is the lack in the other. And the baby seems to have an appetite for this enjoyment that will signify the lack in the Other coming to his world in motherese. The Other also plays a role as validating the fact that the child is real, through a specular image in the mirror (Lacan, 1956). This does not take place in autistic babies. Because in order for that to happen, the baby should experience prosody in the voice of his mother and actively seek for it and the face that accompanies the voice.

The presence of this enjoyment can be traced back to the mother’s speech that is called motherese. The prosody of their voice seems to carry some important emotional elements. It is found that if the child is not active much, it will in turn end up decreasing his mother’s speech. The prosodic effect has an impact beyond need satisfaction for babies. It is discovered that hearing the sound of their mothers, the children showed an intense sucking without experiencing being fed. That is because the voice of the mother can serve as the first object of the oral drive. When the newborn meets the enjoyment of the Other, he meets the barred Other because her amazement and surprise marks her lack.

According to Melman(2014) an autistic baby has a problem for a very simple reason. The mother who can be very loving, cannot somehow pass on her love and the feeling that the baby is a gift to her. It cannot be expressed by the word or lullaby that the child is for the mother and has a place in it. Mother's discourse has a role in the development of autism. If this birth occurred during a mourning period, for example, she may not pass the happiness of the event to the baby. These babies eventually become like self-directed computers. They lack a moral and reflective authority to give them an identity. Many years of practice have shown that behavioral methods in these children do not work in the context of rearranging their functions. Lacan(1977) introduced the question of central drives and understanding the drive mechanism can be helpful in understanding infantile autism. In drive theory, retroactive feedback loop is completed when the baby becomes the object of primordial other’s enjoyment. The last stage of that loop seems to fail in babies who develop autism. After the mother feeds the baby, there is a certain behavior from the baby’s side that evokes maternal pleasure like giving his little food to his mother for her enjoyment. This part does not take place with some babies. Children like this can be said to fail the third stage of the drive circuit. It seems like they are not interested in being heard even when they are stimulated by their parent and they do not seek to be the object of their pleasure. They show no motivation in pleasing the maternal Other by offering their foot to be eaten. This motivation goes beyond the satisfaction of a need like hunger and thirst. It is about what is produced after the need is satisfied. The first step of the three stage drive path Freud(1905) describes is the baby that is reaching for the bottle or the breast. This importance of this stage is known and well assessed by doctors and nurses. The second step involves the assessment of the autoerotism of the baby. Baby's sucking behavior and self calming constitutes the second stage. On the other hand third step is rather ignored among many clinicians and it involves drive satisfaction. This hallucinatory experience takes place when the subject is subjugates himself to the maternal Other. He wants to be the object of her enjoyment and this drive forms the subject by creating alienation. The pretend play that involves the baby's offering his foot to the mother in order to be eaten represents something beyond the need satisfaction and constitutes the closure of the full drive circuit. It produces mother's joy and laughter that will trigger smiles in the baby. Regardless of this failure of the installation of the third stage of the drive circuit is the result of an uninterested and non-responsive baby or a lack of appropriate interactive behavior of the parents who hold the space of primordial other, completion the link can be restored by libidinal investment of a psychoanalyst who is specialized in parent child relationships and this way the mother can see the child as a delicious object that a source of joy and pleasure obtained from it can help the baby emerge as an object of desire. This is the mother's phallic investment (Melman,2013).

A study also defines parentese as the type of speech being used while relating infants that is characterized by higher pitch, slower tempo and exaggerated intonation (Cohen et al,2013). Not only mothers but also fathers can employ parentese while talking to their children. Employing this type of speech is known to have a certain effect on the infants' communication skills that include social interaction abilities and speech and language development. It attracts infants' attention and helps them orient to their caregiver and get involved in a reciprocal relationship. This type of speech contains affect and phonological information and it is directly linked with infants' responsiveness which suggests that infants are active participants in social exchange. Therefore quality of infant's role in the mutual relationship and the reciprocity between infant and the caregiver can contain the first signals related to what will be diagnosed as symptoms of autistic development. Weaker responses to parentese and parental solicitation in general can return dampen parentese production over time and this can further social withdrawal and and cause developmental delays.

Thus, the divergence in the synchronicity in the relationship can also affect the later developing speech and language skills as well as social communication. It is shown in studies that mothers' speech included 40 to 60% parentese while fathers' speech included 15 to 20% parentese. Both parents had the same amount of vocalizations in their child directed speech. While mothers' use of parentese decreased with both children with autism and typical development it is found out that fathers use more parentese with children who give lower rate of responses and later will develop autism. When coming across with fewer responses from their infants parents almost doubled up their vocalizations they directed toward their infants. Fewer responses were present in the first three years of life in infants who will later develop autism. Research using engineer methods was able to investigate dynamic parent infant interaction by focusing on antecedents and consequences of interactive behaviors and help study the acoustic components of prosody of parentese (Werner and Dawson, 2000). It is important to note that parents' communicative behaviors do not cause autism and parents seem to feel the pathological responses of their infants from very early on. It is observed that parents adapt their behavior by increasing their vocal behaviors and using more touching. Mutual responses result in stimulation of each communication partner by one another. While this loop is emotionally charged, it helps to improve infants' attention and learning skills that will later be involved in developing joint attention and communicative skills. Even though it is known that autistic children can process some aspects of human voices, they display no specific preference to human voice and specifically to their mother's voice as opposed to typically developing children. They also show less response when parents' vocalizations involve pointing and describing other people as compared to objects. Therefore exploring the parentese feedback loop is important while studying early onset autism.

Motherese involve intonational and paralinguistic phenomena like higher overall pitch, the more frequent use of third person constructions compared to first and second person constructions and lexical characteristics(Cassel et al, 2014). Infant directed speech communicates affect, facilitates social interaction depending on infants' choices. It helps the infant engage and maintain attention and it fosters language acquisition. Compared to adult directed speech, infant directed speech consists of shorter utterances, redundant and isolated words and phrases and a multitude of questions. Prosodically, motherese involves longer pauses, slower tempo, more repetitions and a higher mean f0 (fundemantal frequency). It is discovered that prosodic characteristics of motherese make it more informative compared to normal speech. And it conveys mothers' intentions more accurately. It is found that infant directed speech has certain elements that signal the infants with cues regarding attention, approval and comfort. It is also discovered that mothers' use different type of vocalizations with different intentions. For example it is discovered that when mothers seek to initiate attention and eye contact they adapt rising contours of frequency while they adapt sinusoidal and bell shaped contours of frequency when they seek to maintain eye contact with a smiling and gazing baby (Cohen,2013). Therefore high pitched vocalizations are aimed to elicit infants' involvement while low pitched vocalizations aimed at strengthening infants' involvement. This shows that features of motherese involve a wide range of emotions directed to the infant while normal speech has more inhibited emotional expression and prosody of motherese helps to convey mothers' emotions and intentions to their infants. Mothers also shape their vocalizations in a way to match their infants' vocalizations according to the response they receive from their infants (Parman,2010). Among 3 to 17 month old infants it is observed that mothers adjusted their vocal patterns to their infants' vocal patterns creating a tonal synchrony. It is also shown that synchrony decreases as the child ages. Mothers' use of infant directed speech is directly related to the infants' vocal preferences and their presence and engagement.

The differences and variations in pitch alone is not sufficient to evoke the infants' interest unless it includes positive affect which implies emotional sharing, mother-infant adjustment, and synchrony and general communication that involves gestural, tactile and visual cues (Duarte and Bordin, 2005). Mothers tend to adjust these cues according to their infants' age, cognitive abilities and linguistic level making their language specifically for them. These adjustments increase and facilitate social exchanges between the infant and the parent. Kuhl suggested that the underlying mechanism in mothers' speech that fosters communication and learning could be motivation. Increased motivation significantly effects infants' cognitive and emotional development. More studies are necessary in order to understand autistic children and their mothers' interactive patterns and how it can impact the development of infants who later turn out autistic. In a research study the use of parentese by caregivers while interacting with children who has typical development and autistic development have been investigating. Statistically significant differences have been found between male and female caregivers and the children with typical and autistic development. The female caregiver spent more time with infants who are both typically developed and autistic compared to the male caregiver. Male caregivers invested more time to infants who are between 12 and 18 months of age with typically developed children and not the children with autism. Typically developed children's response to speech other than motherese increased after 1 year of age but AD children showed lower responses to both types of speech. The children who will later develop autism show initial symptoms of weaker eye contact, less social behavior and joint attention, less frequent orienting to name and limited expression of body language (Goldstein et al, 2009). These divergences in development can pose vital prerequisites for later speech and language development as well as social skills. These initial signs of differences in reciprocal interaction can be consequence of the child's response to the caregivers' vocal behavior which in turn affects the language and social development. These vocal behavior adults adopt while relating to their infant called motherese is characterized by a higher pitch, slower tempo and an exaggerated intonation. This type of speech seems to attract the infants' attention and convey emotional components that will enable bonding with the parent. Caregivers' use of motherese and fatherese is also dependent on the infant's level of responsiveness since infants are active participants of this reciprocal relationship. When the infant shows a lack of interest in the caregiver's voice and does not display a curiosity to its surroundings and engage in a social exchange with people, it can be predicted that the child's language learning will be adversely affected. The infants' lack of interest can also negatively influence parents' use of parentese causing a lag between vocalizations. This can weaken the bonding process between the caregiver and infant and facilitate social withdrawal and developmental stagnation. In a study conducted by Hastings and colleagues (2005), the nature of the parents' vocalizations and the infants' responses has been explored. Children with typical development and children with autistic development have been investigated. It is found out that caregivers with children who have autistic development increase the rate and frequency of their interactions in response to their children's lack of initiations of communication. It is established that they try to compensate for their children’s social difficulty. With the typically developed child, father’s vocalizations seemed to be higher in efficacy compared to the father’s speech toward the child with autistic development and in return typically developed child’s response to vocalizations extended from just caregivers’ voice to different types of voices as well. On the other hand, children with autistic development did not respond to different types of speech while motherese is still shown to be more effective in arousing the infant’s attention compared to other types of speech. For the typically developed group, motherese after the end of the first year was no longer necessary in order to elicit attention in the infant and the infants started to react other modes of communication and initiate vocal exchange with other people. In children with autistic development the response to both motherese and fatherese speech was low and children did not evolve to communicating with different types of speech as well. Not only children with autistic development did not respond to different types of speech, their response decreased as they moved to the third trimester making autistic symptoms more evident.

Computational analysis of home movies helps to investigate the role of parentese which involves an emotional prosody in the parents’ voice on the synchronic behaviors between the infant and the adult (Saint-Georgesi Cassel and Cohen, 2009). Participants were typically developed children and children who will eventually develop autism who are less than 18 months old. Findings suggest a significant association between the infants’ responses and the parents’ vocal behaviors. Through the use of parentese, more orientation towards other people took place. Fathers of infants who will later develop autism altered their responses towards their infant and spoke to them more than parents with typically developed infants. They tried to arouse the infant in order to evoke response. It is found out that infants’ social responses increased when the father introduced parentese to their social interaction. Since autism is characterized by impairment in social interactions, patterns of reciprocal communication and repetitive behaviors and interests, language delays and speech disorders are expected to manifest between 18 and 36 months of age. But before these symptoms appear, it is suggested that there are precursors to these initial symptoms such as weak or lack of eye contact, no orientation to name or a failure for join attention, no pointing or use of body language. These initial signs can be thought as affecting the reciprocal relationship between the infant and the parent adding to the cumulative outcome of what constitutes as autism (Xavier et al, 2015). It is possible that infants whose interactive styles diverge from typical development may end up altering their parents' interactive styles. So it is important to investigate the synchrony and reciprocity between infants and their caregivers by studying home videos in infants who are known to develop autism later. It is known that infants actively engage in communication with their surroundings and show a preference for people over objects. Adults in return anticipate the infants' desire to bound and interact and respond adequately to infants' initiations. So a dialogue takes place between the caregiver and the child. In a study using computational methods in order to show this dialogue it is discovered that early signs could be observed before 12 months. Less initiation of the infant was shown and the parents' increased efforts to stimulate the child with more communicative acts like vocalizations and touching.

1.2.4 Vocal exchanges between children and their parents

Vocal exchanges between children and their parents can also give valuable information about the onset and the course of autism. Studies who examined the nature of these exchanges show that in both autism and typical control groups' parents responded to child's vocalizations frequently within 1 seconds or less (Warlamount et al, 2010). However, in autism group it took longer parents to respond to the child. Also it is found out that in the autism group children tended to follow more and lead less than the typical control group. This study is interesting in terms of recent interest in joint action and coordinative processes in children and adults. It aims to identify leading and following patterns between children and their parents by examining their vocal interactions. In typically developing children more instances of leading is observed whereas in autism group children tended to follow more than lead. It is known that children do not only process information passively and they do not learn language only through contingent reinforcement. Contrarily they are active participants in learning. They respond to communicative acts and engage in active exploration of their surroundings. During this exploration children tend to receive various forms of sensory feedback from their parents and from their environments in general. Parents' responses depend on the infants vocalization characteristics and in turn support infant's communicative development. In autism expected social interaction and language does not take place. Children with autism do not initiate communication, do not take turns or engage in joint attention (Goldstein & Schwade, 2008). Also, the frequency of vocal exchanges is different in autism than in typically developing children. It is found that the time adults take to respond to the children is significantly longer with children who have autism compared to the control group. Children's response also took longer with children who have autism than typically developing children. Since social interaction is impaired in autism, the children tended to follow more than lead and that may have caused the latency of the adult responses to the child. Therefore it can be said that adults responded later than they did to typically developed children due to less interaction being initiated by children with autism (Ouss et al., 2013). This reduced communication starting behaviors of children may have caused parents' attention to vocalizations decrease. This study suggests that communication problems in autism can be the result of the negative feedback loop of vocal exchanges between children and adults.

In order for an early diagnosis of autism, data from different kinds of research can be used. It is important to investigate areas involving atypical social interaction which includes lack of eye gaze, absent orientation to name, poor imitation, absent social smiling, reactivity, lack of social interest and affect and reduced expression of positive emotion (Goldstein et al., 2013). Impaired language and cognitive development, motor problems, lack of imaginative play are also vital signs. While autism screening tests are available for older children, no known tool has been designed to assess infants below 1 year of age (Dawson,2008). Developing such a test may help us earn time for early diagnosis and intervention. Early interaction styles of infants of risk groups should be studied in order to win in this race against time. Infants are active contributors to communication and join this reciprocity with gaze, head and hand position adjustment and vocalization. Infants not only join but lead the social exchange with the adult. Therefore in order to gain more insight home videos of infants who will later develop autism are studied and it is found that interactions between infant and caregiver differentiated from typically developed children in some ways and it can be identified starting from 6 months of age(Saint-Georges, 2009). It is shown that parents increased their verbal responses to infants who will later develop autism because the infant did not engage as much pleasant interactions with others as the typically developing group. It can be thought as a result of the infant’s lack of leading and responding behavior. The infants who will later develop autism were less in search of the caregiver’s gaze and the active desire to catch the caregiver’s attention seems to be weaker. The infants did not emotionally engage with the parent and join a reciprocal interaction with them. PreAut grid can identify these signs at 4 and/or 9 months and(Olliac and Crespin, 2017). Babies score positive if they do not look at the caregiver and avoid their gaze and fail to point. The CHAT is a tool that assesses social interest, motor play, pretend play, pointing and showing, gaze exchange, proto declarative pointing, and pointing comprehension. Babies fail the screening test if they fail these reported areas. But in order to assess babies earlier than the CHAT assessment, it is important take into account the role of emotion, reciprocity of vocal exchanges and synchronicity of the relationship with the caregiver.

1.2.5 Baby and the Caregiver are both active participants in their relationship

During this reciprocal relationship a nonresponsive baby can have a certain affect on his parents. Parents who feel the inadequate ways of the child gradually feel less secure about their parenting skills. Parents who are warm and caring during the first months of the newborn become gradually frustrated and frozen (Melman,2014). When their attempts to solicitude the baby continue to fail, their tiredness starts to manifest in the prosody of their voice. The frozen emotionless natures of their voice represent the effort to protect themselves against disappointment. The autistic child is capable of looking and emoting to his Other if not frequently and what is observed among parents that experience a contact from their normally non responsive baby’s side, while they are thrilled to see that their baby is responding, causing them to create the prosody of parentese, they seem to quit trying to maintain the bound right away once the child cuts the relationship. On the other hand interventions can be made in order to restore the synchronicity between the parent and the child. Another important aspect in the mother child interaction is that the mother speaks words for the baby’s place as well (Laznik,2000). This has been said to be a necessary madness in order for the mother child relationship to consolidate. The mother says words directed to the infant and in return she speaks as if the baby is responding to her. This type of talk that involves speaking in the baby’ place has found to me missing with the parents

The role of prenatal factors is also important to investigate in the development of autistic symptoms. Research suggests that prenatal environment can contribute to the risk of developing autism (Larsson, 2005).Breech presentation, low Apgar (Appearance, Pulse, Grimace, Activity, and Respiration) score, gestational age at birth and parental psychiatric history that includes psychoses is associated with the risk of autism. Also during the prenatal period, exposure to valproic acid, thalidomide, rubella and alcohol may present an increased risk of developing autism in early life. Low birth weight, low Apgar score at 5 minutes and being small for gestational age, gestational age at birth less than 37 weeks, cesarean section and congenital malformations can be considered as perinatal risk factors. These also present as statistically significant increased risk of autism. Perinatal factors are studied in three different categories. Delivery and newborn characteristics include fetal presentation, mode of delivery and Apgar score at 5 minutes, birth weight, gestational age at birth and weight for gestational age. Pregnancy characteristics include multiple gestation, preeclampsia and number of antenatal visits. Parental characteristics include number of previous pregnancies, maternal smoking reported at the first antenatal visit, maternal citizenship and maternal and paternal ages. Maternal and paternal age is positively correlated with the risk of autism. Also increased risk is found among younger mothers (aged<20 years) and older fathers (aged>35). Among perinatal risk factors, low birth weight is found to be associated with the risk of autism. Children whose birth weight is less than 2.501 propose an increase risk of autism. In various studies, birth weight and autism have shown a strong association. Birth weight is related to three main factors: genetic growth potential, duration of pregnancy and the rate of fetal growth. Gestational age at birth of less than 35 weeks is found to pose a high risk for autism. Low birth weight and being small for gestational age have been shown to have an increased risk of autism. Growth retardation can be an important sign in the development of autism. Parental psychopathology is also thought to be a factor involved in the risk of autism. Parental history of a psychiatric disease is found to cause a statistically significant increase in the risk of autism (Wollf et al, 1988).

It is important to ask the question whether maternal stress in autism is related to simply having a child with autism or is it a consequence of maternal personality characteristics. These studies suggest that having personality characteristics that will cause interpersonal and social problems in mother can be related to having a broad autistic phenotype (Wollf et al, 1988). These social and affective problems can be milder forms of social impairment that also present itself a problem in autism. Either way, poor expression of affect, little interest in people, being an older mother and having a younger child are found to be factors that contribute to maternal stress. Receiving social support can help reduce parental stress on the other than perceived social support by parents can be more influential than the actual social support received. Number of available social networks is less important than how effective this support is perceived as plays a larger role in stress levels in parents. In a study Rorschach test variables have been used to detect risk factors and character traits in mothers of children with autism(Keller et al, 2018). In the test, affection and interpersonal relationships were addressed and the relation of these characteristics with maternal stress has been measured. When addressing affection, stimulation of affect and expression of affect were measured. Interpersonal coping, interest in people and self esteem is also included. The results showed that less stressed mothers showed more affect and their expression were more overt than mothers with higher levels of stress. When stress is increased, it became more difficult to handle interpersonal situations and their expression of emotions has decreased. While having a child with autism is the major source of stress, weaker expression of affects, less interest in human relationships, old age of the mother are found to be statistically significant contributors to maternal stress. While less expressing of emotions can be related to feeling overwhelmed with stress about having a child with autism, less interest in relationships and interpersonal difficulties can be an indicator of having a genetic component determining a broader autistic phenotype.

The use of motherese is also affected by maternal depression causing it to be produced less often than non depressed mothers. Research shows that depressed parents were able to show less adjusting behavior to their infants' vocalizations and engaged in less synchrony. They were slow in responding to their infants' interactive initiations and uttered fewer and less emotionally charged words. Mothers with schizophrenia also use less infant directed speech compared to mothers without a mental health diagnosis. It is found that they lack the prosodic elements in motherese that helps the infant perceive their mothers' affect and intentions. Contouring signaling approval has shown to increase infants' gazing behavior whereas contouring signaling disapproval has shown to inhibit infants' looking. The effects of motherese also manifested in the heart and EEG power of 9 month old infants causing a deceleration. This has been found to be linked with affective intensity in the prosody of mothers' vocalizations. The infants' preference of motherese is essentially a preference for positive affect in speech.

In addition to low communicative responsiveness and interest in social relationships, autistic children also do not pretend play. This means that autistic children lack the ability to make his fantasies into scenarios in his games. In the Lacanian sense, the child fails to recall the absent object and he does not have a capacity for representation (Fink, 1995). According Freud (1940), memory and perception are mutually exclusive. The child fails to be evoked an absence and he cannot name a missing object where the memory is supposed to be written.Perceptions originate and consciousness attaches to perceptions. Unconscious is the second registration and it is about relationships. Preconscious is the third registration and it is about work-representations and attached to ego (Freud, 1961). Before the second registration that is related to the unconscious belongs to phenomena that is beyond repression. Therefore it can be said that autistic children's psychical apparatus functions beyond the primal repression. When their functioning is beyond primal repression, they can only perceive present objects but fail to establish that they continue to exist when they disappear from their eyesight. In order to remember a perception when it ceases to exist, a signifier chain is necessary and in the autistic condition, signifiers are not available and not repressed. In order to recollect a memory, the child must recognize a lack in the place of the primal Other which is usually occupied by the mother. In order for the child to create scenarios in his fantasy and act them out in play this stamp of a lack is necessary and it takes place with the help of this imaginary space. The use of words alone does not equate to an emergence of representations. Within that imaginary space that consists of representations an odiepal rivalry also takes place.

1.3 Sexuation and Autistic Traits

Frances Tustin(1981) suggested that in autistic children, the containing function of the other has failed and a splitting between masculine and feminine aspects has happened. Therefore, psychoanalytical treatment should start with restoring this function by working on the transference on the container (Houzel, 2014). After working on transference, the psychoanalytical work moves towards what is called infantile transference that involves the child's fantasy called "nest of babies". This can only take place after a difference between self and others has been realized. In order to move to that stage the child should be able to trust the containing capacities of the analyst. A safe frontier between the self and object must be established with the bisexual quality of the container. This way the child can endure separateness from the Other. Autistic children need to be given psychic shape to their feelings therefore what are worked with is the child's representations. In the second stage of analysis where the infantile transference takes place, the child creates rivals that can throw him out of his place or take him over completely and make violent threats. This imaginary rivalry takes place with imaginary babies in the infants' mind that are competing for the milk in the breast. Third stage of treatment is the stage of Oedipal phase and about the child's sexualisation. It involves rivalry with the same-sex parent and accompanied with castration anxiety (Freud, 1924). The subject at this stage cannot be viewed as autistic anymore since this anxiety causes him to emerge as the castrated subject. The end of the analysis is a matter of discussion that is well beyond the scope of this study.

1.3.1 Gender dysphoria and autistic traits

Sexuation of the autistic subjects has also been subjected to research (Oien, 2018). The co occurrence between people with gender dysphoria and autism has been studied and it is found out that the presence of autistic symptoms is six fold higher in patients with gender dysphoria compared to the general population. It is also found that people who are assigned male at birth are more affected than people who are assigned female at birth. Gender dysphoria and ASD are known to be etiologically similar and their prevalence are both increasing. Both conditions are more common among males than females and co-occur frequently. Extreme male brain theory suggests that higher exposure to testosterone during the prenatal creates a disposition towards gender dysphoria and autism spectrum disorder (Heylens,2018). Participants who took the Social Responsiveness Scale scored higher points in GD group compared to the norm group indicating an overlap between autism symptoms and gender dysphoria. Even though it is found that autism symptoms are found more often in patients who were assigned male at birth compared to who were assigned female at birth, both MAB and FAB group showed higher levels of autistic traits compared to the norm group. So it important to consider the possibility of this co morbidity while assessing and treating people with ASD and GD since both disorders show a substantial increase over the past two decades.

1.4 Formation of The Neurotic Subject

When we look at the formation of the neurotic subject, we see that the mother and child are moving from symbiotic state toward separation. The baby begins to question the behavior of the mother over time and eventually realizes that there is something else the mother desires, namely the phallus. The phallus is the imaginary object of the mother's desire here. However, the child will notice the lack in the mother. Then the father, who is claimed to have phallus, enters the stage and the child sees that he does not have the symbolic phallus and gives up on the mother. Seeing the lack or desire in the mother becomes a basic transformation point in subjectification. In the carved area of the mother, the lack of the Other lies and the desire is formed. Because in this field, the Other cannot offer anything to the baby. That is why a space must be opened for both the subject and the Other, which will cause desire. Desire finds itself in relationship with the lack. In order to talk about identifying with a deficiency in ourselves, we must experience a deficiency in the Other. In this way, we can form our desire and create ourselves as desiring objects (Fink,1995).

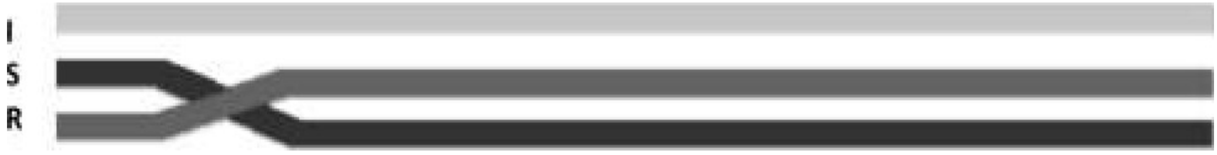
1.4.1 Desire and Anxiety in the Neurotic Subject

In Lacan's sixth seminar (1958-59), anxiety was presented as what’s underlying desire. In this seminar, Lacan states that anxiety positions in the imaginary and the linking of imaginary, real and symbolic register has specific effects. This is included in the seminar as a way of describing object a. Lacan explains that *object a* occurs when these three registers are connected. The intent of fantasy can be explained by connecting these three registers. In neurotic, anxiety may be related to the threat of castration, which is the result of the phallus determined by phallic jouissance. This anxiety is also associated with the reflection of the imaginary register’s dependence on the symbolic register as an affect. The language-forming elements, the way the language is operated creates a cut. But something else is required for this cut. To fully recognize this cut, a reference point to the function of this language is required. So the language fits into place and settles as an end result. Therefore, there is a support for the organization of desire, and every time the language manifests itself, there is sexuality in the repressed object. Everything that leads to a cut has something sexual. We can also put the origins of causality where the cut is.

1.4.2 Tying of the Borromean Knot in Neurosis

In order to start explaining how the Borromean knot (Laznik, 2016) comes to hold, it is important to mention its three strands, the Imaginary (first in the diagram), the symbolic(the second in the diagram) and the real(the third one). Real can be thought in terms of being as the organic baby. Symbolic represents the order of the world and the rules about time and generations that people submit and the Imaginary is about representations of what the baby can become and identification processes and the formation of the ego. These three strands are expected to overlap following a certain course starting from the first knot that is between the Real and the Symbolic.

Figure 1.1 First Knot



This braid involves the nearby helper (Nebenmensch) calming the baby by soothing the excitations that takes place within the baby’s body. These excitations can include hunger, thirst and likewise bodily sensations. These sometimes intense and disturbing sensations can be helped with specific actions by the Nebenmensch. The second braid takes place between the Imaginary and the Real. This phase involves the eyes and the voice of the big Other and they contain surprise and joy that is caused by the baby. The parent’s gaze that contains pleasure phallicises the child’s body. Phallic libidinal investment occurs in this phase and narcissism is introduced.

Figure 1.2 Second Knot

Infants are active in this process and try to attract the Other’s attention with bodily movements and imitation. When the parent starts looking away from the child, he wants the gaze back and actively seeks to gain it. It is provocation from the infant and it paves the way for anticipatory illusion. In the third braid the Imaginary overlaps with the Symbolic.

Figure 1.3 Third Knot

This phase involves symbolic castration and involves the introduction of the order of the family and it can only take place if the Imaginary strain overlaps with the Symbolic. Even though not seen very often, a matter of chronological time is involved here since meeting the mirror stage is necessary for the Imaginary register and mirror stage will appear around six months. The fourth braid takes place between Symbolic and the Real once again because of the nearby humans’s role in aiding the infant deal with the internal excitations coming from his bodily organism, his Real.

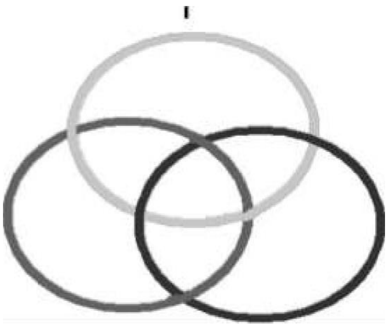
Figure1.4 Forth Knot

Construction of the ego takes place in the Imaginary register that is also called as the mirror stage. While the mirror actually reflects the lack in the baby, when combined with the primordial Other’s gaze causes this image in the mirror phallicize allowing the anticipatory illusion. The real of the infant is surpassed through alienation to an idealized Self. Only through symbolic castration the baby emerges as a barred subject. In order for that to happen the child must lose the mother to his father while waiting alone fantasizing to reunite.

Figure 1.5 Fifth Knot

Tying of all the threads of the strains will in turn produce a Borromean knot. At least for a typically developed child can become a barred object after the symbolic castration takes place.

Figure 1.6 Tying of all threads

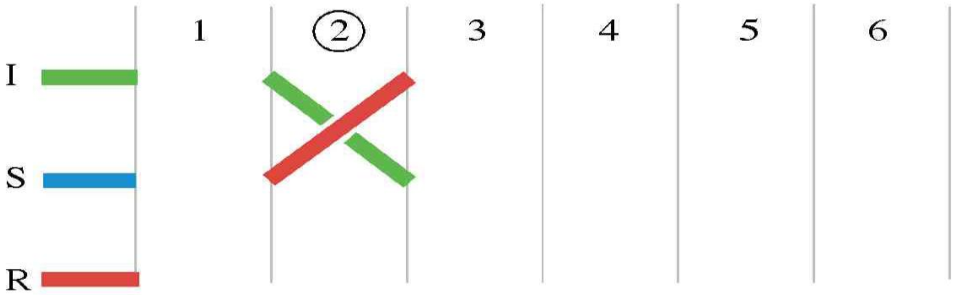


1.5. Formation of the Autistic Structure

In the autistic children it can be said that they have a failure of the Imaginary field being tied to the other strains of registers. The babies who will end up being diagnosed with autism are not going to build an ego during the mirror stage. They do not provoke the parent for her gaze and voice and are disinterested causing an admiration in them. Phallicization (Melman, 2014) does not take place among this children who refuse to alienate from the primordial Other. So errors take place in the braiding of the strains of these children and first of them is the tying of the Imaginary and the Real registers.

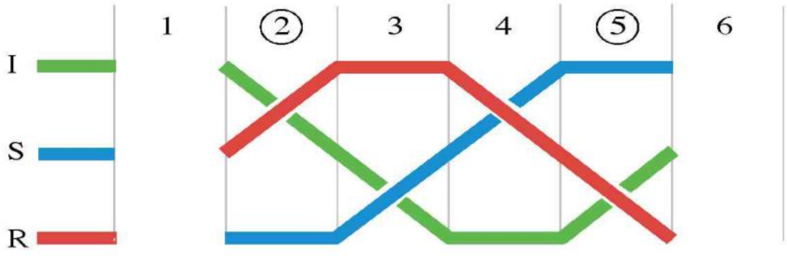
1.5.1 Tying of the Borromean Knot in Autism

Figure 1.7 First Error



With the error that takes place during the mirror stage, the jubilation in front of the mirror never takes place.

Figure 1.8 Second Error



Another failure happens at the tying of the Real and the Symbolic and the name of the Father does not take hold.

Figure 1.9 Third Error

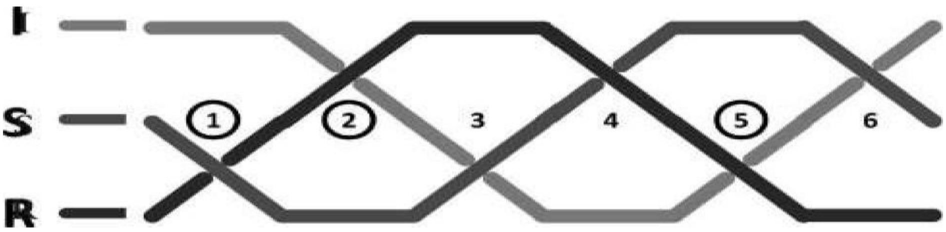
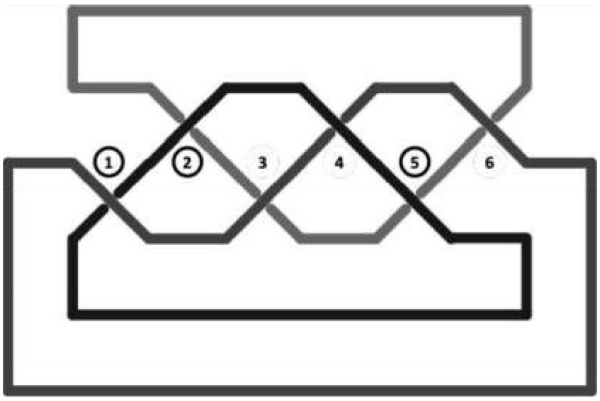


Figure 1.10 Tying of threads in Autism



Eventually we end up with three errors 1,2 and 5 and this is how the production of a Borromean knot fails to take place with the Imaginary register not overlapping with other two registers (Laznik, 2014).

1.5.2 Desire in the Psychotic and the Autistic

For the autistic, mother and father are not different than one another. The father's voice becomes meaningful to the child only by the mother's desire. In autism, the mother is reduced to things in space, and the relationship with the desire in sound and vision is eliminated. The autistic does not want to enter time and space by the desire of the Other. It almost wants to get away from desire, impulse, and juissance that enter through the voice of the Other. At the beginning of the life, autistic will try to avoid from the rest of life, as the voice of the mother is found to be unbearably traumatizing like a foreign entity outside the womb. At this point, he avoids confronting with the desires and demands of the Other by engaging autoerotism. This choice can be explained by frightening experiences with other people in early life. Autistic people are afraid that they will be swallowed extensively and that their insides will be destructively invaded and dispersed by the outside world. This extreme emotional tension affects their daily lives, causing them to live in a state of withdrawal and escape (Fink,1997).

1.5.2.1 Symbolization in the Psychotic and the Autistic

The mother tongue is the registrant of the wound. The talking person does not only accept the wound, but also likes it. When we look at families where parents are in perfect unity, they have rarely positive outcomes for this perfectly articulated couple and this is often a nightmare image for children. The phallus has lost its power to parse and create here. The couple collapses completely into themselves, because they are completely equal, and the phallus cannot replace it as the one that will lead to the cut. The other's space is found to be completely collapsed because the couple finds each other completely happy and united. What psychotic and the autistic suffer is the unrestricted nature of the signifier (Danon-Boileau, 2010). And the master's effects are impossible to take under complete control. This situation is panic-provoking and threatening for psychotic and the autistic (Lacan, 1956-57). There is the impossibility of division, a shelter, a place to hide, by this signifier who will provide subjectification to help face the world

The desire of the mother is the foundation in the formation of the structure, and the psychotic subject is excluded from this symbolization. Since desire is law, the psychotic subject does not recognize the law and cannot exist as a desiring object. Because desire is a defense against going beyond a certain limit in juissance. When we look at the desire of the psychotic, we see a basic relationship with the body. The Psychotic does not recognize the phallus or the Other. And he has a very primal relationship with the body. The autistic also refuses to engage in a relationship with the maternal that is going to lead to alienation. He does not subjugate to the demands and to the prohibitions of the Other. Just like he does not enter language, he does not enter into the spatial and temporal plane that comes with the Other’s desire. Instead he is preoccupied with non living things. The gaze of the Other is tormenting to him and he like the psychotic has a primal relationship with the organic Real.

1.5.2.2 Castration Anxiety in the Psychotic and the Autistic

Since autistic people are alien to castration anxiety and the desire to arise from this anxiety, emotions they experience are structurally differentiated from the emotions experienced by neuroticism. One of the reasons for the fears experienced by autistics concerns the issues of meaning, that is, the borders of the world and their bodies. Another reason is the threatening nature of phallic jouissance associated with not being a castrated subject. The main thing in the phallic jouissance is to be able to control the sphincters, here too, the real exceeds the symbolic. So autistic people may have specific fears associated with what they take in and throw out of their bodies.

The main difference between neurotic and psychotic seems to be that neurotic seems to believe in something, but psychotic really believes in it. Because the psychotic’s signifier directly says what it means, psychotic, like the autistic, have difficulty with double or hidden meanings. Lacan (1957-58) talks about a problematic relationship with the Other in psychosis. There has been a loss of meaning in Schreber's world because what was supposed to cause desire was lacking. There is no “name of the father” to refer to and he has lost his subjective position in the great Other. If we give a clinical example, we can talk about birth psychosis. There are mothers who give birth in clinics and who became psychotic from happiness. This situation sometimes takes a few weeks and disappears on its own. This is almost an experimental psychosis. When the object that is the basis of the woman's desire is there, an unexpected phenomenon becomes necessary, a moment of psychosis. Castration gives language its symbolic function (Dor, 1998). This means that every signifier is symbol of a lack. Signifiers are a symbol of a lack of satisfaction of desire.

Lacan first said that there was no such thing as autism (Melman, 2009). According to him, he was exposed to the Other by being exposed to the language, and therefore he is not alone. However, Melman said that Lacan did not have any experience with children who were indifferent and completely drawn in, who were unaware of the world and who were also deprived of one Other. While this is the point in autism, the situation is different for psychotic. The psychotic is agitated and shaken. In the absence of an Other, the baby seems to not receive messages, except for messages from his own natural needs. Of course, when their demands are not met, they may show anxiety, which may also produce some sounds, but lack of care for the caregiver, lack of fixation to gaze is one of the dramatic elements in the relationship. There is no awareness of the existence of the other in this relationship. Making this investment to object instead of in the caregiver's face, makes this economy in autistic more mysterious. This makes us think that the child can find himself most in a dead object.

In contrast to autism, psychotic engages with the language of the other. The Other for the neurotic person, is entirely mute. In psychosis, the signifier imposes itself to the sound field. The real is where the signifiers are rejected. Psychosis is where the cut does not occur. This means that the state of being one with the truth continues. In psychosis, the subject is not located where the Other is. The subject is always out of it. They are always out of each other. Apart from the subject's externality to the Other, there is always a conflict between them. This means that victory can be expressed only by someone's death. The subject can only move to where the Other is. This means that the Other is only in pure completeness and there is no place where the subject can reveal its existence. Because if the shows himself as the focus of the signifier, that signifier will remain outside the divine signifier or enter a moral race with him. Either the subject or the Other can exist in this duality. On the one hand, different from the autist, the psychotic can speak and express his feelings in the spoken language. Its main feature is to find a deficiency in the structure of the language and try to repair it. His effort is dictated by the voice of the Other, that is, by an imaginary being. Unlike autism, which does not have auditory hallucinations and does not produce a delusional structure, the psychotic can be managed by this voice and forced to repair language. It can do this by trying to build new structures and systems for social ties, places and relationships.

1.6. Having a child with autism

Caregivers of autistic children experience significantly more stress than caregivers of typically developing children and employ different coping strategies. In a study focusing on coping strategies of parents' four types of coping were listed: Active avoidance coping, problem focused coping positive coping, religious/ denial coping (Hastings, 2005).Using escape avoidance coping strategies has been reported to cause more stress than employing positive reframing strategies. It is found that thinking positively is helpful for parents in order to adapt into new life conditions with their autistic child. If they have more positive perceptions about their children, they experience less stress. Also research suggests that mothers experience more stress than fathers and they employ different coping strategies (Lutzky and Knight, 1994). This can be because mothers and fathers view their children's disability differently. Mother' stress tend to be more related to the children's level of development and how self sufficient he is. Children with autism can have varying degrees of behavioral problems and motor control. Fathers on the other hand experience stress concerning family's financial situation and how much their career can provide. Fathers are also show stress regarding child's communication skills, gender issues and physical problems. It is also shown that mothers seek social support and use problem focused strategies compared to fathers (Dabrowska and Pisula 2010). On the other hand, both mothers and fathers tend to avoid social situations and use denial as a coping strategy. Religious coping is also found to be a positive factor that helps improve mental health in parents. Parenting autistic children from different age groups also result in adopting of different type of coping strategies. Since these parents face various emotional, social and communication problems, some coping mechanisms tend to reduce stress while some mechanisms contribute to stress and depression in adults. School age is known to be especially stressful to parents compared to preschool and adolescence. According to research the cause of stress experienced by parents is related to the permanence of the child's condition, society's and family members' disapproval for the child's condition and insufficient professional support (Dabrowska and Pisula, 2010). In order to cope with stress and depression families can use certain resources. Families' personal resources include physical and mental health, financial status and level of education. A family with a child who has autism will also need cohesion and adaptability in order to cope. Their communication styles and support that they show each other is important. Lastly, these families can use social support from their family's network and institutions outside of family too. When emotion-oriented style of coping like rumination and self blaming is adopted mental health problems showed an increase compared to task oriented coping like active approach to problem solving. Task oriented coping showed negative correlation with mental health disorders like depression, anxiety and somatic disorders. When parents adapted low levels of emotional coping and high levels of problem-focused coping, lower levels of stress has been found. Active avoidance is a major contributor to high levels of stress and mental problems in both parents. Seeking informal support is associated with low levels of stress while religious coping can cause higher levels of parental stress according to some research (Sandica et al., 2011). Some studies suggest that parents of children with autism show higher rates of social difficulties such as having smaller social networks and having a shy and aloof temperaments and high levels of social phobia. These parents exhibited difficulties in pragmatic language skills as well as having rigid and aloof personality. Parents of children with autism also tend to be more introverted than parents of typically developing children. These factors are found to contribute high levels of stress in parents.

Different types of coping styles have been established by researchers (Lustig, 2002). These are task-oriented coping, emotion oriented coping and avoidance oriented coping. In task oriented coping, stress is being responded by making efforts order to solve the problem by altering the situation. In emotion-oriented coping, stress is responded with experience of emotions and handling of them by exhibiting emotional reactions. In avoidance- oriented coping, stress is avoided by either using distractions like becoming occupied with a different task or using diversions like socializing with people. Regardless of the coping strategy that is adopted, parents of children with autism are confirmed to experience higher levels of stress compared to parents of typically developing children. Also, these parents report displaying higher levels of stress compared to parents with children who have other disabilities. In order to cope with this stress, parents of children with autism are reported to use less social diversion than other parents. This result can be interpreted as having limited social activities due to the child’s condition. Having a child with autism can severely affect parents’ social life not letting them use social diversion to cope with parental stress. On the other hand, parallel with some studies, this lack of social diversion can be a result of these parents’ personality characteristics. Parents who use less avoidance coping style tend to adapt emotional-oriented coping styles more often than other parents. Using an escape-avoidance style is found to be negatively correlated with emotion-focused coping style. And using emotion-focused coping style is found to result in higher levels of stress. Some of the many emotions parents of children with autism are sadness, concern, pain and despair. After diagnosis, parents go through stages in terms of mourning. It is found out that parents can be in different stages of mourning like acceptance, depression and anger. These measures are taken a certain time between one month and three years after diagnosis. It is also stated that after diagnosis parents used coping mechanisms such as positive interpretation, acceptance, planning the use of social support, active coping and religious coping. People tend to give various reactions to autism diagnosis and it changes from family to family too. These reactions might include disbelief, anger, guilt, helplessness, devastation, surprise and it can also include the rejection of the child. Receiving a diagnosis can also help parents finally have and explanation for their child’s behaviors and give relief. It is important to identify these reactions coming from parents in terms of early intervention because parental involvement is a major part of child’s treatment and can affect the prognosis.. After the diagnosis parents go through various types of emotions ranging from shattered, despaired, worried, panic-stricken to sad, terrified, nervous, furious, grief-stricken, restless, desolate. These feelings can be thought as feelings of sadness, anxiety and rage. %50 of the parents stated that they experience sadness while 40% of parents stated that they feel anxiety. On the other hand only 3% admitted to experiencing fury. This autism diagnosis parents face about their child puts them in a mourning period since it has no known cure. According the Kübler Rose, 75% of the parents are found to be in the acceptance stage of mourning while 10% is in depression stage, 10% in anger stage and 5%in the negation stage (1969). Parents cope with this diagnosis and the morning period that comes after in different ways. It is suggested that parents employ 6 main coping mechanisms regarding raising a child with autism. These coping strategies are planning, acceptance, positive reinterpretation and growth, active coping, use of instrumental social support and religious coping. Locus of control is also a factor related to parental stress and depression. Locus of control is about what extend people think they can control the events that affect them. Research suggests that external locus of control is linked with higher levels of depression while internal locus of control is linked to lower depression scores indicating better adjustment to living with a child who has disability (Lazarus and Folkman, 1984).

The current study's aim is an in-depth investigation of experiences of mothers who have children with autism. This investigation is driven by two main research questions. First question is how an autistic structure comes to form and the second question is what mothers go through while raising an autistic child.

CHAPTER 2

METHOD

This chapter will mention the reasons for choosing a qualitative research method, nature of interpretive phenomenological analysis, participant and sampling method, procedure, data analysis and trustworthiness of the study.

2.1 Qualitative Research

Autism involves difficulties in socialization and forming relationships (Mayes et al, 1993). It also manifests itself in language and how it is used by people with autism. Etiology of autism is claimed to be unknown today (Buxbaum 2009). Since there is no one cause for developing this disorder, it can be said that it is a multi faced and complex issue that is difficult to study. On the other hand, psychoanalysis presents valuable insight regarding the dynamics between an infant and its caregiver and how an autistic structure forms in terms of clinical structure. This point of view to autism is highly subjective and therefore adapting a qualitative approach gives a better opportunity for an in-depth investigation of the participants' subjective position. By using this approach, the participants can express themselves more openly and a more intense research process can be possible. While qualitative research is an efficient way regarding the subjective nature of the topic of this study, it doesn't exclude the subjective role of the researcher either. It is also useful in terms of taking the researcher's personal involvement into account. The unique interaction between the researcher and the participants also serves as another aspect of this subjectivity and qualitative approach enables the researcher to investigate these unique interactions as well (Smith 2004). Among many qualitative approaches, interpretative phenomenological analysis (IPA) was chosen for this study because not only it makes an in-depth study of the material possible but also it creates room for unexpected themes to emerge (Barker, Pistrang, & Elliott, 2002). For reasons as such, IPA was the most suitable approach for the purpose of this study.

2.2 Interpretive Phenomenological Analysis

Interpretative Phenomenological Analysis doesn’t only focus on the collected data independently but rather takes into account the role of whom collects the data (Smith & Osborne 2007). In this approach, the researcher’s role on how the data is processed and interpreted is an important part of the study. Data received from the participants represent those individuals’ unique perspective on a particular issue and they talk about their subjective experience. So the interviewer and the participant’s meeting can be viewed as two different subjective experiences coming together and forming a unique interpretation of the studied phenomenon. Therefore, a double hermeneutic process is involved. In other words, a two-stage interpretation takes place in this type of approach. Another feature of IPA is that it’s idiographic (Smith, 2004). This feature is important for a qualitative study because it is not interested in making generalizations so it solely focuses on each case one by one in detail before moving on to the next one. Every case is studied in detail until the analysis presents a gestalt. This can be a repetitive process because when new themes emerge in a case, the researcher goes back to previous cases and searches for similar themes in those cases. This is one of the reasons that a small sample is preferred in IPA (Pietkiewicz& Smith, 2014).Also, participants are selected through purposive sampling because the aim is to reach a homogenous sample. It is important that the sampling is not overly random and the group is relatively more close to each other so that the interview questions can produce more coherent outputs. Interpretive Phenomenological Approach is an inductive approach in the sense that it allows unforeseen themes to emerge and these themes can also find their place within the study while maintaining coherence (Smith & Osborne, 2007). Therefore IPA adopts a flexible approach by conducting semi-structured interviews so that the participants can speak their mind openly and freely. This creates an opportunity for the researcher to analyze and interpret some novel information that can shape the research. Another aspect of IPA is that it is interrogative (Smith& Osborne, 2007). The detailed analysis of cases of studies that adopt IPA can contribute to the claims of quantitative research by interrogating the existing literature. Thus, what a quantitative study provides can be challenged by the foundings of an in depth qualitative study. Therefore it can be said the subjective nature of the case studies does not exist by themselves in isolation but rather they are discussed in relation to the rest of the psychological literature by using different means than quantitative research (Smith,2004).

This current study aims to understand the experiences of female individuals who are mothers to children who have autism. IPA is selected as the most suitable approach for this study due to various reasons explained above.

2.3 Participants and Sampling Method

According to IPA guidelines, this study aimed to work with a small sample which is homogenous (Smith & Osborn, 2003). Therefore, purposive sampling was used. A small sample was selected in order to obtain detailed information about every participant and analyze them to gain an in-depth understanding of the phenomena. Hence, the depth rather than the breath of the study is a priority for a method like IPA. In order to reach participants, an announcement was made through social media in various platforms. Also before the selection of the participants was made complete, an ethical approval was secured from Middle East Technical University ethics committee. Five participants joined the study and they were females who had children who were diagnosed with autism. The primary criterion for selecting participants was having a child who has autism.   Participants were selected among married women who had children older than 7 years old. The children were diagnosed between the ages of two and four and they are currently between the ages of seven and ten. Before the interviews took place, an informed consent was presented to the participants. The volunteered participants were chosen from various special education centers in Istanbul that specialize on working with children who has autism. Nicknames were used instead of participants' own names in order to protect the confidentiality of participants.

Table 2.1 Information about the Participants

Participant Number	Nickname	Child's Nickname	Child's age of diagnosis	Child's current age

Pt1	Çiğdem	Tolga	2,5	8
Pt2	Güliz	Deniz	4	8
Pt3	Hale	Murat	2,5	9
Pt4	Nihan	Ali	2	9
Pt5	Özge	Koray	3.5	8

2.4 Procedure

First of all, questions that were going to be asked to the participants were discussed and decided by the research team. During the data collection, interviews questions were comprised of open-ended questions and they were semi-structured (see APPENDIX C). After the pilot interview was done, both interview and research questions were reconsidered and updated in the light of the information obtained from the pilot interview. All interviews were conducted in various special education centers in Istanbul. Each interview was conducted in the special education center where that particular participant's child receives education. During the interviews, the interviewer prompted the participants when necessary in order to encourage them to speak openly and freely. They were also informed that they can withdraw from the study at anytime if they don't feel comfortable. The duration of interviews ranged between 100 min to 140 minutes. The conversations were audio-recorded and then transcribed. Participants' personal information in the transcriptions was changed in order to preserve anonymity.

Table 2.2 Semi Structured Interview Questions

1. Can you talk about your pregnancy?
2. Was it a planned pregnancy?
3. Can you talk about whether you had a gender preference?
4. How did you feel when you found out you were pregnant?
5. What does it mean to be a mother for you?
6. How do you spend time with your child?
7. Can you talk about your child's development?
8. Can you talk about your life before and after diagnosis?
9. How much time do you spend together with your child?

7. How do you feel when you are not together?
8. Can you talk about your spouse and your relationship with him?
9. How do you feel about what you can share with your spouse?
10. What does fatherhood mean to you?
11. How do you spend your time?
12. What does your family comprise of in general?
13. What kind of things do you do and how do you manage your time?
14. Can you talk about your life besides your family?
15. What kind of thing do you like to do?
16. What do you do in your spare time?
17. How much time do you spare for the things you would like to do?

2.5 Data Analysis

As the guidelines of IPA suggest, before analyzing the data it is important that the researcher becomes familiar with the transcriptions. Therefore firstly transcriptions were read multiple times by the researcher. Secondly, another requirement of IPA is that only after the analysis of an interview is finished it is proceeded to the next one (Smith, Jarman, Osborn, 1999) . So the analysis has been done consecutively. While reading the transcriptions, left margin of the text was used to take notes and write down what the sentences evoke in the researcher. Right margin of the text is used to write down emerging themes. These emerging themes were initially preliminary themes that were constituted by the information gathered from the notes taken from the left margin of the text. Therefore, some of the preliminary themes were dropped in the later stage when it was discovered that they were not relevant to the overall structure of the study (Howitt, 2010). Remaining themes were grouped as super-ordinate and sub-ordinate themes. One or many sub-ordinate themes can be organized under a super-ordinate theme. After the analysis of the transcription of the first interview, same procedure was followed for the second interview. Following that, all emerging themes of the cases that were compared were listed according to their similarities and differences. All cases were handled using this process. When the cross comparing of all the cases were finished, final themes of the study have been established. The super-ordinate themes of this study are *challenges during pregnancy and child birth, pre-diagnostic stance of mothers about* *raising their child, experiencing negative emotions after diagnosis, efforts to compensate for their child's shortcomings, idealizing their place in their child's life, conflicting attributions regarding the child's father and projections towards others varying by social proximity.*

2.6 Trustworthiness of the study

Qualitative research has certain criteria for trustworthiness including social validity, subjectivity and reflexivity, adequacy of data and adequacy of interpretation (Morrow, 2005). Social validity underlines the importance of naturalness and social value in research regarding the discipline of social sciences. This validity is matter of how qualitative research deals with subjectivity. All research has some degree of researcher bias and qualitative approach tries to study the data as it is without limiting and controlling it. In qualitative studies, subjectivity is variable that is included in the study itself and integrated in research with certain techniques like bracketing(Morrow, 2005). This is called researcher reflexivity and how the researcher makes sense of the data also becomes part of the research process. Adequacy of the data involves taking steps regarding doing adequate sampling, making adequate data collection and finding adequate evidence for the research in general. Adequacy of interpretation is the last criteria for the trustworthiness of a qualitative study. An adequate interpretation should also have a balance between the researcher's subjective interpretation and participants' expressions (Morrow,2005). The researcher's personal involvement in this research is explained below.

2.6.1 Self- Reflexivity

The reason I personally chose to study this topic is multifold. I have always been interested in language and its role in how we relate to one another as people. Autism as a phenomenon first came into my life while working as a speech language therapist and the main focus about autism was lack of a language. These children not only didn't use language but also lacked the representations that normally lead to socialization through speech. It was interesting to me that they seemed to prefer not to engage with people. Psychoanalysis helped me expand my view on the subject and interpret it in terms of clinical structures and in terms of our relationship with the

Other, through desire and law. And with my expanded look on the topic, I wanted to research more about the dynamic around this phenomenon.

Another topic of interest of mine and an issue of frequent contemplation has always been the mother and child relationship. I was a person with a lot of pre conceived notions on the topic for personal reasons and that’s why I wanted to put these notions to test by interviewing these mothers.

Lastly a topic that I wasn’t anticipating to be interested was the concept of loss and grief. After losing my father to cancer last year, I became more interested in how we process loss and how we grieve. And I found out that these mothers were or were not able to grieve their loss in various ways for various reasons too. To sum up, this master thesis that has been conducted includes a standpoint of the researcher that is explained above and this can also explain the subjective role of the researcher in qualitative studies such as this one.

CHAPTER 3

RESULTS

The current study involves seven super-ordinate themes in the light of Interpretative Phenomenological Analysis. The themes are; *challenges during pregnancy and child birth, pre-diagnostic stance of mothers about raising their child, experiencing negative emotions after diagnosis, efforts to compensate for their child's shortcomings, idealizing their place in their child's life, conflicting attributions regarding the child's father and projections towards others varying by social proximity.*

Table 3.1 Themes

1. Challenges during pregnancy and child birth
    a. Having health problems
    b. Anxiety about the baby's wellbeing
2. Pre-diagnostic stance of mothers about raising their child
    a. Feeling positively about working outside home
    b. De-emphasizing the importance of spending time with their child
    c. Shifting child rearing responsibilities to others
    d. Denial through normalizing the early signs of autism
    e. Difficulty accepting the diagnosis
3. Experiencing negative emotions after diagnosis
    a. Guilt and self doubt about the child's condition
    b. Anxiety about their competence in motherhood
    c. Anxiety about child's future and independence
    d. Fear of harm/loss of the child
    e. Frustration about not maintaining authority

4. Efforts to compensate for their child’s shortcomings
    a. Researching about autism as a coping strategy
    b. Monitoring the child’s improvement
    c. Comparing the child’s development to his peers
    d. Controlling their child’s life remotely when they are apart

5. Idealizing their place in their child’s life
    a. Solely responsible
    b. Only person who can cure the child
    c. Dedication by putting their child at the center of their life
    d. Postponing self- care and leisure
    e. Chosen by a higher power
6. Conflicting attributions regarding the child’s father
    a. Successful bread winner
    b. Good father
    c. Good spouse
    d. Inefficient in addressing their child’s special needs
7. Projections towards others varying by social proximity
    a. Institutions as inefficient
    b. Other mothers as judgmental
    c. Teachers as selfish
    d. Relatives as supportive

3.1 Challenges during pregnancy and childbirth

The first super-ordinate theme that has emerged in the current study is about the challenges faced by the mothers during pregnancy and childbirth. This theme involves difficulties participants experienced during their pregnancy and childbirth. The sub-ordinate themes are, *having health problems and anxiety about the child’s wellbeing.*

3.1.1 Having health problems

In this sub-ordinate theme, participants discussed mental and physical health problems that they experienced during pregnancy and childbirth. When they were asked about how they spent their pregnancy, they mentioned various health problems.

While some of them state that they suffered from mental health problems that affected them during their pregnancy, others mentioned they had physical disturbances. In addition, participants described various complications during the development and the birth of their baby. Hale stated that she suffered from panic disorder and used psychiatric medication. She described her fear of death and stopped eating because she believed that if she ate too much, she could have a heart attack and die. She also mentioned her concern about the iron deficiency and B12 vitamin deficiency in her blood tests:

> H: My pregnancy was enjoyable. But I had my own psychological problems. I was having panic attacks. This disturbed me from time to time during pregnancy. I had an attack again towards the end of my pregnancy. It became more troublesome. I felt myself as if the world is a matchbox they put me in. So much so my soul was narrowing. It started when an acquaintance had a heart attack. It happened after a meal. So I started not being able to eat. I thought when I ate, I would die. That's why instead of gaining weight, I lost 12 kg during my pregnancy. During pregnancy, I experienced anemia and B12 discomfort towards the last months, especially after 5 months. I already had the B12 deficiency. I went through that.
>
> H: Hamileliğim keyifliydi. Ama kendi psikolojik sorunlarım vardı. Bir panik atak yaşıyordum. Hamilelik öncesi, yani hamilelikte de zaman zaman bu beni rahatsız etti. Hamileliğimin sonuna doğru yine bir atak geçirdim. Can sıkıntısı oldu daha fazla. Kendimi şey gibi hissettim sanki dünya bir kibrit kutusu beni de içine koymuşlar. O kadar böyle ruhum daralıyordu. Bir yakınımızın kalp krizi sonrası başladı. Yemek yedikten sonra olmuş. Ben de o dönem yemek yiyemiyordum, yemek yersem öleceğim sanıyordum. O yüzden hamileliğimde kilo alacağıma toplam 12 kilo verdim. Hamilelik boyunca son aylara doğru özellikle 5 aydan sonra bir kansızlık ve B12 rahatsızlığı yaşadım. B12 zaten yapımda var eksikliği. Onu yaşadım.

Çağla also mentioned various complications ranging from bleeding to developmental arrest that resulted in a developmental delay in her child. She stated that she initially had some bleeding. She also described that her baby's development slowed down because her placenta stopped feeding the baby properly and the doctors monitored him frequently until he was born:

> Ç: I only had bleeding during my 9^TH^, 11th week of my pregnancy, but it was not an important thing. After I had a rest for two days, I returned to business life and there was no problem. After the 32nd week, the weight gain slowed down and the baby's developmental delay began to develop. Then we came to the 39th week with follow-up. Then there was an excessive resistance in my placenta so the baby could not be fed well. When the weight gain slowed down, I started going for follow up more often and he was checked at work every week. Well, I paid attention to my diet so we came to 39th week. When the 39th week was over I had a cesarean section.
>
> Ç: Hamileliğim sadece dokuzuncu, on birinci haftasında bir kanama olmuştu ama önemli bir şey değildi. İki gün bir istirahat ettim, sonra iş hayatına geri döndüm bir sıkıntı olmadı. 32. Haftadan sonra kilo alımı yavaşladı bebeğin gelişim geriliği olmaya başladı. Ondan sonra takiple 39. haftaya kadar geldi. Ondan sonra benim plasentada direnç fazlalığı vardı o yüzden iyi beslenemiyordu. Sonra kilo alımı yavaşlayınca sık sık takibe gitmeye başladım her hafta her hafta işte bakılıyordu. Beslenmeme dikkat ettim o şekilde 39 a kadar geldik. 39 bitti sezaryen.

Güliz also mentioned that she faced some unexpected issues while giving birth. She stated that it took several hours of pain but she couldn't have a normal birth because of the baby's position:

> G: I was going to have a normal birth, but because it came sideways, they struggled with me quite a bit. So after 12 hours of artificial pain, they forced me to a caesarean section. The boy was now in the pelvic canal. I mean, even the child's head appeared, but it did not come out. They said think of the egg, the sharp edge comes to its side; you cannot do this in any way. At night we went at 1.30, there was an opening of 8 9 cm in the morning, no excuse me, there was an opening of 4 cm. They blew the water at 8 in the morning. They said that the delivery will take place in half an hour, they took me in by one and a half, but I was finished. They said that it cannot normally be born under any circumstances.
>
> G: Normal doğum yapacaktım fakat yan geldiği için kafa baya da bir uğraşıldı benimle yani 12 saat falan bir suni sancı çektikten sonra mecburen beni sezaryene aldılar. Çocuk artık pelvik kanala girmişti. Ve oradan artık geriye yani hani, çocuğun kafası bile gözükmüştü ama çıkmadı. Dediler ki yumurtayı düşün sivri yer geleceğine yan geliyor, hiç bir şekilde yapamazsın bu doğumu. Gece bir buçukta gittik sabah 8, 9lık açılma vardı yok affedersiniz 4 cm'lik açılma vardı. Sabah 8 de suyunu patlattılar. Yarım saatte doğum gerçekleşecek dediler beni bir buçukta sezaryene aldılar ama ben

> bitmiştim yani. Zaten hiç bir durumda normal doğamaz dediler hiç bir koşulda.

Özge talks about going into labor without any preparation because her baby's health was in danger. She mentions that the doctors took her in labor before its time due to umbilical cord entanglement. So the baby was born prematurely and stayed in an incubator. She states that:

> Ö: I went for the blood sugar test. The doctor said let's take you to an NTS test, I said okay doctor. He said, I'm sorry; I don't want to scare you. He said the cord is wrapped around the neck of the baby, and we have to take you for caesarean section immediately. Of course, a sudden fear and a flurry came because I was 8-months pregnant, something like that came 45 days earlier than normal. I was scared, I cried, I got stressed about why it comes early because the doctor said that if we wait a little more, the baby can die and the cord is entangled. I gave birth in half an hour, so let me tell you, the delivery room was immediately called and informed that the patient is coming.
>
> Ö: Şeker testine gittim. Seni bir Nst'ye alalım dedi doktor tamam hocam dedim. Dedi kusura bakma seni de korkutmayayım kordon dolanmış bebeğin boynuna dedi seni de acilen sezaryene almak zorundayız. Tabi o an ani bir korku bir telaş çünkü daha erken daha 8 aylık hamileyim daha var normalden 45 gün önce geldi gibi bir şey oldu. Korktum ağladım strese kapıldım neden erken geliyor çünkü doktor öyle bir konuştu ki az daha beklersek bebek ölebilir kordon iyice dolanmış diye söyledi. Topu topu yarım saat içinde ben doğum yaptım öyle söyleyeyim size hemen doğumhane arandı.

In addition to disturbances in her diet and digestion, Nihan mentions experiencing severe shortness of breath that interrupts her sleep during her pregnancy. After he was born, her child also develops and asthma and that leads to his hospitalization. Her child developed autistic symptoms after he is discharged from the hospital. She states that:

> N: I had a shortness of breath between the first two months or five during my pregnancy and I was constipated a lot. I wasn't eating anything. I could not eat besides the lean salt-free mashed potato salad. In general, I was feeding as far as possible from the oil from the spice, away from all the scented and fragrant things. Because the moment I smelled them, I needed to remove them directly. My shortness of breath was too much, I had shortness of breath while I was sleeping at night, and I could not breathe like that, or I would be as if I was suffocating, I used to wake up like that. My pregnancy of 9 months went like that.

> N: Hamileliğimde ilk iki ay veya beş arası nefes darlığı çok çekiyordum, kabızlık problemi çok fazla vardı. Ali'de ben hiçbir şey yemiyordum. Beslenemiyordum. Yağsız tuzsuz patates püresi ve salata. Genelde olabildiğince baharattan yağdan tereyağından bütün hani kokulu ve esanslı şeylerden uzak bir şekilde besleniyordum. Çünkü onların kokusunu aldığım an direk çıkarma gereksinimi duyuyordum. Nefes darlığım çok fazla oluyordu gece uyurken nefesim kesiliyordu ve hıçkırarak böyle nefes alamazsınız ya hani boğuluyormuş gibi olursunuz o şekilde uyanıyordum o şekilde hani 9 ay boyunca hamileliğim o şekilde geçti.

3.1.2 Anxiety about the baby's well-being

Participants report a great deal of anxiety regarding the well-being of their baby. They describe their overall experience as quite distressing and they state that it kept them in a state of worry. Özge describes her unexpected premature birth like this:

> Ö: I was very scared. My baby may die, said the doctor, if you wait a little longer, the baby may die and I can never get you out of here. The doctor said; do not try to research for hospitals and other doctors. My first pregnancy with the fear in the moment, baby preparation is also at home. So I came to the hospital to do a sugar test to make a sugar check. I didn't come here to give birth. When they said the baby can die, you know that it's your first pregnancy and you do not know anything, if it results in a bad thing, you get scared. On the one hand, I cry a lot and on the other hand, I'm very scared. I had a different feeling. I had very different emotions in that half hour and 45 minutes.
>
> Ö: Çok korktum. Bebeğim ölebilir dedi doktor az daha beklersen bebek ölebilir dedi doktor ve seni asla dışarı çıkartamam. Başka hastaneler araştırayım başka doktor bakayım deme dedi doktor. O anki korkuyla ilk hamileliğim, bebek hazırlığı da evde. Yani ben şeker kontrolü yapayım diye şeker testi yapayım diye gidiyorum. Öyle doğum yapmaya gitmedim. Bebek ölebilir deyince hani ilk hamileliğin hiçbir şey bilmiyorum kötü sonuçlanırsa diye korkuyorsun her şey yani. Bir yandan çok ağlıyorum bir yandan çok korkuyorum. Değişik bir duygu yaşadım. O yarım saat 45 dakikada çok değişik duygular yaşadım

Hale talks about postponing having a second child because of her health problems. She states that she wasn't in a condition to take care of herself or a baby:

> H: I had a child before Murat. There is 7 years age difference between them. In fact, I waited for 7 years until my illness is over, because I could not be psychologically ready for the second child, and I could not feel more comfortable. In my previous pregnancy, I had puerperal syndrome at the birth of his brother, so there is a fear that the hormones do not sit down, do not heal after birth. I did not think of having children for 7 years. With that psychology, I could not be ready for the second child I could not take care of a second child, I started to recover after, and I felt well.
>
> H: Murat'tan önce bir çocuğum da var benim. Aralarında 7 sene yaş farkı var. Hatta 7 sene bekledim rahatsızlığım bitsin ki ikinci çocuk için kendimi psikolojik olarak hazır olamam kendimi daha rahat hissedemem. Ben bundan önceki hamileliğimde abisinin doğumunda lohusalık sendromu yaşadım yani doğumdan sonra hormonların yerine oturmaması, düzelmemesi ve korkusundan dolayı ondan dolayı insana gelen bir korku var. 7 sene çocuk yapmayı düşünmedim. O psikolojiyle ikinci çocuğa hazır olamam bakamam kendime yetemiyorum ikinci çocuğa bakamam diye sonra toparlanmaya başladım ve kendimi iyi hissettim.

Çiğdem states that because she works in a baby intensive care unit, she sees problematic cases frequently and she mentions how it made her feel worried all the time thinking that something may go wrong about her baby's health.

> Ç: My worries are always a concern for me, there is always worry because I work at a baby intensive care unit. Since I always see such problematic children, you always build in your mind, your first child. You know, if something like that happens, if he has a breathing problem when he is born, or if there is any problem when he was born, it was always on my mind. I was constantly worried. Well, after he was born, he had a little bit of a lisp. He was a hypotonic child; we always had a problem with nursing.
>
> Ç: Şöyle endişelerim benim için zaten her zaman bir endişe olur çünkü bebek yoğun bakımcıyım ben. Sürekli böyle problemli çocuklar gördüğüm için sürekli kafanızda kurgularsınız, ilk çocuğunuz. Hani yani böyle bir şey olursa ya doğduğunda solunum sıkıntısı olursa ya doğduğunda herhangi bir sıkıntı olursa falan diye sürekli aklımdaydı zaten. Sürekli bir endişe yaşıyordum. Sonra doğduktan sonra yine biraz pelteliği vardır hipotonik bir çocuktu, emme problemimiz hep oldu.

In this super-ordinate theme, participants expressed their challenges during their pregnancy. The challenges were generally related to their and their child's well-being. They experienced disruptions in their health and the development of their baby. Some of these health issues existed before conception of the baby. They also described being worried about certain complications that can threaten their life and their child’s life.

3.2 Pre-diagnostic stance of mothers about raising their child

Participants explained events and experiences that give information about their mind set, their attitude and their feelings until their child was diagnosed with autism. They described their life as very occupied with work, and the feelings of safety about their mother taking care of their child turned into denial when they were faced with early signs of autism in their child. They expressed great difficulty dealing with their child’s diagnosis and reacted in many ways emotionally and behaviorally. The second super-ordinate theme includes*, feeling positive about working outside home, de-emphasizing the importance of spending time with their child, shifting child rearing responsibilities to others, denial through normalizing the early signs of autism and difficulty accepting the diagnosis* as sub-ordinate themes.

3.2.1 Feeling positively about working outside home

Many participants stated that they loved their job and felt positive about work life. They equated work with socializing, receiving respect and financial freedom. They expressed enjoyment about being in their professional surroundings. Participants weren’t working professionally when they were interviewed because they were taking care of their child with autism. Therefore, they were remembering the times when they were working fondly and expressing a desire to work again if/when their child gets better.

Çağla states that she loves her profession very much:

> Ç. I love my profession. I love baby intensive care; I worked very fondly for years. So, there is a huge gap when you leave. Just like this, my circle of friends has changed. Because of both their busy schedule and my busy schedule, we have not been able to meet very often and the people around me have started to be families with children who do not develop normally. Well, so if I felt a bit strange and I wish I worked so that I get distracted, but if I worked, I would regret not taking care of my child in the future.
>
> Ç. Mesleğimi çok seviyorum. Bebek yoğun bakımı çok seviyorum, çok da severek çalıştım yıllarca. Tabi, çok büyük bir boşluk oluyor ayrıldığınız zaman. Sadece şöyle arkadaş çevrem değişti. Hem onların yoğunluğundan

> hem benim yoğunluğumdan dolayı çok sık görüşemeyip daha çok etrafımda normal gelişim göstermeyen çocuğu olan aileler olmaya başladı. O yüzden biraz kendimi bir tuhaf hissedip keşke çalışsaydım belki kafam dağılırdı moduna girdim ama eğer çalışsaydım da niye çocuğumla ilgilenmedim diye pişman olurdum ilerde işi bırakmasaydım da.

Güliz also remembers her work fondly but puts her child first:

> G: My goal is to pick Doruk up. And after Doruk, it is going back to work. Business life means social life for me. I think I am socializing in business life. It is good for me; it is good to be productive. My first goal is to fix Doruk. You can be sure, mothers like me have this goal. That my child is fine.
>
> G: Hedefim Doruk'u toparlamak yani. Doruk'u toparladıktan sonra iş hayatına geri dönmek. İş hayatı demek benim için sosyal hayat demek. Ben iş hayatında sosyalleştiğimi düşünüyorum. Bana iyi geliyor, üretken olmak iyi bir şey. Benim ilk hedefim Doruk'u düzeltmek. Emin olun benim gibi annelerin hepsinin hedefine bu vardır. Yani çocuğum iyi olsun.

Hale states that she was busy working and enjoyed it until her child stopped speaking. She states that it happened after he started watching cartoons at his grandmother's house:

> H: My friend had a sewing workshop, she was left alone, I went to help her like that, and then she asked me to stay with her. So I went to her like a normal 8 hours working system except Sunday for 8 months or so. Murat was going to his grandmother and my first child was already going to primary school. And I am a person who is very positive about working. I love working. He watched cartoons in my mother's house loved it very much, frankly. But then I don't know how it happened but Murat stopped talking.
>
> H: Arkadaşımın bir dikiş atölyesi vardı yalnız kalmıştı ona böyle yardıma diye gittim, sonra işte kal falan benim yanımda dedi 8 ay falan cumartesi pazar haricinde normal 8 saat çalışma sistemi gibi onun yanına gittim. Murat de anneannesine gidiyordu, ilk çocuğum da zaten ilkokula gidiyordu. Ben iş konusunda çok olumlu düşünen bir insanım. Çalışmayı seviyorum. Murat annemde çizgi film izliyordu, seviyordu da. Ama sonra ne olduysa konuşmamaya başladı.

Nihan talks about the sense of respect she gets at work and how that makes her feel. She also states that she would not stop working if it wasn't for her child's condition.

> N: I have a lot of desire to work now. I really want to work because I have studied two universities; I have a certain administrative experience. I had the

> opportunity to work for a couple of years. While Ali was going to kindergarten from 9 to 5 and I got myself a job from 9 to 5. You have had your education life, have studied university, had a good job, had a good career; you have a boss who is always looking for you. My boss was taking me from my house and taking me to work, even when I was on leave, they wanted me to come back soon. He took me with his car and took me to work; I was so respected at work. I did not want to quit my job. It did not happen after the diagnosis of my Ali
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> N. Şu an hani çalışma isteğim çok fazla var. Çalışmayı çok istiyorum çünkü iki üniversite okudum belirli bir yönetim idari tecrübem var. Çalışırken bile bir iki sene çalışma imkânım oldu Ali anaokuluna giderken 9/5 anaokuluna gidiyordu ben de 9/5 kendime bir iş buldum. Eğitim hayatı geçirmişsiniz üniversite okumuşsunuz iyi bir işiniz iyi bir kariyeriniz var sürekli sizinle ilgilenen sizi arayan bir patronunuz var. Hani patronum beni evimden alıp gelip götürüyordu beni işe sen çabuk gel izne ayrıldığım zaman bile beni arabasıyla aldırıp işe götürüyordu o kadar saygı görüyordum işimde. İşimi bırakmak istemedim. İşte benim Ali'nin teşhisinden sonra olmadı.

Özge states that work gives her independence and helps her distance from the house rush:

> Ö: I loved working. I already loved being in a pharmacy, and then the hostess job I did was very good. I loved to work, it makes you happy, you have your own money, and you earn yourself. It becomes a pastime. It was good because at that moment, for example, it was good to get away from the current house rush. At that moment you are focused on work, you are focused on children. Did they get on or didn't they, did they come or didn't they? It was such a good thing. It was good to work. It is freedom in every sense, in every material and spiritual sense.
>
> Ö: Çalışmayı seviyordum. Zaten eczanede de olmayı çok seviyordum ondan sonra da yaptığım hosteslik işi de çok iyiydi. Çalışmayı seviyordum insan mutlu oluyor kendi paran oluyor kendin kazanıyorsun. Bir meşgale oluyor. . İyiydi çünkü hani o anda mesela o anki ev telaşından ne bileyim uzaklaşmak iyi geliyordu. O an işe odaklısın çocuklara odaklısın. Bindiler mi binmediler mi geldiler mi gelmediler mi. Öyle bir şey yani iyiydi yani. Çalışmak iyiydi yani. Özgürlük her anlamda. Maddi manevi her anlamda.

3.2.2 De-emphasizing the importance of spending time with their child

In this theme, participants expressed that they did not have sufficient time to spend with their children due to their busy schedule at work. They argued that because they worked intensely for so many hours, they could only be with their child when it is their bed time. So they said that they were not able to spend one on one time together with their children. They saw this as the normal flow of life and felt comfortable because they viewed their child as well taken care of by others, especially by the grandmothers.

Çağla worked as a nurse and she had a very busy schedule. She states that when she was finally with her child at the end of the day, it was his time to go to bed:

> Ç: When I said we were spending time with Tolga, we couldn't spend much time because I was going to work in the morning, I was coming in the evening, I was coming home in the evening, and the child was already sleeping. I was working during the day, I was leaving him to my mother and he was spending time with my mother and with his uncle. Well, they were spending time together. We had our meals together in the evenings. The crowd was grandparents, grandmother eating together at my mothers. Then we used to go back to our house with Tolga and he would be very tired at 8.30 or 9 in the evening. So this time we were going to sleep. He was just sleeping at home. I was going to the park on my leave days, but i was working very intensely at that time.
>
> Ç: Şöyle Tolga'yla vakit geçiriyorduk derken, çok vakit geçiremiyorduk çünkü sabah işe gidiyordum akşam geliyordum akşam eve geliyordum akşam çocuğun zaten uyku saati geliyordu. Gündüzleri çalışıyordum ben anneme bırakıyordum annem de dayısıyla vakit geçiriyordu. Birlikte vakit geçiriyorlardı. Akşamları da hep beraber yemeğimizi yerdik. Kalabalık işte dedesi anneannesi hep birlikte annemlerde yiyorduk sonra ben Tolga'yı alıp eşimle birlikte evimize geçiyorduk evde zaten hani çocuk yorulmuş oluyordu akşam saat sekiz buçuk dokuz. Bu sefer uyku moduna geçiyorduk. Evde sadece uyuyordu yani. İzin günlerimde de o süreçte işte o süreç çok yoğun çalıştığım bir süreçti izin günlerimde parka gidiyorduk.

Güzin talks about her intense work life and adds that neither she nor her child had energy to do something together after she picked him up from his grandmother's house. She also described her difficulty to create games to play together with her child.

> G: My work shifts were long and stressful. I was working very hard; I was going early in the morning and leaving late. You are racing with time in export. In a very short time you must meet deadlines, load the goods. You cannot leave work when it's six or seven. I could not. I will finish and leave, it has to finish, and it has to be done. I was in such an intense schedule. His grandmother was taking good care of Doruk. And I would take him from my mother and bring him home. We were going home, of course, being a pulp, you didn't have much energy. We couldn't do much to play with the child. But it does not end with it. They are children ultimately and you have to play games. And it is hard for adults to play games, some people are innate or able

> to play, I play okay, but because our child is not very enthusiastic about doing something, playing was very difficult. Even at the age of 8 now, we couldn't play games together.

> G: Mesailerim uzun ve stresliydi. Çok çalışıyordum, sabah erken gidiyordum akşam geç dönüyordum ihracat olduğu için zamanla yarışıyorsunuz. Çok kısa zamanda her şeyi yetiştirip zamanı ayarlayıp malı yüklemeniz lazım, yani öyle işte hadi akşam 6 oldu 7 oldu çıkayım yapamıyordunuz yapamıyordum yani. Bitireceğim ve çıkacağım bitmek zorunda olmak zorunda. Hep böyle bir yoğunluk içersindeydim açıkçası.Anneanne bakıyordu. Ben anneanneden alıp eve getiriyordum. Eve gidiyorduk tabi pestil oluyorsun çok enerjin kalmıyor çocukla oynamaya bir şey yapmaya çok fazla bir şey yapamıyorduk aslında. İşte onunla bitmiyor işte. Çocuklar sonuçta, oyun oynaman lazım. Bir de büyüklerin oyun oynaması ne kadar zor, ya bazı insanın doğuştan vardır ya o yeteneği, ben oynarım tamam ama bizim çocuk çok hevesli olmadığı için çok zor bir şey yaptırmak oynatmak falan sıkıntı yani oluyordu. Hala bile 8 yaşında artık, beraber oyun oynayamadık.

Nihan worked as a project manager and work was very central in her life until her child got diagnosed with autism. Nihan talks about her stressful and demanding job and how her total investment was on her work:

> N: Before he was diagnosed, his grandmother was taking care of him and I was working. We didn’t do much. They were spending 24/7 together with his grandmother. I was a project manager in a catering firm and I was running their financial work. It was a problematic time. I was working very hard and it was a stressful job. I had this manager over me. My phone was never silent. I used to ring at six in the morning and three in the morning.

> N: Tanı almadan önce zaten babaannesi bakıyordu ona ben çalışıyordum. Bir şey yapmıyorduk. Babaannesi ile birlikte 7/24 vakit geçiriyorlardı. Proje müdürüydüm bir firmada bir yemek firmasında oranın bütün maliyeti ve diğer kurumlarında işlerini ben yürütüyordum. Sorunlu bir zamandı ve çok yoğun çalışıyordum ve stresli bir iş yapıyordum. Başımda bir yönetici vardı. Telefonum hiç susmuyordu. Sabah altıda telefonum çalıyordu gece üçte telefonum çalıyordu.

3.2.3 Shifting child rearing responsibilities to others

This theme involves participants’ attitudes about other people taking care of their child. Participants stated that during their busy work life, grandmothers took the role of the care giver and the children spent the majority of their time at their grandparents’ house. Participants also expressed contentment and gratitude toward their mothers or mother-in-laws about their child rearing skills and expressed safety and comfort. Güliz states that her child was fully satisfied at his grandmother's house and there was nothing left to do with him when she picked him up from her mother's house. She explained that her child was full and satisfied so there was not much left to do together:

> G: He was going to kindergarten. The kindergarten was leaving the service to the grandmother. Granny was feeding him. She was taking good care of him. I would take him from my mother and bring him home. He would have been fed, drank, relaxed with full belly. We were going home, of course, being a pulp, you didn't have much energy, and we couldn't do much to play with the child. Doruk was already saturated and full.
>
> G: Anaokuluna gidiyordu. Anaokulundan servis anneanneye bırakıyordu. Anneanne onu yediriyordu içiriyordu. Çok güzel bakıyordu. Ben anneanneden alıp eve getiriyordum. Yemiş içmiş, rahatlamış, karnı tok bir şekilde. Eve gidiyorduk tabi pestil oluyorsun çok enerjin kalmıyor çocukla oynamaya bir şey yapmaya, çok fazla bir şey yapamıyorduk aslında. Doruk de zaten doymuş ve tok.

Having her baby after an unplanned pregnancy, Nihan stated that her mother-in-law had become the primary care giver for her child. While praising her for taking very good care of her child, she questioned whether her child needs her or not. She also expresses her confusion about whose child Ali was; hers or her mother-in-laws?

> N: Before he was diagnosed, his grandmother was already looking after him. They were spending 24/7 with his grandmother. When he was three months old, I left him and started work. He was with his grandmother, so am I his mother or is his grandmother his mother. I adapted to him in a very different way. I mean, am I his mother or is his grandmother his actual mother because he was always with his grandmother. His grandmother was not giving him to us anyway; I was breastfeeding and bringing the child back. I was going back to work. She was following when I gave him milk and she was telling me that I should pump milk and put in the fridge so she can take it in the morning. She was always telling me. So it didn't feel like he needed me. His grandmother was really taking good care of him.
>
> N: Tanı almadan önce zaten babaannesi bakıyordu ona ben çalışıyordum. Babaannesi ile birlikte 7/24 vakit geçiriyorlardı. Üç aylıkken onu bırakıp işe başladım ben. Babaannesiyle beraber, anne miyim babaannesi mi annesi o durumda çok şeydi çok farklı bir şekilde adapte oldum ben Ali'ye. Yani ben miyim annesi babaannesi mi annesi çünkü sürekli babaannesinin yanındaydı. Babaannesi zaten bize vermiyordu çocuğu emzirmeden emzirmeye ben emzirip geri getiriyordum çocuğu. Geri işe gidiyorum. O takip ediyordu sütünü vermedin mamasını vermedin çabuk sütünü sağ hazırla dolaba koy

> ben onu sabah alacağım. O söylüyordu bana sürekli, Ali'nin ihtiyacı varmış gibi gelmiyordu. Babaannesi gerçekten çok çok iyi bakıyordu.

Çağla also talked about feeling safe about her mother taking care of her son:

> Ç: I was working during the day so I used to drop him at my mother's house. There he would spend time with his grandmother and his uncle. At home, I have a mother whom I trust most with my child. I was feeling safe.
>
> Ç: Gündüzleri çalışıyordum ben anneme bırakıyordum annem ve dayısıyla vakit geçiriyordu. Evde de çocuğumla ilgilenen en güvendiğim bir insan var annem var yanında. Hani gözüm arkada değildi.

Hale was expressing happiness because her child was happy at her mother's house:

> H: I had a working period of 8 months after Murat was one and a half years old, and he went to his grandmother for those 8 months. Murat was going to his grandmother and my first child was already going to primary school. He watched cartoons at my mothers and he loved it so much. He was having such good time at her house.
>
> H: Bir buçuk yaşından sonra 7, 8 aylık çalışma sürecim oldu. O 8 ay içinde anneanneye gitti Murat. Murat de anneannesine gidiyordu ilk çocuğum da zaten ilkokula gidiyordu. Annemde çizgi film seyrediyordu onu çok seviyordu açıkçası. Çok güzel vakit geçiriyordu annemde.

3.2.4 Denial through normalizing the early signs of autism

In this theme, participants' reactions to initial signs of autism are stated. They revealed that they noticed some early signs however they normalized it. The most common sign among these children was lack of speech. Mothers also expressed that their children showed some behavioral problems. Çağla mentioned various complications in her pregnancy like bleeding, developmental delay and after the baby was born, problems with taking the breast, low muscle tonus and lack of speech. Despite these issues, Çağla stressed a lot of times that everything in her pregnancy and her child's early years was normal and things changed only when he was two and a half years old:

> Ç: There was a bleeding in 11th week of my pregnancy, but it was not an important thing. There was mild bleeding, not heavy bleeding. It was a minor bleeding; of course, I went to the maternity ward and get examined with

> ultrasound. There was no problem, just two days of work was given rest. After the 32nd week, the weight gain slowed down and the baby started to have a developmental retardation. In the 39th week he could not gain weight, he was born with cesarean section. I don't know, I didn't have any trouble, I mean, baby had a low weight, 2 145kg, because I saw lower-weight children, maybe I am used to these processes. There was a sucking problem at birth. So he never held the breast. But throughout 17 weeks, I took breast milk and gave him the bottle, but he always refused the breast. Other than that, he was a hypotonic child for the first time when he was born. He was not very active, he was opened after it was born, his development was normal, Doctors were accepting this normally, and they say that the boys talk a little bit later. Everything was normal until the age of two and a half. His perception understanding… Only his speech was delayed.
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> Ç: Hamileliğimin 11. Haftasında bir kanama olmuştu ama önemli bir şey değildi. Hafif yani çok fazla bir kanama değildi, yoğun bir kanama değildi. Az bir kanamaydı tabi ki hemen kadın doğum servisine çıkıp muayene şey ultrasonuna bakıldı. Herhangi bir problem yoktu sadece işte iki gün istirahat verildi iki gün dinlendim. 32. Haftadan sonra kilo alımı yavaşladı bebeğin gelişim geriliği olmaya başladı. 39. Haftada artık sezaryen oldu kilo alamıyordu. Hani öyle sıkıntı yapmadım hani sonuçta kilosu da düşüktü 2.145 ti ama ben daha düşük kilolu çocuklar gördüğüm için bu süreçlere alışığım. Doğduğunda emme problemi oldu. Yani hiç göğsü tutmadı. Ama 17 hafta boyunca anne sütü aldı sağarak verdim ama memeyi hep reddetti. Onun haricinde biraz böyle ilk doğduğu zamanlar için hipotonik bir çocuktu. Çok hareketli aktif değildi sonrasında açıldı sonrasındaki gelişimi normaldi sadece konuşması geriydi kelimeleri vardı ama sayısı fazla değildi. Doktorlar da bunu normal karşılıyorlardı hani erkek çocuklar biraz daha geç konuşur takip İki buçuk yaşına kadar her şey normaldi. Algılaması anlaması. Yani sadece konuşmamız geriydi.

Regardless of the warnings of her surroundings, Güliz responded these comments by saying that there is nothing wrong with her child. She states that at that time she used to tell people that every child’s developmental process is different and her child will grow it out. She tells the story using conflicting information; she refers to normal actions of the child (singing, uttering words etc.) and abnormal behavior (banging his head on the walls) and also discussed the role of the pediatrician who misguided her:

> G: Doruk was a normal developing child. He walked in time, crawled in time. He said mom, dad, and grand dad at the right time. Yes, at the age of two and a half, his speech began to be complete. He went to kindergarten then it was very good, he was the boy who said everything, for example, his teacher said that when she sings a song once then in the second time they can sing it together. We have a pediatrician. I said that this boy was banging his head against the walls from one and a half to three years old. Do you know what the doctor tells me? Children do not grow up with a psychologist. When you

> hear them, you think it will go away, him banging his head, and you think he will speak eventually because I have not seen any other child. My mother said they couldn’t tell us anything because we could misunderstand. My brother told my mother to tell me about Doruk. My mom says that she was always telling me but I said that every child's development is different some things may come develop late.
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> G: Doruk normal gelişim gösteren bir çocuktu. Zamanında yürüdü zamanında emekledi. Anne baba dede zamanında çıktı bu kelimeler. Evet, 2 buçuk yaşında böyle konuşma tam olmaya başladı. Anaokuluna gitti o zaman baya iyiydi her şeyi söyleyen çocuktu yani ama mesela bana anaokulu öğretmenin söylediği bir şarkıyı bir kere söyle ikinci de beraber söylüyoruz diyordu. Çocuk doktorumuz var. Dedim ki bu çocuk kafasını duvarlara vuruyor. Bir buçuk yaşından üç yaşına kadar kafasını duvarlara vuruyordu. Doktorun bana söylediği şey ne biliyor musunuz çocuk öyle psikologla falan büyümez. Bunları duyunca bir şey yok geçecek falan yani kafa vurması falan, başka çocuk görmediğim için herhalde konuşur yapar düzelir. Annem söyledi bize yanlış anlarlar falan diye söylememişler. Anneme söylemişler kardeşimler sen söylesene diye. Annem de diyor ki sana hep söylüyordum sen diyordun ki her çocuğun gelişimi farklı bazı şeyler geriden gelebilir.

Hale shared her difficulty to see what others are referring regarding her child. She explains her frustration in response to her family members’ suggestions about taking her child to a doctor because he cannot speak. She stated that because he was physically normal, she couldn’t see that something was different about her child:

> H: I reacted, I said, why should I take the child to the doctor? Does his arm hurt, his leg hurt? Why do you want to take him to the doctor? Be open with me. He said I am just telling you to take him to the doctor, he does not speak. Now my brother has detected the situation and he sensed a difference because he was already with gifted children. He recognized the autistic child. Yasemin also told me since she knows autistic children. I said that I do not see it he just does not speak
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> H: Ben de hani tepki gösterdim ben neden çocuğu doktora götüreyim kolu ağrısa bacağı ağrısa, neden doktora götürmek istiyorsunuz dedim bana açık olun dedim. Dedi ki ben sana bir şey söyleyeyim yalnızca Murat’ı doktora götür ve dedi ki konuşmuyor. Şimdi ağabeyim durumu tespit etti o zaten üstün zekâlı çocuklarla olduğu için bir farklılık sezdi. Otistik çocuk tanıdı. Yaseminde otistik çocukları tanıdı için bana söyledi. Ben de dedim ki fark edemiyorum hiç sadece konuşmuyor.

3.2.5 Difficulty accepting the diagnosis

Going to the doctor’s office and hearing about their child was easy for none of the mothers. After receiving a diagnosis, they experienced a great difficulty accepting it. This sub-ordinate team explains what they went through when they heard that their child meets the criteria for autism. Hale says that at first she questioned the medical professionals and their methods, finding the tests too simplistic/not scientific enough. She states that after they received a medical diagnosis, it took her a month to accept it:

> H: I did this first. I said no, so I did not accept such a thing. I thought that my child's process was like that, and then I did not stay in this logic. I started researching about autism right away. I mean, I don't know so what if he can’t show his own nose. I didn’t think it was important. More precisely, I was stuck on one thing, there were cubes and you put the cubes on top, he told him to put them on the bridge, then make a bridge, he could not do such a test and I said to myself nonsense. Then he (the psychologist) did other things, to measure the muscles, I honestly saw this kind of thing as nonsense, I saw the simple test, I said, is this a diagnosis? I mean, let me tell you, for example in order to be medically diagnosed with cancer and you have to go through many tests. To say that your body has an anemia, you need to perform a blood count. There it seemed simple to do with papers with cubes. Frankly, it felt inadequate.
>
> H: Ben önce şey yaptım. Yok dedim yani ben öyle bir şeyi kabul etmedim. Benim çocuğumun süreci öyle falan diye düşünüp sonra bu mantıkta kalmadım tabi. Bakayım dedim neymiş bu otizm nasıl bir şeymiş hemen araştırmaya başladım. Yani ne bileyim kendi burnunu da gösteremesin ne olacak açıkçası çok önemsemedim. Daha doğrusu en çok şeye takıldım, küpler var ya küpleri üst üste koy dedi koydu sonra köprü yap dedi yapamadı öyle bir test saçmalık kendi kendime öyle söyledim saçmalık. Sonra işte başka şeyler de yaptırdı yani kasları ölçmek için ben açıkçası böyle şey gördüm saçmalık basit gördüm testi böyle teşhis mi olur dedim. Yani işte şöyle anlatayım size tıbben mesela atıyorum size kanser teşhisi konulması için bir belirtisi lazım ve birçok tahlilden geçmeniz lazım mesela. En basiti vücudunuz da bir kansızlık var demek için bir kan sayımı yapılması lazım. Orada işte küplerle kâğıtlarla yapması basit geldi. Yetersiz geldi açıkçası.

Nihan describes that her child changed after his stay at the hospital due to breathing problems. She states that after he was hospitalized, he stopped talking and became aggressive. She expresses her difficulty to understand and accept this change:

> N: Of course we couldn't believe it. We did not want to accept, because we saw our child as normal. It’s devastating to encounter something we have never heard of. We said that his speech was interrupted. You know, there is a child who talks until the hospital phase. I do not know if the doctors think this is the real reason or is it his brother or something else. We cannot solve the exact cause; can it be the side effects of drugs we use for asthma? Because he also became a nervous and irritable child after the hospital. When he was clogged, he couldn't really breathe. The talking boy started not talking, and started to use violence against his brother.
>
> N: Tabi biz inanamadık. Kabul etmek istemedik çünkü bizim gözümüzde çocuğumuz normaldi. Tabi insan böyle hiç duymadığı karşılaşmadığı bir şeyle karşılaşınca yerle bir oluyorsun. Konuşması durdu dedik. Yani hastane dönemine kadar gayet güzel konuşan bir çocuk, artık bilemiyorum doktorlar neye yoruyor acaba astım ilaçlarının yan etkisi falan mı çünkü bu çocuk hastaneden sonra çok sinirli bir çocuk da oldu. Böyle acayip tıkanıyordu nefes alamıyordu. Sonra konuşan çocuk konuşamamaya başladı ve kardeşine şiddet uygulamaya başladı.

Güliz describes her sadness when she received the news and she mentions a tendency to view it as unfair:

> G: Why, you say why my child is like that, sometimes I say this is unfair, and then say you should be thankful. He is a healthy capable child who can understand. Of course, when I learned this situation, I was very upset; it was an issue we did not know. But I thought the fathers are more difficult to accept. His father accepted it very hard. He said, I was not talking, and I was quiet. Of course, I was devastated at that moment, I was very upset, people tried to calm me, but believe me after leaving the door of the hospital, I said, what should I do, what should I do. And they said to me, this and this. I said okay then.
>
> G: Niye diyorsunuz, neden benim çocuğum böyle, bazen şey bile düşünüyorum haksızlık diyorum sonra şükretmelisin diyorum. Çok düzgün, eli ayağı tutuyor anlıyor sağlıklı bir çocuk. Ben bu durumunu öğrendiğimde tabi ki çok üzüldüm, bilmediğimiz bir konuydu. Ama ben şöyle düşündüm babalar daha zor kabul ediyorlar. Babası çok zor kabul etti. Ben de konuşmuyordum ben de sessizdim falan. Ben tabi o an çok yıkıldım çok üzüldüm beni sakinleştirmeye çalıştı insanlar ama inanın o hastanenin kapısından çıktıktan sonra dedim ki ne yapmam gerekiyor, benim ne yapmam gerekiyor. Ve bana dediler ki bu bu, tamam o zaman.

Özge describes her process of acceptance and how she wishes her child didn’t have autism:

> Ö: We plead. Of course, it was very difficult to accept. I still have my eyes filled. There is nothing to do. How can I say, I researched a lot from the internet; what happens to these children. I read a lot about what stages where they can come. I looked a lot. I wish it hadn't been. We were very effected as spouses, of course, why did this happen? What do we do? We went to some institutions and got reports. What can we do? But then, after sitting down and getting used to the new situation, we started to see him as a normal child.
>
> Ö: Kabulleniyoruz. Tabi kabullenmesi çok zor oldu. Hala gözlerim dolar yani. Yapacak bir şey yok. Nasıl desem. İnternetten çok araştırdım bu çocuklar ne oluyor ne geçiyor. Ne aşamadalar nerelere gelebiliyorlar diye, çok okudum. Çok baktım. Keşke olmasaydı. Biz eşler olarak çok etkilendik tabi hani tabii ki neden bu oldu biz ne yapacağız ne edeceğiz bu tarz çocuklar ne yapar ilerde çok okuduk elimizden geldiğince çok sağa sola sorduk. Gittiğimiz kurumlar olsun raporlar olsun. Ne yapabiliriz diyerekten. Ama sonrasında alışma evresiyle beraber ikimizde oturduktan sonra normal çocuk gibi görmeye başladık.

Çağla states that she denied what happened and she was not able to accept it. She mentions that even though she was not feeling well, she thought she should get better for the wellness of her child:

> Ç: After Tolga started to face such troubles, you are questioning life, thinking why all this happened to me. You can't accept, you deny, you can't accept. Then after some time you say that I have to recover, I cried and beaten, I cried a lot, I have withdrawn, I have been through a lot, but then I said I should recover, I need to recover for this child. What I need to do in terms of education, I have to do it, and this time you are trying to be resistant and trying to continue life. You cannot accept that is you deny it.
>
> Ç: Tolga'nın böyle sıkıntılar çıkmaya başladıktan sonra çok hayatı sorguluyorsunuz niye başıma bunlar geldi. Kabul edemiyorsunuz konduramıyorsunuz inkâr ediyorsunuz. Ondan sonra biraz zaman geçiyor sonra diyorsunuz ki tamam toparlanmam lazım. Ben artık ağlayıp dövünüp ki ben çok ağladım çok içime kapandım çok şeyler yaşadım yani ama sonra dedim toparlanmam lazım. Çocuk için toparlanmam lazım. Bu zamanları geçmemesi gerekiyorsa bu zamanları yoğun geçirmem lazım eğitim anlamında ne yapmam gerekiyorsa yapmam lazım diyip bu sefer dirençli olup hayata devam etmeye çalışıyorsunuz. Kabullenemiyorsunuz yani. Konduramamak aslında.

This super-ordinate theme includes the individuals' life and their relationship with their children. Being fully invested to their work, participants' mothers took the role of primary care giver in their child's life. Mothers either noticed some differences in their child's development but assumed they will go away or other people pointed out to them but they refused to accept. Participants eventually received a medical diagnosis that will start their journey with autism.

3.3 Experiencing negative emotions after diagnosis

This super-ordinate theme relates to the negative emotions of mothers about having and taking care of a child who has autism. Participants expressed several negative emotions regarding their performance and the wellness of their child. The sub-ordinate themes are *guilt and self doubt about the child's condition, anxiety about their competence in motherhood, anxiety about the child's future and independence, fear of harm/loss of the child, frustration about not maintaining authority*.

3.3.1 Guilt and self doubt about the child's condition

This sub-ordinate theme is about mothers' reflections on how and why their child has a developmental disorder. They express guilt and think that they may have done something that caused the child to be autistic. They question themselves and doubt their parenting abilities. Hale contemplates about whether she should feel guilt and blame herself about her child having autism. Without being specifically asked in the interview, she mentions guilt and blame several times while negating it in her sentences:

> H: At first I thought I wonder what caused it, did I cause it? When these diagnoses were investigated, it was said that B12 deficiency causes autism. Then I said, I have a B12 deficiency, but then I said, but I used my medication. What can I do? I was going to hold myself responsible if I did not take this drug, but I did. So I did not hold myself responsible about the diagnosis. I couldn't find anything to blame.
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> H: İlk başta düşündüm acaba neden, ne sebep oldu ben mi sebep oldum. Bu teşhisler araştırıldığında otizme B12'nin neden olduğu söyleniyordu. O zaman ben dedim ki ben de B12 eksikliği var. Ama sonra dedim ki ama ben ilaçlarımı kullandım ne yapabilirim. Belki ilaçlarımı kullanmamış olsaydım vicdanen kendimi sorumlu tutacaktım. Sen bu ilacı içmedin yapmadın. Belki orada hani çok kendime şey yaptım mı kondurdum mu teşhis konusunda kondurmadım. Hani suçlayacak bir şey bulamadım.

Özge reminisces the days of her baby's premature birth and his time in the incubator and asks herself if his autism is related to his premature birth and if she did anything to cause her child's autism:

> Ö: Because Koray was born prematurely and stayed in the incubator for a certain time. I was milking at home and bringing it to him. Since I saw him in the incubator, it was always stuck somewhere, and I can never stop thinking of it. It is all these strange needles and serums. If anything happens that scene comes before my eyes. Because he was born prematurely. Am I feeling guilty, I don't know that either. Sometimes I ask myself a lot. He was born early, did I do something? I don't know, is there something happened? He was born prematurely and I caused it.
>
> Ö: Koray çünkü erken doğduğu için belli bir süre kuvözde kaldı. Ona evde süt sağıp götürüyordum. Onu kuvözde gördüğüm için sürekli ve bir yerlerine bir şeyler takılı o an aklımdan hiç çıkmaz o iğneler serumlar bilmem neler tuhaf bir şey. Bir şey olsa gözümün önüne o hali gelir. Erken doğduğu için. Suçluluk mu hissediyorum acaba onu da bilmiyorum. Bazen kendime çok soruyorum. Hani erken doğdu ben mi bir şey yaptım acaba diyerekten. Ne bileyim bilmiyorum işte bir şey mi oldu da erken doğdu ben sebep oldum.

Çağla states that she often questions her actions wondering if she did anything wrong:

> Ç: I took him to the psychiatry clinic in the state hospital and they made it easy for me because I am a healthcare provider. They immediately issued a report to the child, for example, they made that report, but I did not understand what happened. Then I regretted it for a year, why did I get this report for my child. If he gets better, why did I stigmatize him? When your child has a problem, when something happens you constantly question, even if he is sick. Why did he get sick? Did I make him get cold; you look for something in yourself. Why this, where did we go wrong, you are constantly questioning.
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> Ç: Devletteki psikiyatriye götürdüm. Orada da ben sağlıkçıyım diye hemen kolaylık sağladılar. Hemen çocuğa bir rapor çıkardılar mesela ama ben ne olduğunu anlamadım. Ondan sonra onun için o kadar pişmanlık yaşadım ki raporun süresi bir yıl ben bir yıl boyunca niye ben bu çocuğuma rapor aldım ya düzelirse ben niye buna damga vurdum. Çocuğunuzda bir sıkıntı olunca hasta olsa bile sürekli sorgulayacağınız bir şey olur. Neden hasta oldu acaba ben bunu üşüttüm mü kendinizde bir şeyler ararsınız yani anne olarak. Niye şimdi bu nerede hata yaptık sürekli sorguluyorsunuz.

3.3.2 Anxiety about their competence in motherhood

Mothers express concern about meeting their child’s needs, being enough for them and they contemplate about their own parenting skills. They state that their energy is entirely directed to being a good mother to their child. Çağla feels like her child’s development reflected her own competence:

> Ç: If your child doesn't hold the breast, you get into that psychology. You question whether you are not able to do it, whether you are incompetent. Even if it's a doctor that's questioning this mood, it's a different life when you have your own child. A lot of his behaviors improved and he's better in a lot things but I still question if I went to a different clinic, if I did something else, would he be better or could he speak better?
>
> Ç: O anda çocuğun emmiyorsa o psikolojiye kapılırsın yani ben mi beceremiyorum ben mi beceriksizim bu doktor bile olsa hani bu ruh halini sorgulayan bir insan bile olsa kendi çocuğunuz olunca hayat çok farklı olur. Birçok davranışı düzeldi tabi ki ve hani diğer şeylere göre daha iyi durumda ama sürekli diyorsunuz ki başka yere gitseydim başka bir şey yapsaydım zamanında daha mı iyi şey olurdu daha mı konuşurdu. O hayatta sürekli oluyor.

Hale denies having feelings of guilt, but she expresses her anxiousness about attending to her child's needs and complementing his lack. She views her child's condition as flawed and lacking and expresses anger if she feels like she cannot fix his flaws:

> H: Did I think I was not good enough? Yes, I thought at first. But I did not hold myself responsible regarding the diagnosis. Now I say to myself you can do more at this point. I get mad at myself if Murat ever lacks something in his education. I say to myself you can do more, you can spare more time. I say leave what you're doing and do more for Murat. No parent wants their child to be flawed or lacking. No mother would want it.
>
> H: Yetersiz miyim diye düşündüm mü evet ilk başta düşündüm. Belki orada hani çok kendime şey yaptım mı kondurdum mu teşhis konusunda kondurmadım. Şimdi kendime hani diyebilirim Murat eğitim konusunda biraz eksik kalıyorsa kendime kızıyorum. Diyorum ki sen daha çok zaman ayırabilirsin şu işini bırak bunu daha çok yapabilirsin şu noktada bunu yapabilirim. Hani hiçbir anne baba çocuğunun kusurlu olmasını ya da eksik olmasını istemez yani. İstemez hiçbir anne istemez.

Güliz states that she tried to do everything to be enough:

> G: So you are trying to be enough, you are trying to be strong; you are trying to do everything. For example, I tried to do everything. I took everything upon myself, believe me it's exhausting. Then later you become depressed. You say; am I not able to do it, am I lacking why doesn't it happen. It is because you always have this expectation of yourself.

> G: Yani yetmeye çalışıyorsunuz güçlü olmaya çalışıyorsunuz her şeyi yapmaya çalışıyorsunuz yani ben mesela her şeyi yapmaya çalıştım her şeyi üzerime aldım inanın çok yorucu sonra ne oluyor patlıyorsunuz bir yerlerden sonra siz deprese oluyorsunuz depresyona giriyorsunuz. Yapamıyor muyum eksik mi kalıyorum niye olmuyor niye böyle hep çünkü kendiniz de bu beklenti içindesiniz.

Nihan talks about her desire not to leave her child lacking:

> N: But again, you are hesitating, can I be enough for my child, do I leave my child lacking something? Is there anything I need to do for him? I was writing hour by hour. If there is anything like going to the hospital, like going for an appointment with this doctor at this hour, I would first take him there. He will do this today he will do that today, it was all programmed. I was continuing my work but I could not leave without doing this. I was not comfortable. All I think is how much I can be enough for Ali and how much I can improve him.
>
> N: Ama gene insan çekiniyor çocuğuma yetebiliyor muyum çocuğumu eksik mi bırakıyorum, onun için yapmam gereken bir şey var mı, saat saat yazıyordum. Bu gün bir şey varsa hastaneye gidecekse bu saatte bu doktorda randevusu var, getiriyordum. Bugün bunu yapacak şu gün şunu yapacak, mutlaka programlı işime devam ediyordum. Bunu yapmadan gidemiyordum. İçim rahat etmiyordu. Tek düşündüğüm şey Ali’ye ne kadar yetebilirim onu ne kadar düzeltebilirimdi.

3.3.3 Anxiety about the child’s future and independence

Participants’ children are incapable of taking care of themselves and they are dependent on their care givers. Therefore mothers express great concern for their child’s future and whether the child is going to be self-sufficient. Participants express worry about how their children will sustain themselves when they get old or pass away. Çağla states that their efforts are for their child to have a place in society:

> Ç: In the end, if the child can express himself, he will be better in society. Anyway, what we want for him now is not to become a professor. What we want is that he be able to sustain himself in life. If he can express himself, this process will be faster, so I am working a lot on his speech. Now both of us are worried, for example how Tolga will be in a situation that can sustain himself in this life. God forbid if something happens to us. Relatives can support him but he shouldn’t be hanging and should express himself so that people can understand him and support him accordingly. At the moment, the effort of both of us is to bring our child to the society and to make it socialize.

> Ç: Sonuçta konuşsa çocuk kendini ifade edebilse toplumda daha iyi seviyeye gelecek. Zaten şu an bizim istediğimiz okusun şu olsun bu olsun profesör olsun değil. Hayatta kendini idame ettirebilecek duruma gelsin. Kendini ifade edebilse bu süreç daha hızlanacak şu an o yüzden konuşma üzerine çok gidiyorum. Şu an (eşimle) ikimizin de kaygılarımız mesela işte Tolga şu hayatta kendini idame edebilecek duruma gelsin. Allah korusun bize bir şey olduğu zaman çocuk hayatta tabii ki bir akraba bir şey tamam destek olur ama bu çocuk boşlukta kalmasın. Bir ifade etsin kendini ki herkes her şeyinin anlasın herkes ona göre destek olsun. Şu an ikimizin de çabası eşimin de benim de çocuğumuzu topluma kazandırmak sosyalleşmesini sağlamak.

While being worried about her child’s future, Güliz still hopes that her child will recover from autism one day. She states that:

> G: I wonder if one day he will overcome this problem and come out of this spectrum, and maybe he will be able to perceive the world like us, do things alone, control himself and become a person who can live on his own. I say what will happen to him when I die. As long as I'm healthy, it's okay as long as I'm with him, but I'm going to age. So you always know that mothers like us have this idea. A friend says, ‘I became a mother at the age of 45. I will not see this age of my child, I wonder if he will improve?’ This is always our concern. Will he be able to control himself?
>
> G: Acaba bir gün bu problemi yenecek bu spektrumdan çıkacak ve belki bazı şeyleri bizim gibi dünyayı algılayabilecek mi yalnız başına yapabilecek mi kendini kontrol edebilecek mi tek başına bireysel hayatını sürdürebilecek duruma gelebilecek mi çünkü diyorum ki ben ölürsem ne yapacak diyorum Doruk diyorum. Ben sağlıklı olduğum sürece ben yanında olduğum sürece okey ama ben de yaşlanacağım. Yani hep bizim gibi anneler de bu fikir var biliyor musunuz? Bir arkadaş diyor ki ben 45 yaşında anne oldum çocuğumun şu yaşını göremeyeceğim acaba düzelecek mi. Hep endişemiz bu. Kendi kendini kontrol edebilecek mi bunun endişesi var.

Özge is expressing concern about whether she can be enough for her child and whether she can manage him when he becomes a young adult:

> Ö: Now I think about the child’s future. I am really thinking of its development right now, whether he will grow beautifully and happily. He is 8 years old now. I can say sit, I can hold him, and I can hold him within a certain border of frame. When he becomes young, let’s say 18, can I be enough for him? I can keep this child within the limit I want when he is 8 years old. But I’m thinking whether he will listen to me when he is 18 or 20. I'm thinking about their future age.

> Ö: Şimdi çocuğun geleceğini düşünüyorum. Güzelce büyüyecek mi mutlu olacak mı şu an gerçekten gelişimini düşünüyorum. Şu an 8 yaşında. Otur diyebiliyorum tutabiliyorum, belli sınır çerçevesi içinde tutabiliyorum. Genç delikanlı olduğunda atıyorum 18 yaşında geldiğinde ben ona yetebilecek miyim, ben bu çocuğa şu an 8 yaşında istediğim sınır içerisinde tutabiliyorum. Yarın bir gün 18 20'li yaşlara geldiğinde ben bunu yapabilecek miyim benim sözümü dinleyecek mi, ne bileyim şimdi mesela ileriki yaşlarını düşünüyorum

3.3.4 Fear of harm/loss of the child

This sub-ordinate theme is about mothers' fear about losing their child or the child being harmed in any way. They mention a fear of harm like being hit by a vehicle or getting bullied by peers. They also express fear about losing their child and not being able to find him again. Participants state that they have this fear because their child is not able to express themselves or orient themselves spatially. Hale expresses concern both regarding to the possibility him getting lost, or getting hit by a car:

> H: A child with autism can take care of himself, go to the grocery store, there is a grocery store down the house. I send him to the store. He can buy bread, cake, milk. That is how Murat was able to have these opportunities. Even better, if I knew that he would not get lost in the market and if I was not afraid of the cars, the child would be able to bring his need from the market. But you can't help but having such reservations.
>
> H: Otizmli bir çocuk kişisel bakımını yapabilir dışarıya gidebilir bakkala gidebilir evin aşağısında bakkal var ben Murat'ı bakkala gönderiyorum ekmek alabiliyor kek alabiliyor süt alabiliyor. Yani bu imkânlara sahip oldu için Murat böyle. Daha iyisi olsa ben arabadan korkmasam markette kaybolmayacağını bilsem mesela diyelim ki diyelim ki çocuk marketten de ihtiyacını getirebilecek. Ama işte böyle çekinceleri oluyor insanın ister istemez.

Nihan views her son's peers as cruel and wonders about him when he is outside playing with them. She is afraid that they might harm her child:

> N: And because their peers are so cruel, when Ali plays, I feel the need to be there. Because he can't tell me what people did to him. I always think what

> he’s doing when he’s not with me. They are going to the park with his brother. When Serkan says they are beating my brother, I feel the need to be with him all the time. You will act as he deserves he doesn’t deserve to be pushed around, so I cannot leave him alone.
>
> N: Bir de kendi akranları çok acımasız olduğu için Ali oyun oynarken orada olma ihtiyacı hissediyorum çünkü bana diyemiyor ki anne bana bunu yaptı. Sürekli aklımdan gecen bu yalnız kaldığında ben olmadığında ne yapıyor. Kardeşiyle parka gidiyorlar. Serkan zaten anne kardeşimi dövüyorlar dediğinde zaten sürekli onun yanında olma ihtiyacı hissediyorum. Onun hak ettiği gibi davranacaksın itip katılmak da onun hakkı değildir onu yalnız bırakamıyorum bu yüzden.

Özge explains her fear that her child might hurt himself while playing. She also states that her biggest fear in life is losing her child. She worries that if she loses him, she might not be able to find him again. Hence, she stresses the importance of a loss and views it as more difficult than death because death has a certainty:

> Ö: I’d say son, don’t do like this do not throw the class and do not break it. So I was constantly observing. Because I was so scared that he would hurt himself. I was afraid he would fall. Sometimes I'm so scared, how do I find him if he gets lost. I repeat for him all the time. What is your name, your mother’s and your father’s name, where do you live, constantly. That's what I fear most in life. I can't find him if he gets lost. What can I do if I can't find him? Because loss is a very important thing. God forbid I am not speaking for my child but if he dies, at least you know where he is but in loss you do not know, I am very scared of loss.
>
> Ö: Oğlum, hayır böyle olmaz bardak atılmaz kırılmaz diye sürekli takip ediyorsun. Sürekli gözlemliyordum. Çünkü kendisine zarar vermesinden çok korkuyordum. Düşmesinden korktum. Bazen çok korkuyorum, kaybolmasından kaybolursa nasıl bulurum. Onun için sürekli tekrarlıyorum. Senin adın ne annen ne baban ne, nerede oturuyorsun, sürekli. şu hayatta en korktuğum şey o. Kaybolursa bulamam. Bulamazsam ne yaparım. Çünkü kayıp çok önemli bir şey. Hani Allah gecinden versin ölse çocuğum için demiyorum, dersin ki öldü, yeri belli yurdu belli dersin. Ama kayıp ne oldu ne bitti kayıptan çok korkuyorum.

3.3.5 Frustration about not maintaining authority.

This sub-ordinate theme is about how mothers react when their child does something they do not want to and how difficult it is for them to make their child stop. They describe their great efforts to establish discipline and explain that their child refuses to comply with their directions. Özge describes feeling tired and angry about her child’s misbehaviors:

> Ö: Sometimes I get very angry. It doesn't matter whether the glass is broken, but why are you throwing the glass? I was constantly explaining. Bu somehow some things just settle, now he doesn’t do it anymore. Sometimes I reacted, sometimes I got angry. I was following him like this. I was constantly observing. Because I was so scared that he would hurt himself. Sometimes he acts very spoiled, sometimes he becomes very cross and stubborn. He insists this will happen instead of that. And I was getting tired of it.
>
> Ö: Bazen çok sinirleniyorum. Bardak kırılsın önemli değil ama neden bardağı atıyorsun. Bunu sürekli konuş anlat anlat. Artık bir şekilde bir şeye oturuyor şimdi yapmıyor mesela. Bazen tepki veriyordum bazen de kızıyordum. Sürekli takip ediyorsun. Sürekli gözlemliyordum. Çünkü kendisine zarar vermesinden çok korkuyordum. Bazen çok şımarıyor bazen dediğim dedik diyor bazen çok aksileşiyor, o olmayacak ama o olacak diye diretiyor. Ben de yoruluyordum.

Nihan states that her child never complies with her directions and always wants his mother do everything for him. She explains that her position as a mother makes her discipline less effective. She explains that she can never get him to do anything and he always does things as he pleases:

> N: When he does not want to do it, when he does not want to take it, whatever you do, regardless of how many hours you try, he only looks at you. When I train him as his mother, when I try to do something, he accepts nothing from me; “you are my mother”. You will give my food, you will dress me, you will look after me, you will love me, but you will not give me an education, he does not accept me. Let's read, let's read a book. Never. Wear these pants, no you dress me, he can makes this sentence. You are my mother, you will dress me. He wears it when his father says, but when mom says it, he doesn’t accept. He wears his shoes at school, but my mom will get me dressed when going home. Dress me up mom. Give me my shoes, dress me my coat, my mom will always do these things. My mom will do these things if my mom is with me.
>
> N: Onu yapmak istemediği zaman onu almak istemediği zaman siz ne yaparsanız yapın kaç saat uğraşırsanız uğraşın sadece size bakıyor. Annesi olarak ona eğitim verdiğim zaman bir şeyler yapmaya çalıştığım zaman benden hiçbir şey kabul etmiyor, “sen benim annemsin”. Yemeğimi vereceksin üstünü giydireceksin bana bakacaksın beni seveceksin ama sen bana eğitim verme, bunu kabul etmiyor benden. Okuma yapalım kitap okuyalım. Asla. Bu pantolonu giy, hayır sen giydireceksin bu cümleyi kurabiliyor sen giydireceksin. Sen benim annemsin sen giydireceksin mantık

> bu onda. Babası dediği zaman giyiyor ama anne dediği zaman anne giydirecek. Okulda ayakkabısını kendi giyip çıkarıyor ama evde dışarı çıkarken annem giydirecek. Anne giydir. Anne ayakkabımı ver giydir anne montumu giydir sürekli bu şekilde annem yapacak. Benim annem bunları yapacak benim annem yanımdaysa bunların hepsini yapacak.

Güliz states that the nature of the mother and child relationship is what makes it hard to discipline a child:

> G: Actually, there is something like this. No matter how much you try to discipline, they always try to get away with you. So mother is treated very differently. In other words, all the whims are made to the mother. For example he does not do it with his teacher, but he does it to me. He knows where he will stop, but there is always something for the mother. And I'm not a mother who does whatever he wants, but here your motherhood appears. So they are being spoiled by the mother. It is another, that is, mother-child relationship is never like an educator-teacher-child relationship.
>
> G: Ya aslında şöyle de bir şey var. Ne kadar disipline etmeye çalışsanız da annesiniz ya, hep nazları size geçiyor. Yani anneye çok farklı davranılıyor. Yani hep inadı da anneye yapıyor bütün kaprisler anneye yapılıyor yani. Mesela atıyorum eğitimcisiyle yapmıyor ama bana yapıyor. Duracağı yerleri biliyor ama anneye hep bir şey var ki o kadar şey de değilim her istediğini yapan bir anne de değilim ama burada devreye sırf anneliğiniz ortaya çıkıyor yani. Anneye nazlanıyorlar yani. Başka oluyor yani anne çocuk ilişkisi bir eğitimci bir öğretmen çocuk ilişkisi gibi asla olmuyor.

Participants experienced overwhelming emotions after their child was diagnosed with autism. These emotions were a reflection of how competent they see themselves as mothers. Since they assumed a direct link between their motherhood capabilities and their child's condition, they felt responsible, guilty and anxious about the cause, the course and the progression of autism.

3.4 Efforts to compensate for their child's shortcomings

This super-ordinate theme involves individuals' efforts to improve their child's condition. After participants' children were diagnosed with autism, they felt complied to invest all their energy into meeting their child's needs. With an attempt to divert from their feelings, mothers focused on trying to complement their children's lack with the hope of their child's recovery. Combined with the difficulty in believing in the diagnosis and denial of the child's condition, the mothers believed that their child can improve and they devoted all their economic and psychological resources into the improvement of their children. The sub-ordinate themes are, *researching about autism as a coping strategy, monitoring the child's improvement, comparing the child with his peers, controlling their child's life remotely when they are apart.*

3.4.1 Researching about autism as a coping strategy

In this sub-ordinate theme, participants talk about how as soon as their child got diagnosed with autism; they immediately started researching about it. They state that they wanted to stop being sad and do something for their child instead. Özge stated she consulted institutions and researched using the internet in order to clear her confusion:

> Ö: So I constantly searched on the internet, what is and what is not. How can I say? I researched a lot from the internet about what these children go through. I read a lot, what stages they can improve. I looked a lot. Of course, we were very affected, of course, why did this happen? What do we do? All the institutions we go to or reports. My neighbor is a teacher and we got much information from her. But then, after the accommodation phase, we started to see him as a normal child.
>
> Ö: Yani sürekli internetten araştırdım okudum nedir ne değildir. Nasıl desem? İnternetten çok araştırdım, bu çocuklar ne oluyor ne geçiyor. Ne aşamadalar, nerelere gelebiliyorlar diye, çok okudum. Çok baktım. Çok etkilendik tabi hani tabii ki neden bu oldu biz ne yapacağız ne edeceğiz bu tarz çocuklar ne yapar ilerde, çok okuduk elimizden geldiğince çok sağa sola sorduk. Gittiğimiz kurumlar olsun raporlar olsun. Karşı komşum öğretmen benim ondan çok bilgi aldık. Ama sonrasında alışma evresiyle beraber ikimizde oturduktan sonra normal çocuk gibi görmeye başladık.

Güliz states she is much more knowledgeable about autism compared to before:

> G: We said we'll take him to a psychologist. He gets therapy, he gets something, and he is recovered. We do not know that there is such a big problem. Years of autism or something. we did not know what autism is. We think that there are psychological problems, we will go somewhere and it will pass. We were not very conscious then. Now we are not like that, now I follow the publications, I follow the books, that is.
>
> G: Götürürüz bir psikologa dedik. Terapi alır bir şey alır toparlanır. Biz hani böyle büyük bir sorun olduğunu bilmiyoruz. Yıllarca sürecek otizm falan. Böyle bir şey aklımıza gelmiyor otizmin ne olduğunu bilmiyoruz ki.

> Zannediyoruz ki psikolojik bir sorunlar var götürürüz geçer gider çocuk bu falan hani biz de çok bilinçli değilmişiz o zaman. Şimdi öyle değiliz tabi şimdi artık yayınları takip ediyorum çıkan kitapları takip ediyorum o şekilde yani.

Nihan talks about reading books about Ali's autism in order to be able to help him better:

> N: Whatever time I have left from taking care of Ali, I read books about child education in order to help him better. I always try to improve myself. I always think about ways to make him better to improve him better. I read self- help books. We didn't know any such thing as autism before; we are only learning it now.
>
> N: Ali'yle ilgilenmekten kalan zamanda da çocuk gelişim kitapları okumaya çalışıyorum ki Ali'ye daha fazla yetebileyim. Bu yüzden kendimi geliştirmeye çalışıyorum ki Ali'yi daha iyi düzeltebileyim. Kişisel gelişim kitapları falan okuyorum. Daha önce otizm nedir hiç duymamıştık bilmiyorduk tabi şimdi şimdi öğreniyoruz.

Hale states that after she accepted that her child has autism, she wanted to know more about autism because she felt she was lacking on that subject. So first thing she did was to enroll in a child development class and she received a diploma at the end of the course:

> H: I have accepted that it is something that exists. You can recognize a mongolian or a down syndrom, you know a spastic, but since we couldn't detect anything visually in our children, we couldn't analyze the visuals and we couldn't detect it so well. I was lacking there so I learned more about autism, I was calmer and I accepted that it is a way of being more professionally. At the psychologist's office I was not like that but at the psychiatrist, I said yes this exits so what can I do next. For example I said that I did not accept initially but after I did, the first thing I did was to take a child development course, I finished it and got a diploma too.
>
> H: Onun var olan bir şey olduğunu kabul ettim. Nasıl işte bir mongolu biliyorsunuz ya da bir Down sendromunu tanıyabiliyorsunuz bir spastiği tanıyorsunuz görüyorsunuz ama bizim çocuklarda görsel olarak bir şey görmediğiniz için biz o kadar tespit edemediğimiz için analiz edemediğimiz için burada eksik kalıyordum orada otizmle ilgili bilgi edindiğim için daha sakindim daha profesyonel olarak bunun bir var oluş olduğunu kabul ettim. Ne yapabilirim mantığındaydım, pedagogda öyle değildim. Ama psikiyatride de evet bu varmış gerçekten ben ne yapabilirim. Mesela ben kendim dedim ya ilk başta kabul etmedim ama kabul ettikten sonra ilk işim çocuk gelişim kursuna gitmek oldu kursu bitirdim benim de diplomam var.

3.4.2 Monitoring the child’s improvement

In this sub-ordinate theme, participants describe how much their child has improved with intervention. The children had been receiving a lot of education therefore mothers tend to compare their child’s development to the way he was before. With a desire for improvement or a recovery, they followed their children’s abilities. While showing contentment with their child’s progress, they also expressed frustration and disappointment because of the slow speed of progress. Çağla states that she observed her child’s development and tried to improve it with several educational techniques:

> Ç: So, I think that I supported him very well in that development process, so even though I worked hard, I tried to do everything, as I said, you follow the words like a normal developing child. This month he is supposed to say two and three words but he doesn't say it or he has to have ten or fifteen words but he doesn’t say it. He only has one or two words and you panic. This time you feel the need to speak more and you buy talking toys. You know, when I silence, you press the toys, and those toys talk all the time. We were constantly in this fashion. Whether it is voice or educational toys
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> Ç: Yani o gelişim sürecinde çok iyi desteklediğimi düşünüyorum yani yoğun çalışsam da sonuçta her şeyini yapmaya çalıştım zaten dediğim gibi kelimeleri normal gelişen bir çocuk gibi takip ediyorsunuz. Bu ay bir iki üç kelime söylemesi gerekiyor bakıyorsun söylemiyor veya 10 15 kelimesi olması gerekiyor bakıyorsun söylemiyor. Bir iki kelimesi var ister istemez panikliyorsun. Bu sefer ister istemez daha çok konuşma ihtiyacı duyuyorsun konuşan oyuncaklar alıyorsun. Hani ben sustuğum zaman oyuncaklara basıyorsun o oyuncaklar konuşuyor sürekli. Sürekli bu modaydık. Ses olsun yanında işte eğitici oyuncakları olsun şeyleri olsun.

Özge expressed contentment because her child’s speech improved after they socialized together:

> Ö: Well, sometimes he doesn’t understand a sentence we say. He can say, “what did you say, what did you say?”, but thank goodness he speaks better compared to before, he cannot pronounce or articulate some words but he speaks well. He can speak his mind, he tells when he’s hungry he can tell when he’s full. When we go outside we let him choose what he wants to order. For example, when we go to a grocery shopping, I get a trolley, he gets a trolley and I say buy whatever you want, get what you want, but we will eliminate it before coming to the cash register. We continue socializing.

> Ö: Şöyle geride tam anlamıyla bazen söylediğimiz cümleyi anlamıyor olabilir yani. Ne dedin ne dedin diyebiliyor ama çok şükür eskiye nazaran iyi konuşması yerinde bazı kelimeleri yanlış telaffuz ediyor ya da çıkartamıyor. Ama iyi konuşuyor derdini anlatıyor açsa açım diyor toksa tokum diyor. Mesela dışarı çıktığımızda işte yemek tercihi ona bırakıyoruz. Mesela bir market alışverişine gittiğimizde bir araba ben alırım bir araba o alır ne istiyorsan canın ne istiyorsa al bakalım ama kasaya gelmeden eleyeceğiz bazen böyle yapıyorum. Gezmelere devam ediyoruz yani.

Güliz expresses frustration about her child not improving faster. On the other hand, she appreciates that he is expressing himself better than before:

> G: This is like digging a well with a needle. There must be a reward for all that labor. It is slow but it’s happening. He understands what I say, says his needs. He wants to get married. I said what will happen when you grow up, said that I will be a groom. He says he will be a groom. He knows that he is a man; he knows that he is a man. He thinks about getting married, he knows that he has to marry a girl. Roughly he knows the girls become the bride and the boy is the groom. He said something to his last grandmother, grandmother, where's my black pencil? She replied but she was surprised by what he said. I was probably in another room. He wouldn't make such long sentences.
>
> G: İğneyle kuyu kazmak gibi bir şey bu. Emeklerin karşılığı olacaktır. Yavaş oluyor ama oluyor. Söylediğimi anlıyor, ihtiyaçlarını söylüyor. Evlenmek istiyormuş, büyüyünce ne olacaksın dedim, damat olacağım dedi. Damat olacağım demesi. Erkek olduğunun farkında erkek olduğunu biliyor ben o açıdan bakıyorum. Evlenmeyi düşünüyor, bir kızla evlenmesi gerektiğini biliyor. Kabaca biliyor kızlar gelin olun erkek damat olur. Geçen anneannesine şey demiş, anneanne, benim siyah kalemim nerde? Ben gayri ihtiyari cevap verdim demiş ama a ne dedin sen diye şaşırmış. Ben herhalde başka odadaydım. Bu kadar uzun cümleler kurmazdı.

Nihan also expresses disappointment with her child’s speed of improvement:

> N: The thing that hurts me is that the things we give him are getting to him very slowly. We progress very slowly; we progress so slowly that when he goes slowly, I only feel sorry for him. Because we know that he can do much better. For example, I say 4 and 2 and he says 6 to me. So I say let's do this on the board there is no answer. He just shuts himself. When he does not want to do it, whatever you do, regardless of how many hours you go, he only looks at you.

> N: Beni zedeleyen durum sadece ona verdiğimiz şeylerin çok yavaş teneffüs etmesi. Çok yavaş ilerliyoruz, o kadar yavaş ilerliyoruz ki o yavaş ilerlediğinde ben yalnızca onun açısından üzülüyorum. Çünkü biz onun çok daha iyilerini yapabileceğini biliyoruz. Mesela 4 2 diyorum bana 6 diyor hani bunu tahta üzerinde yapalım toplayalım diyorum cevap yok kapatıyor kendisini. O yapmak istemediği zaman siz ne yaparsanız yapın kaç saat uğraşırsanız uğraşın sadece size bakıyor.

Hale states that it takes time but her child eventually learns what he is being thought:

> H: My child is like this, if you show something for a month to Murat, he will learn at the end of a month. My child did not know how to wait for a school bus beforehand, he was running away, he was mobile, there was hyperactivity besides autism, but now Murat has been accustomed to the school bus for three years. He is waiting for his own bus while sitting down there, a lot of buses are passing through my door and I watch from the window so he can learn, but no matter how many companies pass, but Murat knows his own bus.
>
> H: Şöyle bir çocuğum var Murat'a bir ay gösterseniz bir ayın sonunda öğreniyor. Benim çocuğum önceden servis beklemeyi bilmiyordu sağa sola kaçıyordu hareketliydi otizmin yanında hiper-aktivite de var ama artık Murat üç senedir servisin gelmesinden servise alıştı. Aşağıda otururken kendi servisini bekliyor benim kapımdan camdan ben seyrediyorum öğrensin diye bir sürü servisler geçiyor kaç tane firma geçiyor ama Murat kendi servisini tanıyor bekliyor aşağıda.

3.4.3 Comparing the child's development to his peers

This subordinate theme involves participants comparing their child to his peers. The mothers made comparisons in order to follow their children's level of development. This comparison also resulted in various emotions like surprise, envy and sadness. Güliz states that it is important to compare:

> G: We did not understand much that we have such a problem in our child. I was working very hard and then it was my first child, and you know how they say don't try to compare your child with other children? Actually, it is necessary to compare. No you will compare. You'll see. You have to do this within yourself. Because you know I am shocked by? I was shocked when I witnessed the speech of a child at the same age of Doruk and what he did. I said, uh, how different he was. Doruk can't do what he does. I am talking about such a comparison. An observation.

> G: Biz çok anlayamadık biz çocuğumuzda böyle bir sıkıntı olduğunu. Ben çok yoğun çalışıyordum sonra benim ilk çocuğumdu çok diğer çocuklarla kıyaslamayın deniyor da. Aslında kıyaslamak gerekiyor. Hayır. Kıyaslayacaksınız. Göreceksiniz. Bunu kendi içinizde yapmanız gerekiyor. Çünkü ben ne zaman şok oldum biliyor musunuz? Doruk'un yaşında bir çocuğun konuşmalarını ve yaptıkları şeylere şahit olduğumda ben kaldım yani. Aa dedim yani ne kadar farklı dedim. Doruk yapamıyor onun yaptıklarını. Böyle bir kıyaslamadan bahsediyorum. Gözlem yani.

Özge felt envious of other kids' speech:

> Ö: We didn't understand, my first baby is my first experience. There was no problem, no discomfort in my husband's side or mine. The first baby was not understood, it was fine, and there was no such thing. Or I don't know I didn't understand. There were two months left until he was three years old. He was diagnosed. It happened again with my initiative. Here, I see other children in the site. They speak beautifully with sentences and everything. Our child doesn't.
>
> Ö: Anlamadık ilk bebeğim ilk tecrübem. Eşim tarafından da her hangi bir rahatsızlık bir problem yok benim tarafımda da yok. Hani ilk bebek anlaşılmadı gayet iyiydi öyle bir şeyi yoktu. Ya da ben anlayamadım bilmiyorum. Ta ki üç yaşında iki ay vardı. Tanısı konuldu. O da gene benim şeyimle oldu. İşte site içinde başka çocukları görüyorum yaşıtlarını işte ay ne güzel konuşuyor cümlesi var şusu var busu var. Yok, ama bizde yok.

Hale feels bad about her child being different from the other children in school:

> H: During the class break the other children can go to the canteen and buy something. Murat cannot do that on his own. I feel bad. I say that if my child was a normal individual, I would not have experienced it.
>
> H: Diğer çocuklar zil çalınca teneffüse gidiyor kantine gidip bir şey alabiliyor Murat kendi başına onu alamıyor. Kötü hissediyorum. Diyorum ki çocuğum normal bir birey olsaydı bunu yaşamazdım diyorum.

3.4.4 Controlling their child's life remotely when they are apart

Many of the participants talked about how uneasy they feel when they are not with their child. They feel worried and nervous and in return, they are trying to learn everything about the time they spend apart from each other. They also try to manipulate their child’s surroundings and feel frustrated when they cannot. This need for control is prominent among many of the mothers in this study. Nihan states she feels the need to be with him everywhere because he doesn’t talk and she complains that school administration does not listen to her:

> N: There is nothing when it comes to Ali. Do you have any homework? No answer. I have done this at school, we have done this, we will repeat it, my friend has done this to me, or I asked for this, he tells nothing of that sort. Because I do not know what I have not seen because of this situation, I always face the question of what happened today. What does he do when he is alone, that is constantly on my mind. They are going to the park with his brother. I wonder what he did in the park. I feel the need to be with him when Serkan says they beat my brother. I want to know. I also go to his school because they do not allow these children to go to recess. They say if children run away, we can’t take that responsibility. I tell them that they have a big sports facility so they can give physical training to these children but they just ignore it.
>
> N: Ali’ye sıra geldiği zaman ödevin var mı cevap yok. Okulda bunu yaptık bunu işledik bunu tekrar edeceğiz arkadaşım bana bunu yaptı veya canım bunu istedi durumu olmadığı için görmediğim şeyleri bilmediğim için acaba bugün ne oldu sorusuyla karşı karşıya kalıyorum her zaman. Sürekli aklımdan geçen bu yalnız kaldığında ne yapıyor. Kardeşiyle parka gidiyorlar acaba Ali parkta ne yaptı kim var, Serkan zaten anne kardeşimi dövüyorlar dediğinde zaten sürekli onun yanında olma ihtiyacı hissediyorum. Bilmek istiyorum. Okula da gidiyorum çünkü alt sınıflarda teneffüse çıkma yok. Çocuklar kaçarsa, çocuklara bir şey olursa biz o sorumluluğu üstlenemeyiz diyorlar. Okulun yan tarafında kocaman bir spor salonu var, beden dersi kondisyon eğitimi verilebilir diyorum ama göz ardı ediyorlar.

Çağla states that she cannot trust anyone so she feels like she must be informed about every detail regarding her child:

> Ç: I mean, when we are not together now, I need to call and constantly ask about him, there is a shadow sister at school right now. Tolga was sick on the weekend; he has a cough for example so I am calling during the breaks. How was the lesson passed? Did he cough? She informs me all the time, she just texted me before you came. She even informs that she has changed his clothes. It is so because my child cannot express himself, because he cannot explain himself to me. You cannot trust people no matter how good they are, no matter how comfortably you work with them I want to know everything when it comes to my child. What did they do in the lesson since the morning he started the lesson, was the teacher extra interested in Tolga? Is there homework, did you play games during the break, what games did you set up, did he eat his fruit, his snacks his food? I want to know everything.

> Ç: Yani şöyle beraber olmadığımızda yine arayıp sürekli sorma ihtiyacı duyuyorum. Tolga şu anda okulda yanında gölge ablası var. Tolga hafta sonu hastaydı öksürüğü var bugün mesela teneffüslerde arıyorum ders nasıl geçti öksürdü mü o da bana sürekli şey yapıyor mesela az önce siz gelmeden önce yine mesaj attı. Üzerini değiştirdiğinin bile bilgisini veriyor. Çocuğum kendini ifade edemediği için kendini bana anlatamadığı için öyle oluyor. Yani şöyle güvenemiyorsunuz insanlara ne kadar iyi de olsa ne kadar çok şey güvenle çalışsanız da çocuğunuzla ilgili bir konu olduğu için her şeyini bilmek istiyorum. Sabah derse başladığı andan itibaren derste ne yaptılar öğretmen Tolgayla her hangi bir ekstradan ilgilendi mi şu bir şey verdi mi. İşte ödev verdi mi teneffüste oyun oynadınız mı ne oyun kurdunuz meyvesini yedi mi çerezini yedi mi yemeğini yedi mi her şeyini bilmek istiyorsunuz mesela.

Hale expresses her frustration about not being let into the classroom. She states that she wants to be with her child because she views the education system as insufficient:

> H: They don't want me as a mother inside. In other words, I think the right thing is that they do not want me. Right there is an education. If children see me, how much they can adapt to this education. At the same time, I do not think they are right because their education is not good enough. So some who is capable should stand in place and the state should channel this or I have to be in there.
>
> H: Bir anne olarak beni istemiyorlar içerde. Yani beni istememeleri bana nasıl geliyor bir yandan şöyle düşünüyorum haklılar orda bir eğitim var çocuklar beni görürse bu eğitime ne kadar adapte olabilirler bir ses de içimden diyor ki haklı değiller eğitimleri yetersiz. O zaman ya benim yerimde bu işten anlayacak birinin durması gerekiyor devletin bunu kanalize etmesi gerekiyor ya da benim orada olmam gerekiyor.

Participants' initial reactions to their child's diagnosis were rapidly displaced with the need to take action. This need was comprised of a need for a hope of recovery and worry about their child's future. So their efforts were toward making up for what is missing in their child.

3.5 Idealizing their place in their child's life

The interviews reveal that the mothers idealize their place in the life of their child and glorify their position as a mother. The sub-themes are, *solely responsible, only* *person who can cure the child, devotion by putting their child at the center of their life, postponing self- care and leisure, chosen by a higher power.*

3.5.1 Solely Responsible

This theme reflects participants' views about themselves as the only responsible person about their child's life. Despite the support they received from their surroundings, they state that they chose to take on all the responsibility on themselves regarding the care taking of their child. They explain that they saw themselves as the ultimate person who can impact their child's life. They describe themselves as the sole care taker and Özge states that she carries all of the responsibility about raising her child:

> Ö: Actually, I have the whole responsibility. I am in service 24 hours a day. I don't have weekends, I don't have a salary. I am actually in service 24/7. I take care of the kids, the house, shopping and everything. Koray's lessons and reading. You send one in the morning and you send another in the evening and in the evening you are making games with both of them.
>
> Ö: Aslında sorumluluk tüm bende. 7/24 bilfiil hizmetteyim. Cumartesi pazarım yok aylığım yok. Ben 7/24 bilfiil hizmetteyim. Çocuklarla ilgilen evle ilgilen alışverişiydi şunuydu bunuydu. Koray'ın dersleriydi okumasıydı. Birini sabah gönderiyorsun diğerini akşam gönderiyorsun akşam olunca ikisiyle de oyun kuruyorsun.

Positioning oneself as the sole responsible and expecting to do everything creates the challenge of acting like a supermom for Güliz:

> G: It is a very, very big responsibility and you think about it all the time. You are trying to be strong, you are trying to do everything, and so, for example, I tried to do everything. I took everything upon myself because you expect that from yourself. I must do it, I must take care of it, I must resolve it.
>
> G: Çok çok büyük bir sorumluluk yani sürekli onu düşünüyorsunuz. Güçlü olmaya çalışıyorsunuz her şeyi yapmaya çalışıyorsunuz yani ben mesela her şeyi yapmaya çalıştım her şeyi üzerime aldım hep çünkü kendiniz de bu beklenti içindesiniz ben yapmalıyım ben halletmeliyim ben çözmeliyim.

Çağla states that she is the only one who is in charge regarding the decisions to be made about her child.

> C: Even though I worked hard, I tried to do everything as I said. I did everything. Without me no one can do anything with him. His father has an effect on him but when I say this is supposed to happen for Tolga, he stays there. Because I ran after him and his education life, his father does what I say and leaves it to me. Actually by doing that he gets rid of the responsibility and I always question my decisions. I think whether this is a good place to go. But I wanted to take on this responsibility; I couldn't leave my child to anybody.
>
> Ç: Yoğun çalışsam da sonuçta her şeyini yapmaya çalıştım zaten dediğim gibi. Ben her şeyiyle ben benden ayrı kimse Tolgaya iyi şey yapamaz babasının da etkisi var ama ben hayır o Tolga için iyi değil böyle olması gerekiyor dediği anda orda durur. Hemen her şeyi, eğitim hayatının peşine ben koştuğum için ben ne dersem onu yapar bana bırakır. Aslında bırakmakla üzerinden yükü atıyor aslında. Bana atıyor ben de bu sefer hep iyi yerler doğru kararlar verme şeyi oluyor bu seferde kararlarımı sorguluyorum. Bu gittiğim yer iyi bir yer mi acaba? Bu rolü üstlenmeyi de ben istedim, zaten bana kaldı gibi oldu ama ben de bu role bürünmeyi istedim çocuğumun şeyini kimseye bırakamazdım yani.

Nihan states that her child only needs her. She explains that what her child truly needs is to be always with his mother and this need is more central and important than any other need. She undermines her child's bond with his father and states it is as less important:

> N: I feel more like a mom next to him. Because he is the only one who needs me. Nobody else. He does not need others in anyway. Even when he goes to school, if I am at school, I will stand by him. There is always the fear of being lost if he doesn't see me. At night, he says mom, lie next to me. Normally, when he was 3 months old, he could sleep alone, and his brother did not sleep with us either. Let me hug my mother, let's smell each other and then I'll go to bed, but this is not so much like that with the father.
>
> N: Anne olduğumu onun yanında daha çok hissediyorum. Çünkü bana ihtiyacı olan tek kişi şu an o. Başka kimse değil. Başkalarına ihtiyacı yok hiçbir acıdan. . Okula gittiği zaman bile okulda ben olursam ben duracağım onun yanında ben olacağım. Sürekli beni görecek, kaybolma korkusu var yalnız kalma korkusu var. Gece anne yanıma yat. Normalde 3 aylıkken yalnız yatan bir çocuktu. Kardeşi de öyle kardeşi hiç bizle yatmadı zaten. Anne yanıma yat bir sarılalım bir koklayalım birbirimizi ondan sonra yatağana git durumu mevcut ama bu babayla çok mevcut değil.

3.5.2 Only person who can cure the child

This sub-ordinate theme is about mother's perception of themselves as the person who willfix their child. They believe that the child will grow out of the spectrum and this is only possible with their efforts as mothers. They see their role as more essential than the rest of the family members' and professionals'. Güliz states that more than anyone else she will make professionals. She also expresses a need for hope for the betterment of her child's future:

> G: I should do it, I should take care of it, I should solve it. I said I will get through to him, I will fix my child. I will do it. I will correct my child. I am the one to do it. So when I say I will correct him, there are therapists and everything but I am with him as his mom. I will do it. You are always looking for hope and remedy. There is always hope. Hopefully one day it will happen.
>
> G: Ben yapmalıyım, ben halletmeliyim, ben çözmeliyim. Hani ben şeye kadar gittim yani bir kanaldan gireceğim ben düzelteceğim çocuğumu. Ben yapacağım bunu falan. Düzelteceğim ben çocuğumu, yani düzelteceğim derken tabi ki terapistler vesaire ama hani ya ben yanındayım ben yapacağım ya hani yani hep umut, çare arıyorsunuz ya. Hep umut yani bir umut var insanın içinde inşallah olacak bir gün yani.

Çağla also feels that it is up to her to fix her child:

> Ç: Yes, after all, this is my child, I have made so much effort, I have done so much, I have to follow everything according to him, whether it is a wrong case or a wrong approach, I have to follow it and warn people. If someone can do something about Tolga's recovery, who can it be besides his mother?
>
> Ç: Evet aynen sonuçta bu benim çocuğum o kadar emek vermişim o kadar şey yapmışım herkes ona göre her şeyi planların yanlış bir davranış olsun yanlış bir yaklaşım olsun ona göre uyarmak zorundayım takip etmek zorundayım yani. Yani Tolga'nın düzelmesi için yaparsa ben bir şey yapacağım, annesi olarak başka kim olabilir?

Nihan states she's the person to meet all her child's social and physical needs and she's the one who will cure him:

> N: Motherhood is nothing else for me than to meet all his social and physical needs. I’m always thinking what I can do more and what I can do to be enough for him. In the end I will fix my child some way.
>
> N: Annelik benim için onun bütün sosyal ve fiziksel ihtiyaçlarını karşılamak başka bir şey değil. Ben sürekli onun için daha ne yapabilirim ona yetebilmek için ne yapabilirim onu düşünerek yaşıyorum. Bir şekilde ben düzelteceğim çocuğumu.

3.5.3 Dedication by putting their child at the center of their life

Many participants stated that their child is at the center of their life now, and they plan everything around their child’s needs. They state that they devote themselves to their child and his education. None of the mothers are employed at the time of the interviews and given that they associate work with socializing, their quitting their jobs after having a child with autism also limits their social life and leisure. Nihan expressed directing all of her energy into taking care of her child:

> N: After he has been diagnosed, I have completely stopped working, and I have not continued to work in any way. In order to take care of him, when they say work, I say first of all, Ali. I must complete the shortcomings of the Ali. We are constantly like, let’s go the pool, go to the school do the puzzle. I was like this, only thinking about Ali. Nothing else crossed my mind. Neither work nor career nor work life has passed into my mind, but all I ever thought is how much I can be enough for Ali and how much I can fix him.
>
> N: Tanı konulduktan sonra zaten iş hayatını tamamen bıraktım zaten hiçbir şekilde çalışmaya devam etmedim. Onun eğitimine ilgilenebilmek için iş dendiği zaman bana diyorum önce Ali. Ali’nin eksikliklerini tamamlamam lazım. Biz Ali ile sürekli olarak hadi eğitim gidelim havuza gidelim okula gidelim puzzle yapalım. Bu şekilde Ali’yi düşünüyordum sadece başka hiçbir şey aklımdan geçmedi. Ne iş ne kariyer ne iş hayatı aklımdan geçmedi hala öyle tek düşündüğüm şey Ali’ye ne kadar yetebilirim onu ne kadar düzeltebilirimdi.

Hale states that it is her responsibility to make her child the priority:

> H: Murat belongs to me. This responsibility belongs to me, so I am strong and dedicated to him. So I cannot go out, I do not have the opportunity and when I can go somewhere I go with Murat. So let's see with plain logic. Murat is my child, if I am not going to give up Murat, I have to shape my day accordingly. If I am going to give him up, I can look for other methods, I can

> cry about not going out, not doing things but I can’t do these things so I am devoted to him. Our other children, everyone in the house, we are programmed according to Murat, our priority is Murat.
>
> H: Murat bana ait. Bu sorumluluk bana ait dolayısıyla kendimi güçlü ve ona adamışım. Ay dışarı çıkamıyorum. Gezmeye gidemiyorum yapmıyorum fırsat varsa ve Murat’la gidebilirsem. Murat benim çocuğum ben Murat’tan vazgeçmeyeceksem günümü ona göre şekillendirmek zorundayım. Eğer Murat’tan vazgeçeceksem kendime başka işte yöntemler arayabilirim ağlayabilirim sızlayabilirim dışarı çıkamadım gezmeye gidemedim oralarım eksikliğim kaldı onu yapamayacağıma göre kendimi Murat’a adamış durumdayım. Diğer çocuklarım da evdeki herkes de Murat’a göre programlıyız önceliğimiz Murat.

Çağla states that their schedule revolves around Tolga’s needs:

> Ç: We would definitely go to Düzce when we had day off from work for two consecutive days, because the Tolga’s psychologists said to go to places with gardens. And because my husband was living in the center but we went to the village to my aunt so that he can spend more time with children outside. Wherever Tolga is going to be good, we have always organized our lives according to the Tolga. Since the child is at the forefront now, I don't think of anything for my own life right now. Everything is according to his plan.
>
> Ç: Daha çok iki gün üst üste iznimiz olduğunda mutlaka Düzce’ye giderdik. Çünkü Tolga’nın psikologları bağ bahçe falan olsun dedikleri için orada da mesela hatta eşim merkezde oturuyor benim halam var köyde oturuyor halamın yanına götürürdük ki çocuğu sırf Tolga orada daha köyde bağda bahçede daha çok çocuklar dışarıda onlarla daha çok vakit geçirsin diye. Tolga nerede iyi olacaksa Tolgaya göre hayatımızı hep düzene soktuk. Şu an çocuk ön planda olduğu için şu an kendi hayatım için bir şey düşünmüyorum. Her şeyimiz onun planına göre.

Güliz states that because her child has special needs, he becomes the center of her life. She prioritizes his wellbeing over hers:

> G: He is at the center of your life, we all have our own lives, but when it is a problem and when it’s a special child, and it becomes different. I should fix him first; I can do something for myself anytime. You know they always say you will be good so he will be good, I say if he is good only then I can be good. I always think of him first, his well being. I don’t want him to lack anything, I want people to be nice to him I want him to meet nice people.
>
> G: Hayatınızın aslında merkezinde o var şu an aslında tabi hepimizin kendine ait hayatları var ama üstüne üstülük problem olunca özel bir çocuk olunca bu daha farklı oluyor. Yani işte, onu bir düzelteyim de diyorsunuz nasılsa

> kendim için bir şey yaparım. Hani hep derler ya siz iyi olacaksınız ki çocuk iyi olacak. Ben de diyorum ki o iyi olursa ben iyi olacağım diyorum. Hep ilk önce onu düşünüyorum ilk önce onun iyi olsun onun bir şeyi eksik olmasın o iyi olsun insanlar ona iyi davransın yani öyle hep diyorum ki hayatta iyi insanlarla.

3.5.4 Postponing self-care and leisure

This sub-ordinate theme is about participants stating that they actually do not do anything for themselves. They explain that they don’t spare time for leisure activities or engage in any pastime activities individually. They postpone self care to an unknown future when their child is recovered from autism. Çağla states that she doesn’t think for herself because she prefers to invest all of her time to her child:

> Ç: Oh, right now, not at all. I do not want to do anything. It's just about Tolga. It's actually something like this now. I couldn't spare myself a lot of time. I did not even spend any time in the process. There was always education in our lives, there was always something, but not only for me individually but as a family. For example for myself I am thinking about an English course. But I don't have time to do anything individually. Since our lives are shaped according to the Tolga during the day and if I set something according to my leave days, we make other plans including my husband and the kids. There is nothing I do for myself individually right now. For example, if I have free time at the moment, in order not to leave him idle, I take him to the shore, to the park so he can ride his scooter there. He shouldn’t be idle. That’s why I don’t think anything for myself. There are things that I think, there are courses, there are things, but I need to go to them regularly and I can't spare time for them. Since the child is at the forefront now, I don't think of anything for my own life right now.

> Ç:Ay şu an hiç bile. Hiçbir şey yapmak istemiyorum. Sadece Tolga. Şu an aslında şöyle bir şey. Kendime çok vakit ayıramadım. Süreçte hatta hiç vakit ayırmadım. Hep hayatımızda eğitim vardı hep bir şeyler vardı ama bireysel olarak kendim için değil de yine ailecek. Kendim için mesela şu an İngilizce kursu düşünüyorum. Ama bireysele şu an bireysel yapabilecek vaktim yok. Gündüzleri mesela zaten hayatımız Tolgaya göre şekillendiği için izin günlerimizde de izin günlerime göre bir şey ayarlasam eşim evde eşim ve çocuklar başka bir planımız oluyor. Şu an kendime bireysel yaptığım bir şey yok. Mesela şu an boş vaktim olsa Tolganın da boş vakti olsun Tolga boş kalmasın diye hiçbir şey olmasa sahile götürürüm bisiklet sürdürürüm parka götürürüm scooter sürdürürüm çocuk boş kalmasın o yüzden şu an kendim şu an bireysel bir şey düşünmüyorum. Düşündüğüm şeyler var kurslar var şeyler

> var ama düzenli onlara da gitmek gerekir ve onlara zaman ayıramıyorum. Şu an çocuk ön planda olduğu için şu an kendi hayatım için bir şey düşünmüyorum.

Güliz states that she's not doing anything apart from taking care of her child. She also states that instead of spending money for herself, she would prefer to pay for more of her child's therapy sessions:

> G: Apart from taking care of Doruk? Honestly, I'm not doing much. So it is general, and since we have a very routine, I take Doruk everywhere.. I don't do much when he is at school either. Then I take him from school, I dress him, I feed him, we go to therapies. So we are together. He's my friend. Of course there are many things I want to do, but since the priority is always Doruk, I am postponing some things. Some things are also a matter of finance, because you know we spend everything for him, these things are very expensive. So I say instead of doing this for myself, I will take him for two more sessions.
>
> G: Doruk'a bakmak dışında valla çok fazla bir şey yapmıyorum açıkçası. Öyle genel yani ve çok rutinimiz olduğu için Doruk'u her yere ben götürüyorum. Genelde okuldayken de çok bir şey yapmıyorum. Okuldan getiriyorum giydiriyorum içiriyorum terapilere gidiyoruz. Beraberiz yani. Arkadaşım o benim. Tabi yapmak istediğim çok şeyler var ama öncelik hep Doruk olduğu için öteliyorum bazı şeyleri. Bazı şeyler de imkân meselesi, çünkü biz bütün imkânlarımızı, bütün her şeyimizi ona biliyorsunuz bu işler çok masrafları. Ben bunu yaparsam bunu yapana kadar iki seansa götürürüm diyorum yani. Öyle düşünüyorum.

Nihan states that she spends her spare time by reading child development books for her child to better equip herself as a mother of a child with autism:

> N: I can't really say I do much for myself. What time I have left from taking care of Ali, I read books about child education in order to help him better. I always try to improve myself. I always think about ways to make him better to improve him better. I read self- help books.
>
> N: Kendime pek bir şey yapıyorum diyemem. Ali'yle ilgilenmekten kalan zamanda da çocuk gelişim kitapları okumaya çalışıyorum ki Ali'ye daha fazla yetebileyim. Bu yüzden kendimi geliştirmeye çalışıyorum ki Ali'yi daha iyi düzeltebileyim. Kişisel gelişim kitapları falan okuyorum.

Özge says that all her time goes to taking care of the kids and doing house work:

> Ö: Not much is going on with me other than kids and housework actually. When kids are asleep I do some house work. Just some routine housewife duties. They take so much of my time anyway.
>
> Ö. Valla çocuklar ev işi falan derken pek de başka bir şey yok. Bunlarla, bunlar uyudukça şey oldukça evin işi. Rutin ev hanımı yani. Zamanımın büyük bir kısmını alıyor bunlar zaten.

3.5.5 Chosen by a higher power

This sub-ordinate theme is about participants' attributions about why their child has autism. In order to make sense of their experience, participants resort to spiritual concepts. They state that it came from a higher power and that's how they are trying to accept their situation. Çağla states that it was meant to be:

> Ç: Fortunately, this is something I should have experienced and I am glad that Tolga happened. It was supposed to happen. Good and bad, there is Tolga. Tolga is a completely different issue, for example, now there is a little one Mert, but the place of Tolga is always different.
>
> Ç: İyi ki bu benim yaşamam gereken bir şeymiş ve iyi ki Tolga oldu diyorum. Olması gerekiyormuş. İyisiyle de kötüsüyle de iyi ki Tolga var. Tolga bambaşka şu an mesela mert de var küçüğü de var ama Tolga'nın yeri hep farklı.

Özge thinks that it came from God:

> Ö: How should I know, my mother-in-law asked a lot, nothing like that on our side, nothing like that in your side, how did this happen? In other words, we say we are willing to accept everything that comes from my Lord and we step aside. We plead. Of course, it was very difficult to accept. I still have my eyes filled. Nothing to do. It's God's discretion.
>
> Ö: Ne bileyim, kayınvalidem de çok sordu biz de yok öyle bir şey dedi sen de yok dedi nasıl oldu böyle bir şey dedi yani ben de bilmiyorum. Yani rabbimden gelen her şeye razıyız deyip kenara çekiliyoruz. Kabulleniyoruz. Tabi kabullenmesi çok zor oldu. Hala gözlerim dolar yani. Yapacak bir şey yok. Allah'ın takdiri.

Güliz believes that she is chosen:

> G: I wish I had a normal developing child, I had dreams, things I would do, I was thinking so much. Now this boy came to me, I believe that I was chosen. When I think about it, I feel better. They say this for autism, autism is for a lifetime, but it can be pulled somewhere by doing certain things. I will not be able to make a hundred percent, but I want to bring him to an 80 percent.
>
> G: Keşke normal gelişen bir çocuk olsaydı ne hayallerim vardı neler yapacaktım o kadar çok şey düşünüyordum ki. Şimdi de bu çocuk bana geldi ben seçildim inanın öyle düşünüyorum. Bunu da düşündüğümde kendimi daha iyi hissediyorum. Otizm için şey diyorlar ya, otizmse ömür boyu otizm, ama belli şeyler yaparak bir yerlere çekilebiliyor. Ben yüzde yüzü yapamayacağım belki ama yüzde 80 bir yere getirmek istiyorum Doruk'u.

Hale believes it's her and her child's fate:

> H: As a religious person I think that this is my fate and this is his fate but how can we change his fate and make it different. This is my fate and I must do this. Murat belongs to me. This responsibility belongs to me.
>
> H: Ben inançlı bir insan olarak şöyle düşünüyorum bu benim kaderim onun kaderi de böyle ama bu kaderi biz nasıl değiştirebiliriz nasıl farklılaştırabiliriz yani bu benim kaderim bunu yapmak zorundayım. Bu bana ait Murat bana ait. Bu sorumluluk bana ait.

Participants exaggerate their responsibility in their child's life and explain that they had to become self- sacrificial for the well- being of their child. They express feeling uneasy and unsafe about other people's involvement in their child's care giving so they feel obliged to control everything.

3.6 Conflicting attributions regarding the child's father

The super-ordinate theme includes participants' conflicting attributions about their child's father. While portraying their child's father in certain light such as a successful and a sufficient person, they also view their spouse as insufficient regarding the care of their child with autism. . Glorifying their own role as mothers and sole caregivers, they express the inefficiency of the fathers. The sub-ordinate themes are as *successful breadwinner*, *good father*, *good spouse, and insufficient* in *addressing their child's special needs* as sub-ordinate themes.

3.6.1 Successful breadwinner

The participants showed appreciation towards their spouse regarding their hard work and their financial support to their family: There is a division of labor in the sense that the father is the breadwinner to finance the expensive therapies and extracurricular activities of the child while mother is responsible from taking care of the child. Çağla states that her husband’s role is to provide for their family financially:

> Ç: He does his own job and works intensely, but in the end, there is something like this, of course, I have mentioned all the education we received, and the fact that we didn’t leave our child idle. This is only possible with the financial resources. And someone has to carry this financial load so in this direction, my husband works hard and provides us with all kinds of resources. At the end of the day, we focus on Tolga. One of us is concentrating on the material part of the training to be provided for Tolga. His role is different, mine is different.
>
> Ç: Kendi işini yapıyor ve yoğun çalışıyor. Ama sonuçta şöyle bir şey var tabi ki bu saydığım bu süre boş geçmeyen zamanlarda aldırdığımız eğitimlerde hep maddi imkânla oluyor. Bunu da birinin karşılaması gerekiyor bu yönde de eşim yoğun çalışıp sonuçta bize her türlü imkânı sağlıyor. Sonuçta Tolga’ya yoğunlaşıyoruz. Birimiz de Tolga için sağlanacak eğitimin maddi bölümüne yoğunlaşıyoruz. Onun rolü farklı benim farklı.

Hale states that her family is not in a miserable state because her husband’s devotion:

> H: My husband is now honestly devoted to his family. He brings everything, he brings his earnings to us he shares everything with us and thinks of his family If the families do not have the financial ability, if you do not have power, you will be miserable. For example if you have the finances you can hire a shadow teacher, you can hire one and pay her. It’s much easier.
>
> H: Eşim şimdi Allah için ailesine karşı fedakâr biri. Kazancını nesi varsa her şeyini bize getiren bize paylaşan çocuklarını düşünen ailesine karşı fedakâr. İnsanın ailelerin maddi yeterliliği yoksa gücü yoksa sefil oluyorsun maddi gücün olsa bir gölge abla denen bir olay var tutarsın parasını verirsin mesela çok daha kolay.

Nihan states that her family can afford her child’s demanding financial load because of her husband’s earnings:

> N: He has the obligation to work. Unfortunately, when you go to a psychologist and tell your troubles and when you really want to get an individual education, we live in an industry that receives exorbitant numbers from you. You want to take him to a speech therapy; you have to leave at least 250 liras on the table at that moment. Only then they'll have a dialogue with you. After all, he is a person who wants to contribute to the education of his child in a way so he has to earn some money, so he cannot do any other job because he has to work, but that's how we can overcome the expenses of the child, so we can meet our social needs in this way.
>
> N: Hani çalışmak durumunda çalışmak mecburiyetinde. Gerçekten bir yere gittiğiniz zaman bireysel eğitim almak istediğinizde bir psikologa gidip derdinizi söylediğiniz zaman sizden fahiş rakam alan bir sektörde yaşıyoruz maalesef. Bir konuşma terapisine götürmek istiyorsunuz en az 250'yi bir kere o an masaya bırakmak zorundasınız ki sizle diyaloga girsinler. Sonuçta bir şekilde para kazanmak zorunda bir şekilde çocuğun eğitimine katkı sağlamak isteyen bir insan o yüzden hani çalışmak durumunda olduğu için başka bir iş de yapamıyor ancak bu şekilde çocuğun masraflarıyla aşabiliyoruz altından kalkabiliyoruz sosyal ihtiyaçlarımızı bu şekilde karşılayabiliyoruz.

3.6.2 Good father

Participants described their spouses as good fathers. Özge says that her child's father socializes with them:

> Ö: His father is good, as good as possible. He takes the kids out. He takes them to cinema, he makes some activities. We started doing that this year. Here I take care of her and he takes him into the cinema and we come and go like this.
>
> Ö: Babası iyi yani, olabildiğince iyi babası. Gezdirir tozdurur. Sinemaydı işte böyle etkinlikler yapar. İşte ben bunla ilgileniyorum (kızı) o da sinemaya onu sokuyor böyle gidip geliyoruz.

Çağla praises her husband's relationship with their children:

> Ç: At the weekend, because we were told to speak with Tolga all the time we used to spend time with him in our off days so there was a mode where we used to talk all time and tell him everything. We used to talk about everything about life. And when he comes home to spend more time, of course, his communication with his children is very good. They both play games and spend time together.
>
> Ç: Hafta sonu zaten eşimle ben de izin günlerimizde sürekli Tolgayla vakit geçirdiğimiz için ve sürekli konuşmamız söylendiği için zaten o dönem öyle bir moddu ki sürekli konuşuyorduk sürekli her şeyi anlatıyorduk. Hayatla

> ilgili her şeyi. Eşim de eve geldiği zaman tabi ki çocuklarıyla iletişimi çok iyi. İkisiyle de birlikte mutlaka oyun oynar zaman geçirir.

Hale talks about her husband's emotional investment to his children:

> H: When the evening comes, the father comes and the father starts to take care. I'm going back home and to myself, dad takes care of them. If the lessons are going to be done, we are doing the lessons. If I don't have anything and I have time I take care of his lessons too but it's usually his father. And when we go out, my husband always wants to take the kids with us. He wants to be with them. For example, sometimes I say, especially in the mall. Please, let's not go with them because we leave before we can shop every time we go. My mother-in-law is looking after them and my mother looks after them. Let's leave them. But he says no, he will come with us. He says it will be a change for Murat too, and we come back without shopping.
>
> H:Akşam olunca baba geliyor baba ilgilenmeye başlıyor. Ben eve ve kendime dönüyorum baba onlarla ilgileniyor. Dersleri yaptırılacaksa dersleri yaptırıyoruz benim şey yoksa vaktim varsa Murat'ın dersleriyle ben de ilgileniyorum ama ağırlık baba ilgileniyor. Eşim şöyle ben gezmeye gidiyorsam çocuğum da gelsin. Onlarla olmak istiyor. Bazen şey diyorum, lütfen onlarla gitmeyelim çünkü her gittiğimizde alışverişimizi yapamadan çıkıyoruz. Ya dün annem bakıyor kayınvalidem de bakıyor sağ olsun. Bırakalım, hayır bizimle gelecek. Ona da değişiklik olsun ve biz hiç alışveriş yapamadan geliyoruz.

3.6.3 Good spouse

Many of the participants state that they have a good relationship with their spouse and state that their husband is a good spouse. Çağla says that they know each other very well:

> Ç: My relationship with my husband is very well, thank goodness. But of course we have been very tense after the troubles of Tolga because we did not know what to do with the child. There was a confusing, trying time but apart from that, we recovered and there is no problem. Our relationship was already very good. It was not an arranged marriage or anything. It was a love marriage. Before that, he was my school friend for years and after school finished we started dating and he was someone I know for years. We knew each other very well so we had no difficulties.
>
> Ç: Eşimle ilişkim gayet iyi Allaha şükürler olsun ama tabi ki bu Tolganın sıkıntılarından sonra çok gerginleştirdiğimiz zamanlar oldu çünkü çocuğun peşinden ne yapacağımızı bilemiyoruz O bir karışıklık bir bocalama süreci oluyor ama onun haricinde toparlıyorsunuz bir sıkıntı yok. Ondan önce de

> gayet iyiydi zaten sonuçta görücü usulü falan değil severek evlendim. Ondan öncesinde yıllardır okul arkadaşımdı okul bittikten sonra çıkmaya başladık. Ama yıllardır da tanıdığım birisiydi huyumuzu suyumuzu biliyorduk zorluğumuz olmadı.

Hale states that her husband is a good husband and she misses the times they used to spend alone together:

> H: My husband support me my husband's family support me my own family support me I was very lucky about that. He is a good husband, but we cannot spare time for each other because of the children. Our life is always in front of children. Let's go to have a coffee alone or have tea alone. Let’s go out, go on a holiday or something. But we can’t. Of course we were doing before Murat. According to our budget, we were doing it by ourselves, because there were no children. Now unfortunately we can’t.
>
> H: Eşim bana destek eşimin ailesi destek kendi ailem destek ben o konuda çok şanslıydım. İyi bir eş kendisi ama biz birbirimize çok zaman ayıramıyoruz çocuklardan dolayı. Hani hayatımız hep çocukların önünde, çocuklarla. Biz baş başa bir kahve içmeye gidelim bir çay içmeye gidelim. Bir dışarıya gidelim bir tatile çıkalım yapamıyoruz. Murat’tan önce yapıyorduk tabi. Bütçemize göre baş başa yapıyorduk çocuklar olmadığı için. Şimdi yapamıyoruz maalesef.

Nihan also states having a good relationship with her husband and reminisces about the times they used to spend before they had children:

> N: We have a good relationship. Of course we used to spend more time together before. We were a couple that never stayed home. We go to work, we do not come home, we travel, we go here and there, and we have fun. Because my husband was interested in football at that time, and he was playing, we were going to the games, we were going to watch his games, we were going to training together, and we were going to watch the games of other teams.
>
> N:İlişkimiz iyi. Eskiden tabi daha çok vakit geçiriyorduk beraber. Biz hiç evde durmayan bir çifttik. İşe gidiyoruz eve gelmiyoruz geziyoruz tozuyoruz eğleniyoruz zaten eşim o zaman futbolla ilgilendiği için o zaman oynuyordu hani maçlara gidiyorduk onun maçlarını izlemeye gidiyorduk beraber işte antrenmanlara gidiyorduk beraber diğer takımların maçlarını izlemeye gidiyorduk.

3.6.4 Insufficient in addressing their child's special needs:

While talking positively about many aspects of their child's father, they state that the fathers are insufficient regarding their child's condition. They describe the father's position as more lacking and less essential than the mother's position regarding the effect they have on their child's life. While viewing the fathers as carrying less responsibility than them, they also stated that this is actually they way they are comfortable with. Çağla states that her child's father has little influence on their child's life:

> Ç: Because I run after his education life, he leaves it to me and he does what I say. So there is a responsibility to it and it's a burden. He never says no to any decision of mine about Tolga. He says go for it. But by saying that, he's removing himself from that responsibility. So I have the responsibility to make good decisions select good places so I end up questioning my decisions..So he has a certain influence but still I carry most of the load.
>
> Ç: Eğitim hayatının peşine ben koştuğum için ben ne dersem onu yapar. Bana bırakır o yüzden onun bir sorumluluğu bir yükü da var aslında ben de. Çünkü Tolga'ya ne yapacaksam hiçbir yere götürme demez şuraya götüreceğim götür buraya götüreceğim götür. O götür demekle üzerinden yükü atıyor aslında bana atıyor ben de bu sefer hep iyi yerler doğru kararlar verme şeyi oluyor bu seferde kararlarımı sorguluyorum. Babasının da biraz etkisi var ama yükün büyük çoğu ben de oluyor yine de.

Güliz states that she has become both mother and the father:

> G: Of course, when I learned this situation, I was very sorry; it was an issue we did not know. But I thought the fathers more difficult to accept. His father accepted it very hard. I was not talking either, I was silent, he said. And the whole thing is up to me, so I think everything. I am trying to find his trainer, I am trying to find his therapist, I wonder if we go to this place, it would be better if I do this, whether he goes to sports or not, find a shadow teacher, do this, do that. If only the father says that I found a place, the child will go too far here and let's try this place. But he doesn't. And because he doesn't come to me with something like that, it always happens that I handle them. I arrange his doctor and everything.
>
> G: Ben bu durumunu öğrendiğimde tabi ki çok üzüldüm bilmediğimiz bir konuydu. Ama ben şöyle düşündüm babalar daha zor kabul ediyorlar. Babası çok zor kabul etti. Ben de konuşmuyordum ben de sessizdim falan. Bütün

> ihale bana kalıyor da o yüzden yani ben düşünüyorum her şeyini. Eğitimcisini ben bulmaya çalışıyorum, terapistini ben bulmaya çalışıyorum, acaba şuraya da gitsek iyi olur şunu da mı yapsam iyi olur spora da mı gitse iyi olur, gölge öğretmen bul, onu yap bunu yap getir götür. Baba dese ki ben bir yer buldum çocuk burada çok ilerleyecek hadi bir de burayı deneyelim gibi bir şeyle bana gelmediği için hep ben kendim hani bunları halletmeye çalıştığım için öyle oluyor ister istemez. Doktorunu siz ayarlıyorsunuz işte ne bileyim.

Hale states that her husband was unable to comprehend the seriousness of the issue:

> H:. My husband took it normally. So I thought he wasn’t aware. I thought my husband wasn't aware. That he doesn't know autism. I thought that he perceived the course as a headache. He couldn’t understand the seriousness of the issue like me. He is grasping it much better now.
>
> H: Eşim normal karşıladı. Yani o yüzden farkında olmadığını düşündüm. Eşimin farkında olmadığını düşündüm. Otizmi bilmediğini. Gidişatı yani nasıl söyleyeyim bir baş ağrısı gibi algıladığını düşündüm. Benim gibi işin ciddiyetini anlayamamıştı başta. Şimdi daha iyi kavrıyor.

Nihan states that her child’s father can never be as important to the child as his mother.

> N: He has a fear of getting lost and he is afraid of being alone. He needs to see me all the time. But this is not how things are with his father. Father may play with him, entertain him, but that’s all. In terms of need, he needs his mother. His father can’t replace his mother.
>
> N: Sürekli beni görecek kaybolma korkusu var yalnız kalma korkusu var. Ama bu babayla çok mevcut değil. Baba oynasın gezdirsin eğlendirsin o kadar. Ama ihtiyaç kısmında anne. Baba, annenin yerini tutamıyor.

Özlem states that her spouse cannot be as giving as a mother. She also explains how he can be intolerant to their child’s misbehaviors:

> Ö: Sometimes he tries to support as much as he can, and sometimes there are moments when he is not enough. So for example, he doesn't want to go to the cinema, he says I'm tired, says I want to rest. As I said, he is as good a father as possible. He's trying too, but it is mom who takes care. He can't be selfless like mother. He tries to help as much as he can, trying to do something. He wants the child not to cry, not to insist, he wants him to walk like an adult. So for the father there will be no crying and yelling. But this kid will be like that. This is a kid. Haven’t we been kids? Who knows what we did to our parents? But that’s a kid. The father doesn’t want that.

> Ö: Bazen elinden geldiğince destek olmaya çalışıyor da bazen de yetemediği anlar da oluyor. Yani atıyorum işte sinemaya gitmek istemiyor yorgunum diyor dinlenmek istiyorum diyor. İşte dediğim gibi yetebildiğince olabildiğince iyi bir baba. O da uğraşıyor ediyor ama anne bakar. Anne gibi özverili olamıyor yani. Elinden geldiğince yardımcı olmaya çalışıyor bir şeyler yapmaya çalışıyor. İstiyor ki ağlamayacak zırlamayacak tutturmayacak öyle yetişkin gibi yürüyecek gezecek hiç ağlama zırlama gibi bir şey olmayacak baba için öyle. Ama bu çocuk, çocuk öyle olacak. Biz çocuk olmadık mı biz kim bilir annemize babamıza neler yaptık. Çocuk ama o. Yok baba istemiyor bunu.

While being viewed as a good father and a good spouse in general, fathers' financial contribution was especially praised and appreciated. They were seen as enablers of their child's needs such as his education and therapy sessions. On the other hand, they were regarded as insufficient in attending to these needs mentally and physically.

3.7 Projections towards others varying by social proximity

This last super-ordinate theme is about participants' projections involving other people. The mothers have certain attitudes and projections of their own feelings towards the people around them and these projections are more positive to those in close proximity like family members and more negative towards institutions and people like teachers and doctors who represent those institutions. The sub-ordinate themes include; *institutions as inefficient, other mothers as judgmental, teachers as selfish and relatives as supportive.*

3.7.1 Institutions as inefficient

Participants state that they find institutions such as the state, the schools and the hospitals insufficient to guide them properly and to give their child a good education. They express a strong lack of trust to these institutions. Güliz's narrative about the pediatrician who misguided them about the condition of her son is indicative of this lack of trust towards institutions and their representatives:

Güliz states that:

> G: They mislead us so much that the head of the kindergarten, what we went to, said that our psychologists and pedagogues are young and inexperienced. Apart from that, we went to kindergartens and nobody said that there is a difference in this child. Take him to a psychologist. We have a pediatrician. I said that this boy was banging his head against the walls. He used to bang his head from one and a half to three years old. Do you know what the doctor is telling me? The doctor says that a child doesn't grow up with a psychologist. A doctor is saying this. And he is a good doctor and all.
>
> G: Bizi o kadar yanlış yönlendirdiler ki ne gittiğimiz anaokulunun müdürü dedi ki bize bizim psikologlarımızın ve pedagoglarımız genç ve tecrübesizler dedi. Bundan başka anaokullarına da gittik kimse de bize bu çocukta bir farklılık var bunu bir psikologa götürün demedi. Çocuk doktorumuz var. Dedim ki bu çocuk kafasını duvarlara vuruyor bir buçuk yaşından üç yaşına kadar kafasını duvarlara vuruyordu. Doktorun bana söylediği şey ne biliyor musunuz çocuk öyle psikologla falan büyümez. Bunu doktor söylüyor, bir de iyi bir doktor öyle şey de bir doktor değil.

Hale states that, her desire to be in the classroom with her child and to take more responsibility is the result of her belief that education system is insufficient. As mentioned in earlier themes, her idealization of her role as a mother also manifests itself as devaluation of the quality of support they receive from school. She states that:

> H: Although the state is doing its best, it is still inadequate. He throws a law and cannot think of the point the law will reach. For example, the simplest is a very simple example, they have given education, they have given something, I cannot ignore them, God bless them, but my child has been educated here, but I think we are facing serious difficulties in the elementary school. They have a point in not wanting me in there, so they are right. If he sees me, how much they can adapt to this training but then a voice says to me that they are not right, their education is insufficient. Then either someone who understands this work must stay in my place, and the state needs to channel it or I have to be there.
>
> H: Devlet elinden geleni yapıyor olsa da yetersiz. Ortaya bir kanun atıyor kanunun varacağı noktayı düşünemiyor. Mesela en basiti çok basit bir örnek, eğitim vermişler şey vermişler bunları da görmemezlikten gelemem. Allah razı olsun fakat benim çocuğa eğitimi vermiş benim çocuğum burada eğitim veriyor ama ilkokulda ciddi zorluk yaşıyoruz. Yani beni istememeleri bana nasıl geliyor bir yandan şöyle düşünüyorum haklılar orda bir eğitim var çocuklar beni görürse bu eğitime ne kadar adapte olabilirler bir ses de içimden diyor ki haklı değiller eğitimleri yetersiz. O zaman ya benim yerimde bu işten anlayacak birinin durması gerekiyor devletin bunu kanalize etmesi gerekiyor ya da benim orada olmam gerekiyor

Nihan states that teachers do not let her child to take a class break because they are not able to take any responsibility if anything happens to her child. She criticizes the education system and finds teachers incompetent:

> N: They lock the door so that the child does not go out. The teacher has the keys. If you stay closed for 4 hours, sit down, do math, how efficiently can you work. If you let me go out, drink water, get out, get an air, go to a sink, go to wash my hand, even this is a plus for the child. I do not believe that a hundred percent education was given because none of these are done. They say that our children are prohibited from television and tablets. They reflect movies on the wall and watch movies on cartoon children. There you have a contradiction. Here I cannot understand how educators approach the child. Those people doesn't seem so conscious to me. I don't understand how they can become educators, how they are class teachers, and how they got psychological pedagogical formation in order to be teacher.
>
> N: Çocuk dışarı çıkmasın diye kapıyı kilitliyorlar. Anahtarlar öğretmende siz 4 saat boyunca kapalı dursanız size deseler ki otur matematik yap ne kadar verimli çalışabilirisiniz hani çıkayım bir su içeyim çıkayım bir hava alayım bir lavabo ya gideyim elimi yüzümü yıkayım bu bile çocuk için bir artıdır bana göre. Onların hiç biri yapılmadığı için yüzde yüz bir eğitimin verildiğine inanmıyorum zaten. Diyorlar ki bizim çocuklarımızı televizyon tablet yasak. Duvara film yansıtıp film izletiyorlar çizgi film çocuklara. Diyorsun ki bu ne perhiz bu ne salata. Burada ben eğitimcilerin çocuğa nasıl yaklaştığını anlayamıyorum. O kadar bilinçsiz geliyor ki o insanlar bana. Onlar nasıl eğitimci olabildiğini onların nasıl sınıf öğretmeni olduğunu nasıl psikolojik pedagojik formasyon alıp öyle öğretmen oldukları aklıma almıyor.

3.7.2 Other mothers as judgmental

Participants expressed that they feel judged by other people because of their child's autism. They described an anticipation to be judged because of their child's misbehaviors and they thought people will attribute it to their motherhood skills. They also stated that they get a negative reaction from people around them when they try to discipline their child. Hale states that she is judged by her peers regarding her child's behaviors. She views her child's autism as a lack and says that people's reactions make her experience a lack that upsets her:

> H: The lack makes me sad. But let's not remember the child with that lack, I don't want my child to be defined by a lack. But now when my child goes to a house, he won't be aware that it's someone else's house. Then I will be a mother who couldn't raise her child well. Or my child will be someone who doesn't listen. So it will have a name. I mean, you will make them feel sorry for you. You have to say I am ill, understand me, and then they will

> understand you. It is obvious that when people say awareness they mean a lack, and they make you feel this lack. In other words, they do not say awareness; they think there is a deficiency and they make you upset for it.
>
> H: Eksiklik beni üzüyor. Ama çocuk onla anılmasın ben de çocuğumun bir eksikle bir kusurla anılmasını ama şimdi benim çocuğum bir eve misafirliğe gittiğimizde o evin yabancı bir ev olduğunun farkında değil o zaman çocuğu yetiştirememiş becerememiş bir anne olacağım. Ya da benim çocuğum laftan anlamayan, yani bunun bir adı olacak yani. Yani illa onlara kendini acındıracaksın ben hastayım anlayım beni diyeceksin ki anlayacaklar seni. Farkındalık denen şeyin eksiklik olduğu açıkça ortada bunu da insanlar sana yaşattırıyor. Yani hiç farkındalık demiyorlar bir eksiklik olduğunu düşünüyorlar ve bundan seni üzebiliyorlar.

Nihan states that because her child has autism, people judge her parenting style:

> N: Any discipline you try to give to your child gets a reaction from people around you. They say, why you say that to him, he is different. But if he is my child I have to teach him things and sometimes I have to be strict. But it’s not acceptable. I can be stern with Serkan but when it comes to Ali, people think I’m a bad mom. If I can’t teach him certain values and rules now, how am I going to when he is older? So of course I will be strict with him sometimes. But people doesn’t see all the times that you care for him, all the times you look after him and give him affection, but they only see it when you raise a brow.
>
> N: Kendi çocuğumu disipline etmeye çalışmam insanlara garip geliyor. Niye öyle yapıyorsun, Ali farklı bir çocuk diyorlar. Eğer o benim çocuğumsa bazı şeyleri ona öğretmem gerekiyor bazen kızmam da gerekiyor. Ama yok kabul ettiremiyorum. Serkan’a gelince ona kızabilirim ama Ali’ye gelince ben kötü anne oluyorum. Ona şimdi bazı kuralları bazı değerleri vermezsem ilerde hiç veremem. O yüzden tabi ki bazen kızacağım yapmaması gereken bir şey yaptığında. İnsanlar senin onca yaptığın iyi şeyi görmüyorlar, çocuğuna nasıl bakıyorsun nasıl emek veriyorsun sevgi şefkat anlayış gösteriyorsun. Sadece kaşını çattığında görüyorlar.

3.7.3 Teachers as selfish

Participants described teachers in their child’s school as selfish, insensitive and rejecting. They state that teachers refuse to empathize and meet their child’s needs. They also view the teachers as rejecting and express frustration about their child not being accepted in school because their condition. Hale feels frustrated and views her child’s teacher as selfish:

> H: I say I think that if I agreed to work here, this should not come to me, as an order or a heavy burden to take a child if his mother asks me. I already have two kids in the classroom. I would say to his mother, of course, when you want, put his pocket money and we'll go get it from the canteen and he can learn how to get it too. People don't sacrifice anything or do it with love. When you ask for something, they perceive it as "oh look at the parent making me get a bagel. It is not my job to buy a bagel". Of course, your job is not to buy a bagel, but I do not do it to you for…, because there is a bagel in that school, my child can buy it. I am not incapable of buying bagels. If necessary, I will take it out half an hour in advance, but I will come, but if these opportunities are provided, my child can achieve it.
>
> H: Ben derim ki şunu düşünüyorum ben buradaysam ve anlaştıysam bu bana şey gelmemeli bir çocuğu alıp annesinin bunu benden rica etmesi bir emri vaki ya da bir ağır külfet olarak gelmemeli. Benim sınıfta zaten iki çocuğum var. Derim ki tabi ki annesi, siz istediğiniz zaman koyun beslenmesini biz Murat'la gider alırız hem de Murat nasıl alındığını görürsün. İnsanlar da şey kalmamış fedakârlık bir şeyi severek yapmak kalmamış. Onu şey yaptığın zaman şey gibi algılıyor, veliye bak bana simit aldırtıyor benim görevim simit almak değil ki. Tabi ki senin görevin simit almak değil ama ben de onu sana şeyden yapmıyorum hani o okulda bir simit var benim çocuğum da o simidi alabilir. Ben simit almaktan aciz biri değilim. Gerekirse yarım saat önceden çıkar gider alır gelirim ama bu imkânlar verilirse benim çocuğum onu başarabilir.

Hale also states that teachers are intolerant and rejecting towards problematic children:

> H: Whatever the problem is, even the teachers have no tolerance for that problematic child. They can't be patient. They accept a child, for example, you can accept 19 of them with their character at school, and this is the character of the 20th child. Why can't Murat be accepted?
>
> H: Ne problem varsa mutlaka o problemli çocukta hocaların bile tahammülleri yok. Sabredemiyor Bir çocuğu kabul ediyorlar mesela okulda 19 tanesini karakteriyle kabul edebiliyorsun bunun karakteri böyle şunun karakteri böyle. 20.çocuk Murat neden kabul edilemiyor.

Nihan criticizes the school system and states that her child is not accepted. She states that people are selfish and she had to fight for her child's right to education:

> N: They take him to the classroom as an inclusion student otherwise they do not take him to the class. Anyway, they do not accept you and your child in any way. We fight for a month, I went to school for a month, I talked to the manager, I talked to the teacher, I met the parents in the class. Doing all that, the child started school in the middle of October. The teachers there and all

> those people took away my child's one-month of education. I think people are very selfish. People live by thinking that this will not happen to them. It might not have happened to me either, but it did, and I have to look for a way to deal with it. If it is a fight with you, I will fight with you. If I argue with you, to petition someone, to complain to someone, I will do this. Because this is my dear and the training of him is the first thing for me. If my child cannot exercise a right, the state says to me that your child has the right to be educated with normal students in normal class under normal circumstances. Nobody can take this right away. Why is everyone trying to take my right to education away from me?
>
> N: Kaynaştırma öğrencisi olarak sınıfa alabiliriz onun dışında sınıfa almıyorlar zaten. Kabul etmiyorlar zaten sizi ve çocuğunuzu hiçbir şekilde kabul etmiyorlar. Biz bir ay kavga dövüş ben bir ay okula gittim müdürle görüştüm öğretmenle görüştüm sınıftaki velilerle görüştüm tartıştık onu yaptım bunu yaptım şunu yaptık derken çocuk eylülde açılan çocuğa ekimin ortasında başladı. Benim çocuğumu bir aylık eğitimini oradaki öğretmenler bilmem neler onun bir aylık eğitimini elinden aldı. İnsanların çok bencil olduğunu düşünüyorum. İnsanlar kendilerinin başına gelmeyeceğini düşünerek yaşıyorlar. Benim de başıma gelmeyebilirdi ama geldi ve ben bununla baş etmenin yolunu aramak zorundayım. Senle kavga etmekse bunun çıkış yolu senle kavga da ederim. Senle tartışmaksa birilerine dilekçe vermekse birilerine şikâyet etmekse bunu da yaparım. Çünkü bu benim canım ve bunun eğitimi önce benim için hiçbir şeyin anlamı yok. Benim çocuğum bir hakkı kullanamıyorsa devlet bana diyor ki senin çocuğun normal şartlarda normal sınıfta normal öğrencilerle eğitim alma hakkına sahip diyor. Bu hakkı elimden kimse alamaz. Neden sen o bu şu eğitim hakkımı elimden almaya çalışıyor?

3.7.4 Relatives as supportive

While participants were frustrated about institutions and their peers, they viewed their inner social circle as more supportive. Çağla states that she's thankful that her aunt moved in with them to help take care of her children:

> Ç: Right now for example, because I have this little one and I was running after Tolga, my aunt has been staying with me for the last a year and a half. She stayes in order to support us to go through that phase more easily because Tolga started first class last year. Two months after Mert was born, Tolga started school. My aunt started to stay with us to support this process. Thank her, my aunt supports us and god willingly she will continue to support us. Everyone was supportive, my friends, my family. With their help we could go on with our lives.
>
> Ç: Şu an benim için mesela benim küçüklük olduğu için ve ben Tolga'nın peşinde koşturduğum için bir buçuk yıldan beri halam benim yanımda kalıyor destek olmak için, bu süreci rahat atlatmak için. çünkü Tolga 1. Sınıfa

> başlamıştı geçen yıl. Tam Mert oldu iki ay sonra Tolga birinci sınıfa başladı. Bu süreçte destek olmak için halam bizim yanımızda kalmaya başladı. Halam sağ olsun bize destek oluyor destek de olacak inşallah. Arkadaşlarımın yanında herkes destek yanında ailem olsun arkadaşlarım, herkes destekçi oldu sonra bu şekilde devam ettik hayatımıza.

Güliz expresses that her parents' presence in the house is good for her:

> G: We are with grandmother and grandfather. They are in the summer house in Çanakkale for 8 or 9 months of the year. They are here for the rest of the year. Then we are together. Usually it's me and Doruk. Now we are together for 3-4-months with grandmother and grandfather. Then they leave. But it is very very good that they are with us. Having people at home. They take a lot of care, thank them.
>
> G: Anneanne dedeyle birlikteyiz. Onlar yılın 8 9 ayı Çanakkale'de yazlıktalar. Yılın geri kalan zamanında buradalar. O zaman birlikteyiz. Genelde Doruk'la ben. Şu an bir 3 4 aylık anneanne dedeyle birlikteliğimiz oluyor onlar gidiyorlar sonra. Ama onların da bizle olması çok çok iyi yani. Evde insan olması. Anneanne dede de çok ilgileniyor sağ olsunlar.

Hale states she's lucky in terms of family:

> H: I was not in trouble, and in terms of family, I was in a comfortable family, in a supportive family. Not only me but my husband supported me my husband's family supported me, my own family supported me, I was very lucky.
>
> H: Sıkıntıda değildim aile olarak da rahat bir ailedeydim destekçi bir ailedeydim. Sadece ben değil eşim bana destek, eşimin ailesi destek, kendi ailem destek; ben o konuda çok şanslıydım.

In addition to her mother-in-law's caregiver role before her child was diagnosed with autism, she also appreciates her in-laws support when her child was hospitalized because of asthma:

> N: I could not stay with him. I went and came. Grandmother has remained with him 24/7. His grandmother and grandfather were coming and going. They were excellent support during that time. My husband was already working. I didn't want to leave Serkan alone because he was so young. If I leave him, that is, who is going to breastfeed him who will feed him? That's why his grandmother and grandfather always looked after him. In those 10 days, they went to the hospital and kept an eye on Ali.

> N: Ben kalamadım arada gidip geldim onun yanında 7/24 babaannesi kaldı. Babaannesi ve dedesi gidip geliyordu. Acayip iyi destek oldular o dönem. Eşim zaten çalışıyordu. Serkan'da çok küçük olduğu için onu yalnız bırakmak istemiyordum. Onu bıraksam yani kim emzirecek kim yemek verecek. O yüzden hep babaannesi dedesi ilgilendi. O 10 gün içerisinde onlar gidiyordu hastaneye ve gözleri hep üstündeydi Ali'nin.

While they viewed their inner circle as friendly and understanding, participants evaluated their farther surroundings strongly negatively. Being focused on complementing their child's shortcomings, they felt frustrated with institutions because they saw them as incompetent and thus creating them an obstacle to reach that goal. They also expressed anger and sadness about their peer's comments regarding their child's condition and hence they viewed them as judgmental. Being in the society with an autistic child created a lot of negative emotions in mothers making them come to terms with their reality.

CHAPTER 4

DISCUSSION

In this chapter findings of this current study will be discussed according to the existing literature. The aim of this current study is to gain an in-depth understanding of how women experience having a child with autism. For this purpose, semi structured interviews were conducted with five married women who had children diagnosed with autism ranging between the age of seven and ten. Interview questions were designed to study individuals' perspective about having and raising their child, their attribution regarding receiving a diagnosis such as autism for their child and how they make sense of this experience and how it impacts them. IPA is a suitable approach to obtain participants' unique experiences therefore interviews were transcribed and collected data is analyzed using interpretative phenomenological analysis (IPA). The analysis of the data revealed seven super-ordinate themes. These themes are titled as: *challenges during pregnancy and child birth, pre-diagnostic stance of mothers about raising their child, experiencing negative emotions after diagnosis, efforts to compensate for their child's shortcomings, idealizing their place in their child's life, conflicting attributions regarding the child's father* and *projections towards others varying by social proximity.*

4.1 Challenges during pregnancy and childbirth

This super-ordinate theme involves statements of participants regarding the distress they experienced during pregnancy and childbirth. When they were asked to describe the time of their pregnancy, individuals expressed that they went through a difficult time mentally and/or physically. While some of them were dealing with physical complications, some of them reported having psychological issues. For almost all of the participants, this distress included intense feelings regarding the safety of the baby and themselves.

In Lacanian psychoanalysis desire is a very central, multifold and unconscious topic (Lacan, 2014) And in order for a neurotic subject to develop, mother's lack or desire is crucial. While desire of the mother is very difficult to investigate in an interview setting, participants' statements regarding their process of having a child will be discussed.

Before the conception of a baby, the baby appears in the mother's mind as an idea (Winnicott, 1957). This way a psychical space is created for the baby to exist even before being born. A mother's projections about her unborn baby can be viewed as the manifestation of desire. The projections can vary from person to person. But before opening space in her womb, a mother opens a space for a child psychically. So it was important to investigate the thoughts and feelings of participants about how they planned to have a child. While individuals' answers to questions about whether their pregnancy was planned varied from one another, there were a lot of similarities in their experiences during pregnancy and childbirth. It can be discussed that a dramatic change like pregnancy may cause conscious and unconscious conflicts in a person. The considerable fear, worry and especially anxiety that the participants have expressed can be regarded as an outcome of being a subject of desire, a subject with a lack (Fink,1997). According to Lacan, pregnancy is something very desirable for women because it provides an experience of fullness and completeness (2014). Coming close to that feeling of fullness and completeness is also anxiety provoking because the subject needs to be lacking in order to continue to desire. Therefore an anxiety surfaces when they are about to reach their desire during their pregnancy phase. Psychoanalytically speaking, the anxiety they feel about the health of their child is a concern of the baby's completeness and fullness.

In that regard while desire that represents the mothers' lack may have paved the way for the development of a neurotic structure, it can be argued whether the mother of a baby who later becomes autistic has or has not made libidinal investment in the first months of life since the initial installment of the gaze is the priority for the absence of the mother to make a difference in the baby.

In addition to psychoanalytical literature, prenatal studies also provide insight regarding the development of autism. While the etiology of autism is unknown, it is suggested that complications during pregnancy and child birth may increase the risk of autism (Fombonne, 1999). Since all the participants report unexpected disruptions during their pregnancy and childbirth that can risk the life of their baby, the current study can support that a link between prenatal factors and autism can be discussed (Maiello, 2001).

4.2 Pre-diagnostic stance of mothers about raising their child

Lacanian psychoanalysis explains the mother and child relationship with the “mother crocodile” analogy (Fink, 1997). The symbolic father’s separative role is what saves the child from being devoured and enables subjectification. In order to become a subject, one must go through stages of alienation and separation. This journey of the infant starts to take place during the times when the mother is not there with the baby and Lacan (1957) states during those moments, the child becomes intrigued with where the mother goes and what she wants. When this happens, it can be said that the child recognizes desire in the mother and tries to figure it what it is. That is basically the phallus and the child strongly wishes to be it (Evans, 1996). And in the case of the castrated subject, this intense wish is brought to symbolization and the neurotic subject takes place in society by entering into language and accepting castration (Lacan, 2014). This is the paternal function. Mother’s desire and mother’s lack plays a key role in this process. The mother should be able to desire outside her child.

Yet, alienation phase does not take place in autistic people. Mirror stage does not build up. This intense need to be around their mothers and being one with them persists. And even though autistic individuals may use language, they do not submit to language. So it can be said that the autistic structure starts to form since almost as early as 4 months old (Laznik, 2013). Therefore, early clinical intervention is necessary in order to help the child alienate and recognize the mother and self as separate entities and later move on to the separation phase where the name of the father comes in.

The participants’ enthusiastic statements about working are important to discuss. Almost all of these individuals spoke highly of their work life even when they said it was stressful. They stated that they wished to be back in business life both after birth and when/if their child is cured from autism. They also said that they miss it because they felt useful and valuable and independent when they're working.

So just like it could be observed in the anxiety they felt before child-birth, the participants' positive attitudes about work life can also be seen as declarations of desire, and mother's lack. Yet, the autistic child's growth does not take place like their neurotic peers.

The research participants also stated that during their child's early years, their mothers or mother-in-laws took care of their child. And their child was with their grandmother most of the time. When they picked their child from their mother's house, it was already their bedtime, leaving no time for interaction between the mother and the infant. They stated that it is because of long working hours, they were not able to play or spend time with their child.

Melman(2004) states that autism is about the mother not being able to connect with her child due to structural or situational reasons. According to him when the mother fails to give the phallic medal to the child, it is expected that the child cannot be a subject of desire. When the child is not represented in the world he exists, he cannot find a place in language either. Laznik(1998) also suggests that phallisization must take place when the baby is born. Consequently, the very early months of mother and child relationship should be studied. Only through that libidinal investment of the mother, the child can move forward to the mirror phase where they recognize themselves as a whole and separate entity from the mother.

Mother's desire is essentially what brings the baby's fragmented body into a one piece whole (Lacan, 1949). Here it can be interesting to add that children with autism also have a different relationship with their bodies. They especially have problems in their oral area. They have problems holding their saliva; they have feeding problems like chewing and swallowing. In the light of this information, it can be useful to investigate the nursing experiences of mothers and children who later develop autism. Here it is important to note that most autistics also do not recognize themselves in the mirror. An ego fails to form even before primal repression is able to take place. Since ego presents itself in our speech as "I", it is interesting to note that autistic individuals do not use first person pronouns and simply do not refer to themselves as "I". Also in this current study, mothers were worried about their child's different use of language and their inability to orient their body spatially in the outside world.

It is difficult to say how these participants related to their child during their infancy since it is a force of complex conscious and unconscious conflicts (Winnicott, 1967). But it is widely known that early years are very important. Laznik(2017) states that even though symptoms start to appear after the age of two or two and a half years, intervention as early as four months is necessary so that the baby can find a place within the mother's desire and stages for subjectification can take place later on. The research participants also stated that they were happy and content about their mother's child rearing practices. They said that they were feeling safe and comfortable that their child is in good and capable hands.

But before child is able to recognize the mother's lack, initial investment of the Other is necessary to make the child a phallic object. This is how the gaze can be installed and through that gaze of the Other and how the infant can identify with his or her image in the mirror. Therefore, the clinician must be involved in the phallicization of the baby in order to revive it as an object of desire. When this intervention is employed, eye contact can be formed, the baby's attention develops, and limbs start to move and eventually vocal folds start to work. This is a result of the libidinal investment to the baby (Melman, 2004). Therefore while working with newborns and infants, it is important to go beyond physical and motor examination and take into account other aspects. Clinicians who are working with that age group must investigate where the child developmentally stands in relation to the big Other. That is because before the psychical development that takes place between the absence and the presence of the mother happens, this investment must be made. In order for this enjoyment of the baby to be abandoned and the child can register mother's absence, initial gaze must be installed. Therefore while these participants' absence could be able to help their children form a primal phantasy and pave the way for alienation, the possibility of a lack of the initial gaze is complex and unconscious and it could be investigated more deeply in a different setting.

When interviewees were asked questions regarding how they experienced or viewed their child's development and the possible early signs of autism, they stated that when they think of their children's early years, they refused to indulge in other people's warnings, suggestions and advices regarding their child's deviating development. They talked about expressing anger or choosing to ignore, when family members or relatives pointed out the developmental differences in their child. Most of the participants said that they responded such comments by normalizing the condition of their child, saying that it is just the way their child is developing and there is nothing wrong with their child and every child is different and their development can be unique as well.

It can be said that denying the initial signs that manifested themselves even before the participants' children met with a diagnosis have increased the chances of a fully developed autistic structure. The importance of early intervention in autism is widely known and accepted (Camarata, 2014). It can be a huge gain to start working with children and their parents at an early age. However parents' difficulty with coming to terms with their children's condition can delay the start of the intervention process. Clinicians who have access to such families should place emphasis in helping parents deal with difficult emotions regarding their child's condition and help them manage it in a way that will also help their child to get better or maybe even overcome the syndrome entirely.

Still after some lost time, these families eventually end up at the doctor's office. A lot of parents, including all of the participants that were interviewed in this study go through various emotions when their doctor diagnosed their child with autism. Most of them expressed that their initial reaction was shock and disbelief. They report having a hard time accepting that their child has autism. This difficulty to accept can also imply a difficulty to start grieving since grief requires an acknowledgment of a loss. And in denial, there is no loss so there is no reason to grieve. Therefore denial as a defense mechanism served to protect them from the harsh reality. Later chapters will discuss how the diagnosis impacted their lives and how they reacted to it.

4.3 Experiencing negative emotions after diagnosis

When the initial shock and disbelief subsides and acceptance comes into play, it is often reported that people experienced feelings of anxiety, guilt, anger and loneliness

(Worden, 2018). The participants reported often contemplating about why their child became autistic and they expressed frequent feelings of guilt and self doubt regarding their child rearing practices and their capability as a mother in general. Most of them stated that they felt conflicted about whether they should blame themselves for their child's autism. Some participants also expressed regret about their parenting skills while some of them expressed fear of regret in the future. Feelings of guilt can be viewed as an outcome of internal destructive wishes (Kübler-Rose and Kessler, 2005). Also, these experiences of guilt and self-blame that is related to loss can also be interpreted as a kind of revival of these participants' psychic dynamics from their own early developmental stages (Klein, 1948).

In addition to frequent guilt feelings, participants reported fear and anxiety regarding their capabilities as mothers and their child's well-being. They reported usually fearing not being able to be sufficient for their child. They stated that most of their efforts and concerns are related to being enough for their child. They felt like they should be able to help their child improve as much as possible so they can function independently in the future when they won't be able to be with them. They expressed fear for their child's future regarding whether or not they will be able to sustain themselves. It is shown that their wish to "fix" their child also causes a major frustration for them when they feel like their child doesn't listen to them or do as they say. In addition to their child's future, participants expressed fear that their child can be harmed by other people or get lost. It can be also interesting to note that expressions like "to be enough for my child" and "to fix my child" were used extensively by the participants of this study. While their intense focus on their parenting skills and the wellness of their child were evident, their personal needs and a motivation to fulfill those needs were missing from their statements. Based on previous research on grief, it can be suggested that this behavior might serve as a means to gain control and make them feel powerful in the midst of uncertainty (Pusa et al, 2012).

4.4 Efforts to compensate for their child's shortcomings

After receiving diagnosis from their doctors, the participant expressed the need to take action immediately. They stated that they thought that they should let go of the difficult emotions they are feeling and start doing something about their child. This can be viewed as a strong effort to escape facing negative emotions resulting from this hard to process experience. Their fast forward leap into reading and researching about autism can be seen as a counter act for dealing with their loss that they have faced at the doctor’s office. Their efforts to “fix” their child can be considered as an outcome of their desire of making their child “normal” again with education and help them get out of the autistic spectrum. This was a very common wish among these participants. So as a result of that wish, they stated that they were very closely monitoring their child’s education and development, comparing it to how it was before, comparing to typically developed children at school and at their surroundings, hoping for improvement. They were intensely worried about the things their child is not capable of and all their energy was directed to making this incapability disappear. When they felt like their efforts were not working, they became frustrated with themselves, with their child or with their surroundings. It can be said that it was difficult for them to face their child’s lack and accept it. It can be suggested that these participants were deeply concerned with what they view as their child’s lack and showed immense desire and effort to fill that lack.

Control was a very central behavioral outcome of these participants regarding how they manage their parenting. In the interviews they stated that their fear of harm to their child was causing these controlling behaviors. They were especially worried about their child’s well-being because he was not able to speak. The participants were worried that since their children won’t be able to express themselves, they won’t be able to defend themselves in a threatening situation. Participants were afraid that, their child can be hit by a bus or a car, they can get lost or their child’s peers can hurt them. They were also worried about their child’s time in school and how he is spending it. They were concerned about their teacher’s attitudes toward their child and how their child takes up a place within the school system. They have stated that they experience worry and anxiety most of the time but these feelings especially aggravate when they are not with their child. Participants talked about thinking about their child constantly when they are not with them and as a result they ask and try to know everything that goes on with their child. They also expressed a wish to be around them at most times but they explained they can’t be because they are not allowed in places like classrooms. Confirming the current literature, it can be said that their highly anxious state made them exert more control over their child (McLeod, Wood, & Weisz, 2007).

The participants in this study expressed going to great lengths trying to control their environments in order to feel sure of their child's safety and well-being. This way their personal worries, fears and their emotions in general that can make them feel vulnerable are never discussed or worked with.

While working with this demographic as clinicians, it can be important to discuss with them their underlying feelings about this experience and how they are processing being a parent to a child with autism. Helping these mothers implement more adaptive coping strategies can result in reduced stress, improve both their lives and the lives of their children and provide them a better family life in general (Gray, 2006).

4.5 Idealizing their place in their child's life

This theme emerged as a result of participants' statements regarding how they view themselves as mothers. The mothers' most common and prominent claim was that they are the only person responsible for their child and their child needs them more than anyone and anything else. They stated that everyone else involved in their child's care like teachers, doctors and therapists can only do so much to help their child, but in the end they are the one their child only needs and they are the one who can cure their child. The participants talked extensively about duty and responsibility. They viewed themselves as under immense responsibility and they view their responsibility as much bigger than everyone else. As it will be discussed in later chapters, they have devaluated other people's contributions and criticized them involving several topics. The participants view the surroundings either as insufficient or unreliable. Hence, they saw themselves as the ultimate decision maker and bearer of the responsibility and they view themselves doing it alone. They stated that taking on the entire responsibility of their child is anxiety provoking and difficult but they said they felt like this is what their child needs. It can be said that they tended to idealize their position as the mother. Freud (1905b) states that this idealization of motherhood can present itself as a consequence of the negative emotions they feel. This idealization of motherhood can be viewed as a defense for experiencing ambivalent emotions toward their child. This self-sacrificial sense of attitude also made it difficult for them to fully accept the support they receive from others and their efforts to prioritize their child end up neglecting themselves and their own needs. They also added that this is their choice and they created this setting for themselves, for their child and their family. Therefore their decision to stay strong and do all the work caused a lot of anxiety, frustration and feelings of inadequacy. But in return it probably serves to protect them from this ambivalence.

All participants declared that they have dedicated themselves to their child and they do not do anything for themselves or spend time for themselves. They claimed that they can only start thinking about themselves when their child is better. Participant stated that they felt guilty when they directed their resources like money, time and attention to a place that doesn't involve their child and they felt like they should be doing everything they can for their child. Some participants said that instead of spending money for themselves they can pay for a few sessions more of their child's therapy or education. So their lives revolve around their child.

This devotion also has its roots in hope and the hope they feel about improving their child's development or even curing them from autism urges them to become self-sacrificial in order to turn that hope into reality (Bouchal et al., 2015). In addition to hope, making the child the center of their life indicates that they have limited their freedom and suppressed their personal needs (Wong & Chan, 2007).

The need to attach a meaning to an unexpected loss and trauma is usually observed in people (Neimeyer, 2001). Also in this study all participants talked about trying to find meaning regarding their child's autism. They stated constantly thinking about why this happened to them and come up a reason behind it. Their general tendency within this theme's frame was towards believing that they were chosen by a spiritual or higher power. They expressed that they found comfort in believing that it came from a higher power and it was a part of a divine plan. It is evident in previous research that in response to a loss, people resorted to spiritual or religious beliefs and practices as a coping mechanism (Wortmann &Park, 2008). Parallel with the current research, these beliefs and practices helped these participants to create meaning out of their experience (Rogalla, 2015)

Most of the participants' understanding of a higher power stemmed in Islamic religion and culture. Islamic understanding dictates the concept of fate. Fate implies that Allah is all knowing and all powerful, the destiny of all is written by him and it can’t be changed (Rassool, 2000). Participants in this study also have expressed that they surrender to Allah’s discretions and if this is written in their destiny and this is what Allah has planned for them they can only accept it. Among these participants, accepting loss was mostly spoken of only with the aid of spiritual and religious references.

4.6 Conflicting attributions regarding the child’s father

When participants were asked of their spouse and how they view their spouse as a partner and a father, they commonly described them as someone who provides for their family financially. Fathers were most appreciated for their role as the bread winner and as someone who works very hard for their family. Participants have emphasized the importance of financial resources in order sustain their family. They stated that taking care of their child with autism is demanding in many ways but monetary issues have primary importance in order to receive any kind of education or treatment for their child. They explained that while they are spending time with their child, taking care of them and arranging appointments for them, the father’s role is to take care of the family financially.

Another topic where the participants talked about the children’s fathers was their involvement with their children. The participants stated that fathers spared time to spend with their child and family.

The fact that fathers took time to play with their child and take them out to socialize was appreciated and praised. The participants essentially viewed their spouse as a good father.

When they were asked about their relationship as a couple, the participants spoke positively about their union. They stated that they get along well and share a good time together. They also shared that they used to spend more time together before autism became a part of their life and they remember those times in good light. Freud stated that in order to be a woman, one must go after the one who has the phallus (1920). And in this study the participants showed desire to be with their husband as an object of love.

While sharing such positive aspects about their spouse as partner and father, they also mention that the father is absent most of the time even if it’s for work and the participants are the ones shouldering the responsibilities for their child. They emphasized the insufficiency of the father about attending to their child. They state that they are the ones who plan and organize everything, take care of their child, take him to his appointments like doctors’ office and his therapy sessions. Hence, the mother is not only physically with the child but also she is the one taking important decisions for their child.

Lacan states that it is the symbolic father who saves the child from the crocodile mother before she devours him (Evans, 1996). The father’s intervention is critical in the sense that his law is what separates the child from the mother and in a sense saves him. The father’s introduction of law that causes triangulation when he enters between the dyadic relationship of the mother and the child is called the paternal function. It is symbolic above all and it manifests itself in the mother’s language (Lacan, 1957). And the child enters the symbolic order through his mother’s language and hence become a subject. Also, while the paternal function separates the child from the mother, it feminizes the mother once again leading her turn to her husband as a woman (Faure-Pragier, 2009). Therefore, it is the father that determines the relationship of the mother and the child by entering this dyad as the third party (Abrevaya,2007).

Hence, it is not the father’s physical absence or presence that determines the functioning of the paternal law but mother’s language (Lacan, 2004). The symbolic father can be explained as a position that represents law and social order rather than a real person. Therefore even though information is unknown regarding these fathers’ attitudes toward their child and spouse, they are mentioned as insufficient. In the words’ of the participants, they are neither essential nor influential. Many of the participants state that the father’s role can never be as important or as essential as the mother’s role. They regard their spouses as someone with less responsibility, but they also add that it is them who took on that responsibility themselves. The mothers’ desire to maintain a dyadic relationship with their child with idealized notions of motherhood that views it indispensible is evident in their language (Freud, 1940). These statements can be an example that shows how the separative role of the father may have failed to function.

4.7 Projections towards others varying by social proximity

Participants viewed their immediate surroundings as helpful and supportive. They talked about at least one family member or relative who is involved in taking care of their child with autism. They talked positively about the support they receive and expressed gratitude for people's help. They viewed themselves as fortune for having family and relatives who are there for them. Existing literature emphasized the contribution of getting adequate support to the well-being of these individuals (Burke et al., 2015). While it is important that some kind of support is available in order to cope with their situation effectively, it is also critical that the individuals can be able to receive and make use of that support. Therefore, participants' subjective experience regarding the availability of the support is primarily considered.

Nevertheless, they showed anger and frustration to their farther surroundings such as peers and institutions such as the government, hospitals and schools and its representatives like doctors, school managers and teachers. While viewing other people as insensitive and inconsiderate, they viewed the establishments as inefficient.

Participants also felt like their parenthood was being judged and people didn't understand them. They felt responsible for their child's actions and felt blamed by others if their child misbehaves in a certain environment. As a result, they showed anger and frustration and saw people as selfish and uncaring. Their perspective can be viewed as projection of their own guilt feelings regarding their child's autism. It is shown that guilt is a common reaction to guilt (Maraş, 2016). Therefore from a clinical point of view it can be suggested that while working with such clients, it is important to be aware of such dynamics and tackle with unexpressed emotions such as sadness and grief.

Establishments like the state, the government and the school and how they are structured is a part of the social order and can be viewed in relation to paternal function and symbolic father. Just like the actual father of their child is viewed as inessential and inefficient, these establishments are also viewed as having great deal of shortcomings. They showed resentment towards the government about their laws and regulations involving autistic children and they saw the school system insufficient and not good enough for their child. They also viewed teachers as unqualified and didn't trust the quality of education their children received at schools. They are also viewed as an obstacle in their child's developmental progress. They have suggested that their child could have become "normal" if he had received adequate education in schools. Similar to their view of their child's father, they viewed their own care giving as superior to what everyone else offers.

Just as mentioned before within this study, having a child who has autism can evoke several conscious and unconscious conflicts. These unconscious conflicts are handled by using various psychological defenses (Vaillant, 1994). These experiences of participants show that they use psychological projection in order to cope with how they are feeling. In projection, a part of the self that is difficult to bare is split and attributed to others. As previously shown in this study, these participants' wish and effort to be strong is maintained by shifting their own feelings of inadequacy onto others.

Clinically speaking, in the light of information presented in this theme, the mother's language as the carrier of law and desire and defense mechanisms these mothers used and coping strategies they employed can be seen as important concepts to investigate and work with.

4.8 Limitations of this study and suggestions for further research

This current study was conducted with participants whose children are between the age of seven and twelve. Diagnosis of these children and the course of development in an autistic structure can be quiet heterogeneous and unstable before the Oedipus stage ends. Therefore this demographic was chosen in order to make sure that participants' children have an autistic structure. So while the participants explain their current experiences, they also gave a lot of information about their past experiences including deciding to have a child, their pregnancy and their experiences as their child grow older in retrospect.

Therefore while this study is helpful in understanding participants' current experiences regarding raising an autistic child, it was difficult to draw a conclusion regarding how autistic symptoms appear and develop into an autistic structure.

Knowledge gathered was discussed in the light of theoretical information from the literature but it can be said that not only the design of the study but also the current literature give conflicted results to that question (Maino, Viola&Donati, 2009). Therefore, it can be suggested that studying the mother-infant relationship at a very young age can contribute to our knowledge on the subject in the future. This is especially important since this current study only includes the mothers but not the children. Hence, for future studies it can be suggested that in order to understand the phenomenon of autism, it is important to study with children and to study with them in relation to their parents.

4.9 Conclusion

In conclusion, this study is an attempt to gain an in-depth understanding of mothers whose children has autism and their experiences. It is found that both the development of an autistic structure and raising an autistic child involve complex and multifold dynamics.

Events leading up to the development of autism were discussed only in retrospect. Participants' statements were discussed in the light of psychoanalytical literature while putting an emphasis on the Lacanian paternal function.

Shock and disbelief have been found to be the initial reactions to their children's autism. It can be suggested that denial is a crucial concept to tackle with while working with such mothers. In addition to the difficulties with coming to terms with a lifelong syndrome, this experience can be viewed as loss in many ways. It is a loss of a relationship and a loss of having a healthy child. Therefore from a clinical point of view, these mothers should be encouraged to go through their own mourning period because as this study points out, instead of experiencing feelings of sadness and grief, these participants tend to engage in a self-sacrificial mode while idealizing motherhood. Another prevailing emotion that is presented itself in this study was guilt. Guilt was either strongly felt consciously or projected to others as blame. This was another founding of this study showing that these participants tend to focus on others instead of dealing with their own emotions and well-being. Hence, it can be said that caregivers of autistic children can benefit from a clinical intervention in order to develop better coping skills.

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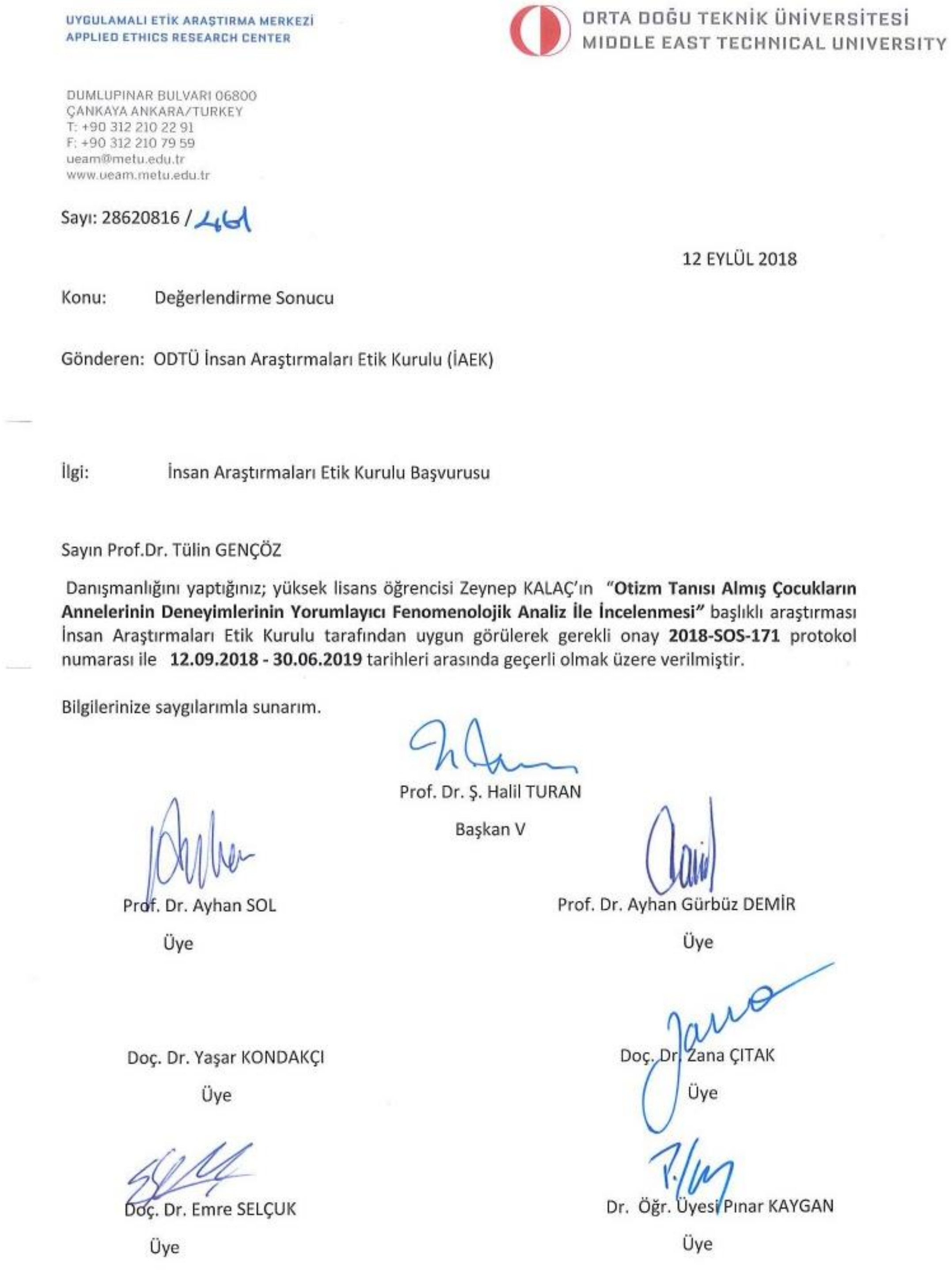
APPENDICES

A. APPROVAL OF THE METU HUMAN SUBJECTS ETHICS COMMITTEE



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12 EYLÜL 2018

Konu: Değerlendirme Sonucu

Gönderen: ODTÜ İnsan Araştırmaları Etik Kurulu (İAEK)

İlgi: İnsan Araştırmaları Etik Kurulu Başvurusu

Sayın Prof.Dr. Tülin GENÇÖZ

Danışmanlığını yaptığınız; yüksek lisans öğrencisi Zeynep KALAÇ'ın **"Otizm Tanısı Almış Çocukların Annelerinin Deneyimlerinin Yorumlayıcı Fenomenolojik Analiz İle İncelenmesi"** başlıklı araştırması İnsan Araştırmaları Etik Kurulu tarafından uygun görülerek gerekli onay **2018-SOS-171** protokol numarası ile **12.09.2018 - 30.06.2019** tarihleri arasında geçerli olmak üzere verilmiştir.

Bilgilerinize saygılarımla sunarım.

Prof. Dr. Ş. Halil TURAN
Başkan V

Prof. Dr. Ayhan SOL
Üye

Prof. Dr. Ayhan Gürbüz DEMİR
Üye

Doç. Dr. Yaşar KONDAKÇI
Üye

Doç. Dr. Zana ÇITAK
Üye

Doç. Dr. Emre SELÇUK
Üye

Dr. Öğr. Üyesi Pınar KAYGAN
Üye

B. TURKISH SUMMARY / TÜRKÇE ÖZET

OTİZMLİ ÇOCUĞU OLAN ANNELERİN ÖZNEL DENEYİMLERİ

BÖLÜM 1

GİRİŞ

1.1 Otizme genel bir bakış

Otizm; sosyal etkileşimi, iletişim ve konuşmayı etkileyen, aynı zamanda tekrar eden stereotipik davranışları ve ilgi alanlarını içeren bir durumdur. Çalışmalar, yaklaşık iki yaş altı ay civarında ilk belirtilerin görülmeye başlandığını göstermektedir. Çocukların tanı aldıkları ortalama yaş ise dört yaş beş aydır. Otizm ilk başta bir tür çocukluk şizofrenisi olarak görüşmüştür. 1980'de ise Amerikan psikiyatri sınıflandırması otizmi Yaygın Gelişimsel Bozukluk başlığı altında değerlendirmiştir. Epistemolojik çalışmalar her altmış sekiz doğumda bir bebekte otizm görüldüğünü ve erkek ve kızlarda görülme oranının 3.8/1 olduğunu ve bu vakaların yüzde sekseninde zihinsel gerilik eşlik ettiği görülmüştür.
Karşılıklı sosyal etkileşimde bozulma otizmin temel özelliklerinden biridir. Anneleri veya babaları isimlerini çağırdıklarında tepki vermezler. Diğer insanlara karşı duyarsızlardır ve sınırlı yüz ifadesine sahiptirler. Otistik kişilerin dil kullanımı akranlarından farklıdır. Hayali oyun bu kişilerde görülmez.

Otistik yetişkinlerin ilgisini çekmeye çalışmaz ve başkalarının varlığında kaygı veya sevinç ifade edilmez. Göz kontağından korkar ve ilgi alanları takıntılı biçimde nesnelere yönelmiştir. Bu kişilerin aynı zamanda yemek ve tuvalet alışkanlıklarında problemler vardır (Erickson, 2005). Otizmin tedavisine dair psikojenik yaklaşımların yaygınlığı özellikle 1970'li yıllarda azalmış ve otizmin biyolojik temelleri üzerinde durulmaya başlanmıştır. Altta yatan muhtemel bir tıbbi veya genetik bozukluğa dair araştırmalar artmıştır. Otizmin tıbbi tanısı psikiyatristler ve nörologlar tarafından yapılır. Tanıdan sonra çeşitli test ve bataryalarla tarama süreci ve terapötik değerlendirme başlar.

1.2 Otizme dair psikanalitik yaklaşım

Otizmin kökenlerine dair açıklamalara bakıldığında iki grupla karşılaşırız; organistler ve psikanalistler (Melman,2004). Nörohormonal bozukluklar araştırmaya değer gibi görünse de, Melman'a göre genetik önermeleri savunmak güçtür. Buna karşılık psikanaliz, çocuğun annesiyle yapısal veya durumsal olabilecek sebeplerle bağ kuramadığında otizmin ortaya çıktığı tezini önerir. Annenin sözcükleri, fallik nesnesiyle ilişkisine dair veya çocuğunun doğumuyla ilgili kişisel bir göndermeye dair bir içerikten yoksundur. Bu durumda çocuğu sağır yapar, temsil edilmediği bir dünyada yapacak bir şey bulamaz. Organistler, insan davranışının daha önceden belirlenmiş ama bilimsel olarak kontrol edilebilir fizyo-kimyasal faktörler sonucu oluştuğunu söylemektedirler. Lacanyen bakış açısı ise çocuğu bir ses vermenin ona dilde bir yer açmakla gerçekleştiğini söylemektedir (Melman,2009). Bu çocuğu görevle değil, sevgiyle yetiştirmeyi içerir. Terapistin uygun müdahalesiyle bebeğin dikkati uyanabilir, göz kontağı gerçekleşir ve bebeğin uzuvları hareketlenmeye ve ses telleri çalışmaya başlayabilir. Melman'a (2009) göre, davranışsal metotlar bu çocukları matematik dâhisi yapabilir ancak onları bir soya kaydetmez. Çocukta bir çaba ve arzu uyandırmaz.

1.2.1Preaut girişimi ve anne olarak *Başka*'nın rolü

Melman'ın projesi otizmi dört aylık kadar erken bir sürede yakalamak ve otistik yapının oturmasını önlemeyi amaçlamaktadır (Laznik, 2014). Araştırmacılar ve klinisyenler otizmle zamana karşı bir yarış içinde olduklarından, Lacanyen metodolojiyi otizm araştırmalarına dâhil etmek yararlı olacaktır. Koruyucu çalışmalar, çocuk ve ebeveyn arasındaki ilişkiyi düzenlemeyi içerir. Ebeveyn ve çocuk arasında bakış olmadığında ve oral dürtü devresinin üçüncü aşaması gerçekleşmediğinde koruyucu müdahale yapılabilir. Bir bakışın yokluğu aynı zamanda ayna evresinin gerçekleşmemesi durumuyla birlikte olur. Eğer bir çocuk ayna evresindeki görüntüsüyle özdeşleşebilecekse, bu Ötekinin bakışı sayesinde gerçekleşmektedir.

Başka'nın libidinal yatırımı çocuğun fallik bir nesne olmasını sağlamaktadır. Çocuk ancak aynanın karşısında Başka'nın bakışını yakaladığında kendi eksiğiyle karşılaşır. Bu eksiğin tanınması için, annenin de eksiği olan bölünmüş bir özne olması gerekmektedir. Bu eksik olmadığında, çocuğu fallik bir nesne kılacak libidinal yatırım da gerçekleşememektedir. Bu noktada hekimler ve klinisyenler, genel değerlendirmelerini yaparken çocuğun Başka'nın bakışıyla ilişkisini de değerlendirmesine dâhil edip, çocuğun fallikleşmesine katkıda bulunabilir.

Melman'a göre otizm, anne çocuğa fallik madalyayı veremediğinde olur (2014). Otistik, büyük Başka'nın diline girmeyi reddetmektedir çünkü annesel Ötekinin arzusunun nesnesi olmaya yol açacak yabancılaşmaktan kaçınmaktadır. Otistik özne kendi zihinsel temsillerinin olduğu halüsinatif bir evrende kalmayı tercih etmektedir. Başkanın arzusuyla yabancılaştırıcı bir ilişkiye girmemektedir ve böylece Başkanın ondan uymasını istediği bir çok norm, ideal ve yasağında dışında kalmış olur. Otistiğin girmediği bu sistem, yerler, nesneler ve kişilerle ilişkileri yöneten bir yasanın sistemidir. Bir çocuk dil ile düzenlenmiş bu sisteme girmeden önce, annesi ona bu yerlerin isimlerini verir ve bu sayede çocuk, annesiyle paylaşabileceği bir uzamsal yer inşa edebilir. Bunun gerçekleşmesi annenin arzusunu taşıyan sesinde yatar. Ancak otistik çocuk bunu reddetmektedir (Melman,2004).

Otizmin belirtileri iki yaşından sonra daha belirgin olmaktadır ((Larrson, Eaton and Madsen, 2005). Bu belirtiler, kendi ismine daha az tepki verme, diğerlerine daha az bakma, zayıf göz kontağı, az yüz ifadesi ve iletişimsel davranış ve ortak dikkattir. İnsanlarla ilişki kurmaya dair genel bir ilgisizlik, uygunsuz yüz ve duygusal ifadeler ve iletişimsel jestler görülmektedir (Warlamount, Voller and Dale,2010).

İletişimsel ilgisizlikle beraber bu çocuklar yaşamlarının ikinci yılında ayrıca motor gelişimlerinde de birçok farklılık göstermektedirler. Alışılmadır bir postur ve hipotoni bu çocuklarda sıklıkla görülmektedir. Otistik yapının bir diğer önemli özelliği ise sembolik oyunun gerçekleşmemesi ve akranlarla oyun oluşturmaya dair ilgisizlik olarak ifade edilebilir. Bu belirtiler altı aylıkken ortaya çıkmakta ve iki yaşa kadar artıp belirgin hale gelmektedir.

Bununla beraber, araştırmalar otizmin daha geç başlayabildiğini de göstermiştir. On iki ay civarında normal duygulanım gösteren, babıldayan ve uygun iletişimsel jestler kullanan ve taklit oyun oynayabilen kimi çocukların da yirmi iki ay civarı geri çekilme gösterip sessizleştiği ve tekrarlı davranışlarına ve oyunlara yöneldiği ortaya çıkmıştır (Larrson, 2005)

Fransız projesi “Preaut” bu sebeple dört ay gibi erken sürede bu belirtileri ortaya çıkarmayı hedeflemekte ve karşılık bir ilişki geliştirmek için haz uyandırmanın ve arzunun önemini vurgulamaktadır (Olliac, Crespin and Laznik, 2017). Otistik yapı oluşmadan önce bu belirtilere müdahale etmek ve zaman kazandırma açısından da önem teşkil etmektedir.

Otistik yapının iki temel belirtisi vardır. İlki anne ve bebek arasındaki bakışın yokluğudur ve bu da skopik dürtünün çalışma şekliyle ilgili bilgi verir (Lacan, 1977). İkinci belirti ise oral dürtü devresinin tamamlanamaması yani bu devrenin üçüncü ve son aşamasının gerçekleşmemesi ve böylece devrenin tamamlanamamasıdır. Ego oluşumunun ayna evresinde gerçekleştiği düşünüldüğünde, çocuğun beden bütünlüğünü kavradığı ve kendi eksiğini Başkada gördüğü bir deneyimden bahsedilebilir. Çocuk kendi eksiğini, Başkanın bakışında ve bu bakıştaki yatırım ve ilgide görür. Ayna evresi ancak ilk bakışın var olması üzerine gerçekleşebilir. Bu yüzden depresyonda ve kendi eksiğini tanıyamamakta olan bir anne, çocuğuna libinidal bir yatırım yapamayabilir (Melman, 2014).

Otizm geliştiren bebekler arasında görülen ikinci belirti ise dürtü devresindeki geribildirim döngüsünün tamamlanmamasıdır. Dürtüler, ihtiyaçlardan farklıdır ve dürtü doyumu ancak bu devrenin bir döngü içinde hareket etmesiyle gerçekleşebilir. Bir dürtü devresinin üç aşaması vardır ve otistik çocuklarda üçüncü aşamanın tamamlanmadığı görülmektedir (Lacan, 1963-1964).
İlk aşama bebeğin memeyi veya biberonu alıp tutması olarak tanımlanabilir. İkinci aşama ise bebeğin emdiği ve kendini yatıştırdığı oto-erotik evredir. Otistik çocuklar bu iki aşamayı gerçekleştirebilen, hayatta kalma becerileri olan çocuklardır. Ancak doktorlar genel muayenelerinde bu iki aşamayla ilgilenirken, üçüncü aşamanın da değerlendirilmesi önem taşımaktadır. Bu üçüncü aşama, Başkanın zevkinin bir parçası olmayı kabul etmektir. Bu zevk kendini beslenme zamanı bittiğinde bir

hayali oyun içerisinde kendini gösterebilir. Örneğin anne bebeğin yemeğini yiyormuş gibi yaparak ne kadar lezzetli olduğu ile ilgili yorum yapabilir. Bu bakışla bebek, annesinin gülümsemesinin ve aldığı zevkin farkında varır. Bu temel oluşturulduğunda, annenin yokluğunda da arzunun bu halüsinatif kutbu kendini gösterebilir ve arzunun temsillerin oluşmasına ön ayak olur. Bu temsiller bilinçdışı düşüncelerle ilişkilidirler. Bu gerçekleşmediğinde, dil işlevini gerçekleştirmemiş demektir ve özne metafor ve metonimiden mahrum kalmıştır. Annenin sesindeki prosodi, onun sevinç ve hazzının bir yansımasıdır ve bu prosodi, çocuk için ihtiyaç ve dürtünün arasındaki farkı belirler. Çoğunlukla ilkel Başkanın yerini tutan anne, eksiği olan bir açıklıktır ve annenin şaşkınlığına ve hayranlığına boyun eğmek, bebeğin arzunun nesnesi yapar. Öznenin, ihtiyaçlarıyla ve onların doyumuyla tanışmadan dahi önce, annesel zevke karşı bir yönelimi vardır (Laznik, 2013).

1.2.2 Lacan'ın Dürtü Kuramı

Lacan (1963)'ın dürtü kuramına göre, dürtü içgüdüden farklıdır çünkü bir nesneyi yoktur ve tatmin olmayı amaçlamaz. Dürtü, nesnesinin etrafında devamlı dönmek isteyen bir daire olarak görülebilir. Özneyi, tatmin nesnesine iten şey o nesnenin eksikliğidir. Nesne yalnızca bir boşluğu ve hiçliği kaplar. O kayıp nesnedir. Dürtü devresi tekrar eder ve ve zevk, bu döngünün kendisindedir. Dürtünün bir kaynağı, bir hedefi bir nesnesi ve basıncı olduğu açıklanmıştır. Bu zevkin kaynağı arzudur ve yalnızca bölünmüş öznede bulunur. Arzu bu tekrar eden döngünün içinde devam etme sebebidir.

Lacan, Freud(1915)'un oral ve anal dürtülerine, skopik ve işitsel dürtülerini de eklemiştir. Erojen bölgeler özne ve Başka'nın ilişkisinde önemli yer tutar ve zaman içerisinde birbirlerinden ayrı hale gelebilirler. Bu ilişki öznenin zevkle olan kişisel ilişkisini oluşturur. Yabancılaşma ile birlikte, ilk nesne olan meme kayıp nesne olur ve Başkanın alanında tekrar inşa edilir. Bu alan talebin alanıdır. İhtiyaç tatmini sağlandığında geride kalan önemlidir çünkü geride kalan şey asla tatmin edilemez çünkü sonsuza kadar kaybedilmiştir.

Otistik bir çocuğun ailesiyle yapılan bir çalışmada, annenin sesinde anneceyi oluşruracak bir prosodinin eksik olduğu bulunmuştur (Laznik,2005). Ses analizlerine bakıldığında, prosodisinde bir tepe noktası görülememiştir. Annenin sesindeki prosodide görülen yükselmeler, annesel Başkanın zevkinin bir yansıması olarak görüldüğünde bu bulgular önem teşkil etmektedir. Annecenin üretimi, annenin ve bebeğin aktif katılımını ile gerçekleşen karşılıklı bir deneyimdir. Annenin sesindeki şaşkınlık ve hayranlık artıkça, bebeğin tepkilerinde artış gözlenmiştir. Annece için gerekli prosodiyi üretemeyen bir anneye tepkisiz kalan bir bebeğin, amcasıyla konuşurken normal bir bebek gibi güldüğü, seslemeler yaptığı ve baktığı görülmüştür. Bu bulgu, bebeklerin Başka ile bir ilişki içinde olma donanımına sahip olduğunu ifade etmektedir. Nörobilimsel çalışmalar ayrıca, otistik kişiler için insan sesiyle herhangi bir diğer sesin birbirinden farklı olmadığını ve otistik çocukların insan sesi ve yüzüne daha fazla ilgi göstermedikleri ortaya koymuştur(Fernald and Kulh, 1987). Lacan(1973)'a göre bu ilgisizlik daha sonraki ayrışmayı getirecek olarak birincil özdeşimin oluşmasını engellemektedir. Birincil özdeşim aynı zaman beden bütünlüğünün oluşmasını sağlayan bir durumdur. Bunun gerçekleşmediği çocuklarda, iletişimsel içe çekilmelerle beraber bedensel farklılıklar da görülür. Çünkü erojen bölgelere yapılan yatırım Başka ile ilişkiyle ilintilidir(Lacan,1983). Bu ilişkinin oluşmadığı otistikler, sıklıkla salya akıntısı gösterirler ve buna karş kayıtsızlık içindedirler.

Psikanalitik bakış açısının yerini yaygın olarak bilişsel modeller ve müdahaleler almış olsa da, arzunun özne olmadaki rolünü otizmle ilgili çalışmalara dâhil etmek önleme açısından önem teşkil etmektedir (Laznik, 1995).

1.2.3 Annece

Bebeklerin annece denilen içinde zevki barından bir konuşma türünü tercih ettikleri bilinmektedir (Saint-Georges,2013). Annece; duraklamayı, kesmeyi, çeşitli dilbilgisel özellikleri içeren bir prosodik niteliğe sahiptir. Bu tercih, bebeklerin annelerine ilgisinin ihtiyaç tatminin ötesine geçtiğini göstermektedir. Bebek farklı bir tür tatmin aramaktadır ve bu arayış annecenin hayranlık ve haz içeren yapısında uyanır. Annece, aynı zamanda annedeki eksiğe gönderme yapmaktadır. Çocuğun aslında annedeki eksiğe yönelik bir tercihi olduğu söylenebilir. Lacan (1956), Başkadaki bu eksiğin çocuğun gerçek olduğunun kanıtı olabileceğini ve bu gerçekliği de aynadaki speküler imge yoluyla gösterebileceğini ifade etmiştir.

Melman(2014)'a göre otizmde anne, çocuğuna bir şekilde sevgisini ve çocuğunun onun için bir hediye olduğu hissini geçiremez. Bu yüzden annenin söyleminin otizmin gelişiminde bir rolü olduğu söylenebilir. Bu çocuklar aynı zamanda annesel Başkayı memnun etmek gibi bir motivasyon da taşımazlar.

Annece yalnızca anne tarafından değil ayrıca babalar tarafından da üretilebilen bir tür konuşmadır. Çalışmalar annelerin konuşmasında %40 ile %60 arasında, babaların ise %15 ile %20 arasında annece içerdiğini göstermiştir. Yetişkinlere yöneltilmiş konuşmayla kıyaslandığında, bebeklere yöneltilmiş konuşma daha kısa cümleler, gereksiz ve tek başına kelemeler ve öbekler ve birçok soru içermektedir. Prosodik olarak ise annece daha uzun duraklamalar, yavaş bir tempo, daha fazla tekrar ve daha yüksek bir f0 (temel frekans) içermektedir. Bununla beraber annelerin farklı niyetleri farkı tarzda seslendirmelerle ifade ettiği görülmüştür (Cohen,2013).

1.2.4 Çocuklar ve ebeveynleri arasındaki sessel alışverişler

Otistik çocukların ebeveynlerinin diğer çocuklarının ebeveynlerine kıyasla çocuklarına daha geç yanıt verdiği bulunmuştur (Warlamount,2010). Bununla beraber otistik çocuklarda yönlendirme davranışının daha az, takip etmenin daha fazla olduğu gözlenmiştir. Daha büyük çocuklar için otizm tarama testleri mevcutken, bir yaş altı çocuklar için tasarlanmış her hangi bir değerlendirme aracı bulunmamaktadır (Dawson,2008). Böyle bir testin varlığı erken tanı ve müdahale açısından önem teşkil etmektedir. Preaut sistemi dört aylıktan itibaren bu çocukları tespit edebilmektedir (Olliac ve Crespin, 2009)

1.2.5 Bebek ve bakıcı ilişkilerinde aktif katılımcılardır

Bu karşılıklı ilişkide tepki vermeyen bir bebeğin ebeveynler üzerinde de belirli bir etkisi vardır. Çocuklarındaki farklılığı hisseden ebeveynler, ebeveynlik becerileri ile ilgili giderek daha güvensiz hissetmeye başlayabilirler. Yenidoğanın ilk aylarında sıcak ve şevkatli hisseden ebeveynler zaman içerisinde engellenmiş hissedip donuklaşabilirler (Melman,2014).

Araştırmalar ayrıca doğum öncesi çevrenin de otizmin gelişimesinde bir rolü olduğunu önermektedir (Larrson,2004). Ters doğum, düşük Apgar testi, doğumda bebeğin kaç haftalık olduğu, doğum kilosu ve ebeveynlerin psikiyatrik öyküsü gibi olguların otizm riskiyle ilişkili olduğu öne sürülmektedir.

Annelerin kişilik özellikleri üzerinde duran bir çalışmada, geniş otistik bir fenotipe sahip annelerin kişilerarası ve sosyal problemler yaşayabileceği iddia edilmiştir (Wollf, 1988). Bir çalışmada otizmi olan çocukların annelerinin karakter özelliklerini ve olası risk faktörleri çalışma amacıyla Rorschah testinin değişkenleri kullanılmıştır (Sandica ve Patca, 2011). Araştırma sonucunda daha az stresli annelerin daha fazla duygu gösterdikleri ve kendilerini daha açık biçimde ifade edebildikleri görülmüştür. Duyguların daha az ifade edilmesi otizmli bir çocuğa sahip olmaktan kaynaklanan strese bağlı olabileceği düşünülürken, ilişkilere dair daha az ilgi sahibi olma ve kişisel arası problemler yaşama daha geniş bir otistik fenotipin göstergesi olarak değerlendirilebilir. Annelik depresyonu annece kullanımını olumsuz etkilemektedir. Bu ebeveynler, bebeklerinin etkileşim kurma girişimlerine, seslenmelerine daha az uyum sağlayabilmektedirler. Arzuya dair temsiller oluşturamayan bu çocuklar, hayali oyun oynayamaz ve bu oyunlarda fantezilerini hayata geçiremezler (Fink, 1995). Birincil bastırmanın gerçekleşmediği bu çocuklar (Freud,1905), nesnelerin kendi görüş açılarından çıktıktan sonra da var olmaya devam ettiğini kavramayamamakta, sahip olamadıkları bu imgesel alanda ödipal bir rekabete de dâhil omları mümkün olmamaktadır.

1.3Cinsiyetlenme ve Otistik Özellikler

Francis Tulsin (1972) otistik çocuklarda Başkanın kapsama işlevinin başarısızlığa uğradığını ve maskülen ve feminen yanların bölündüğünü iddia etmektedir. Bu yüzden psikanalitik tedavinin amacı, tutucuya olan aktarımı çalışmak yoluyla bu işlevi tamir etmeye çalışmaktır. Tutan olarak büyük Başkanın biseksüel yapısı sayesine benlik ile nesene arasında güvenli bir alan yaratılmalıdır. Bu sayede çocuk, Ötekinden ayrı olmaya katlanabilir. İkinci aşamada çocuk imgesel rakipler yaratabilmeli ve Ödipal dönem olan üçüncü aşamada ise cinsiyetlenme gerçekleşmelidir. Bu seviyedeki bir çocuk artık otistik yapıya sahip olarak görülemez.

1.3.1 Cinsel Kimlik Disforisi ve Otistik Özellikler

Araştırmalar, cinsel kimlik disforisine sahip kişiler, normal kişilere göre altı kez daha fazla oranda otistik belirtiye sahip olduğunu göstermiştir (Oien,2018). Ayrıca otistik belirtilerin doğumda erkek olarak atanmış kişilerde daha sık görüldüğü bulunmuştur. Cinsiyet Kimlik Disforisine sahip kişiler ve otizmli kişilerin toplumda yaygınlığı artmaktadır (Heylens,2018). Bu çalışmalar otizmli kişilerin cinsiyetlenmesi ile ilgili önemli bilgiler vermektedir.

1.4Nevrotik Öznenin Oluşumu

Nevrotik öznenin oluşumuna bakıldığında, öznenin anne ve çocuk simbiyozundan ayrışmaya doğru ilerlediği bir tablo görülebilir. Bebeğin, annenin arzuladığını düşündüğü imgesel fallus, annenin eksiğini fark etmesine yol açar. Bu eksik ile beraber oluşan arzu ile beraber, kişi bölünmüş özne olarak simgeselde yerini alır (Fink, 1995).

1.4.1 Nevrotik Öznede Arzu ve Kaygı

Lacan(1977) anksiyeteyi, arzunun altında yatan olarak tanımlamıştır. Nesne a reel, imgesel ve simgesel düzlemin birbirine bağlanmasıyla var olabilir. Nevrotikte kaygı, kastrasyon tehditi ile ilgili olabilmekte, bu da fallik zev tarafından belirlenen fallus yoluyla ortaya çıkmaktadır. Dilin işlevi bir kesiğe yol açmasıdır. Ancak bu kesiğin tanınması için bir referans noktası gerekmektedir. Arzunun organizasyonu gereği, dil kendini gösterdiğinde, bastırılmış öznede cinsellikten söz edilebilir.

1.4.2 Nevrozda Borromean düğümünün olmuşması

Borromean düğümü üç halkadan oluşmaktadır; Reel, İmgesel ve Simgesel (Laznik,2016). Reel halkası, organik bir varlık olarak bebektir. Simgesel dünyanın düzenini temsil eder ve imgesel bebeğin ne olabileceği ile ilgili temsilleri içerir. Bu üç halkanın belli bir sırayı takip ederek düğüm oluşturması beklenmektedir. İlk düğüm reel ve simgesel arasındadır ve Başkanın bebeğin bedenindeki uyarımları yatıştırmasını içerir. İkinci düğüm imgesel ve reel arasındadır ve Başkanın bakışını ve sesini içerir. Bu ses, bebeğin yol açtığı şaşkınlık ve neşe içermektedir. Ebeveynin bakışı çocuğun bedenini fallik bir obje yapar ve libidinal yatırım gerçekleşir. Bu seviyede birincil narsism oluşur. Üçüncü düğümde imgesel ve simgesel bir araya gelir. Bu aşama simgesel kastrasyonu içerir. Dördüncü düğüm bir kez daha simgesel ve reel arasında gerçekleşir. Bu düğüme de bebeğe kendi reelinden yani bedeninden gelen iç uyarımları yatıştırma rolüne sahip Ötekinin varlığı sebep olmaktadır. Bütün bu aşamaların gerçekleşmesi Borromean düğümünün oluşması ile sonuçlanmaktadır.

Bu şekilde tipik gelişen bir çocuğun simgesel kastrasyonla beraber bölünmüş bir özne haline gelmesinde bahsedilebilir.

1.5. Otistik Yapının Oluşumu

Otistik yapıda, imgesel alanın diğer alanlarla düğüm oluşturmasında problem olduğu söylenebilir (Laznik, 2014). İlksel Başkaya yabancılaşmayı reddeden bu çocuklar, fallik nesne konumu alamazlar (Melman,2014). Bu çocuklarda borromean düğümlerinde bir çok hata olduğunda söz edilbilmekle beraber, bunlardan ilki imgesel ve reel alanlardır.

1.5.1 Otizmde Borromean düğümünün oluşması

Ayna evresi gerçekleşmediği zaman, bebek için jübilasyonun gerçekleşmediği söylenebilir. Bununla beraber, reel ve simgesel alanların düğümünde de sorun yaşanmaktadır çünkü babanın hayırı işlevini gerçekleştirememiştir. Sonuç olarak, bu çocuklarda birinci ikinci ve beşinci düğümlerin bağlanmasında hatalar olur ve imgesel alan diğer iki alanla bağlantı kurmaz (Laznik, 2014)

1.5.2 Psikotik ve Otistikte Arzu

Otistik için anne ve baba birbirinden farklı değildir çünkü ancak annenin arzusu ile babanın sesi anlamlı hale gelir. Yaşamın başında bir otistik için annenin sesi kaçınılmak istenen travmatize edici ve rahmi istila eden yabancı bir varlık olarak algılanabilir. Otistik Başka ile ilişkilenmekten kaçınarak oto-erotik davranışlar sergiler. Bu kişiler aynı zamanda yoğun yutulma ve dağılma korkuları deneyimleyebilirler, bu da onların korku içinde yaşarak geri çekilmelerine ve kaçma davranışı içinde olmalarına yol açabilir (Fink, 1997).

1.5.2.1 Psikotik ve Otistikte Simgeselleşme

Lacan, (1957) psikotik ve otistik gösterenin sınırlandırılmamış doğası sebebiyle acı içinde olduğunu ifade etmiştir çünkü efendinin etkileri kontrol altına alınamamıştır. Bu sebeple psikotik de otistik durum panik uyandırıcı ve tehdit edicidir. Onlar için özneleşmeyi sağlayacak bir gösteren yoktur. Bir yapının oluşmasında annenin arzusu temel rol oynar ancak psikotik özne bu simgeselleşmenin dışında kalmıştır. Bu yüzden hem psikozda hem otizmle bedenle temel bir ilişki görülmektedir.

1.5.2.2 Psikotik ve Otistikte Kastrasyon Kaygısı

Psikotik ve otistiklerin kastrasyon kaygısına yabancı oldukları söylenebilir. Bununla beraber bu kişiler bedenleri ve bedenlerinin sınırlarına dair korkuları ve anlam oluşturma çabalarıdır. Kastrasyonun gerçekleşmemesinin yol açtığı fallik zevk ve onun tehdit ediciliği buna yol açmıştır. Başka ile ilişkideki bir takım öğelerin psikozla ilişkisinden bahsedilmiştir (Lacan, 1954). Schreber'in dünyasında anlam kaybı gerçekleşmiştir çünkü arzuya sebep olması gereken, mevcut değildir Babanın adı yoktur ve dolayısıyla Başkaya göre alınabilecek öznel bir konumda oluşmamıştr.

1.6. Otizmli bir çocuğa sahip olmak

Otistik çocukların ebeveynlerinin, tipik gelişen çocuklara kıyasla daha stresli olduğu ve çeşitli baş etme stratejileri kullandıkları görülmüştür (Hastings, 2005). Bunlar; aktif kaçınma ile baş etme, problem odaklı baş etme, pozitif baş etme ve dini/inkar ile baş etmedir. Araştrmalar ayrıca annelerin babalardan daha fazla stres yaşadığını ve daha farklı baş etme stratejileri kullandığını göstermiştir (Lutzky, 1984). Ayrıca annelerin babalara kıyasla daha fazla sosyal destek aradığı ve problem odaklı baş etme stratejileri kullandığı bulunmuştur (Dabrowska, 2010). Ebeveynlerin stres kaynakları arasında çocuklarının durumunun kalıcılığı, aile üyelerinin ve toplumun çocuğun durumunu onaylamaması ve yetersiz profesyonel destek yer almaktadır (Dabrawska and Pisula, 2010). Kullanılan baş etme stratejilerinden bağımsız olarak otizmli çocuğu olan ebeveynler hem tipik gelişen çocuklara kıyasla hem de diğer engel gruplarına kıyasla daha fazla stres deneyimlemektedirler (Lustic,2002). Otizmli bir çocuk sahibi olmak ebeveynlerin sosyal yaşamlarında sınırlılıklara yol açmıştır. Üzüntü, endişe acı ve çaresizlik gibi birçok duygu deneyimlemektedirler. Tanı sonrası ebeveynler yas açısından birçok evreden geçmektedirler ve birçok değişik tepki verebilmektedirler. Bu tepkiler, inanmamayı, öfkeyi, suçluluğu, çaresizliği, yıkılmışlığı, şaşkınlığı ve ayrıca çocuğun reddini içerebilir. Kübler Rose'a göre ebeveynlerin %75'i kabul evresinde, %10'u depresyon evresinde, %10'u öfke evresinde ve %5'i inkâr evresindedir. Ebeveynlerin deneyimlediği stres ve depresyon için kontrol odağı önemli bir faktördür. Araştırmalar dışsal kontrol odağına sahip kişilerin içsel kontrol odağına sahip kişilere kıyasla daha yüksek depresyon seviyeleriyle ilişkilendirildiğini önermektedir (Lazaruz, 1984).

Bu çalışmada ise, otizmli çocuğu olan annelerin öznel deneyimlerinin derin bir araştırma ile anlaşılması amaçlanmaktadır.

BÖLÜM 2

METODOLOJİ

2.1 Niteliksel Araştırma

Otizmin etiyolojisi henüz bilinmemekte olduğundan (Buxbaum,2009), bu bozukluğun çok boyutlu ve karmaşık doğası gereği araştırması zor bir konu olduğu söylenebilir. Bu açıdan niteliksel bir yaklaşım derinlemesine bir araştırmayı, katılımcıların öznel konumunu da dâhil ederek mümkün kılar.

2.2 Yorumlayıcı Fenomenolojik Analiz

Yorumlayıcı Fenomenolojik Analiz'de, katılımcıların belirli bir konudaki eşsiz bakış açıları ve öznel deneyimleri ele alınır. Bu yaklaşım,, araştırmacının da çalışmaya olan katkısını anlamaya odaklanır (Smith& Osborne, 2007).

2.3 Katılıcılar ve Örneklem Yöntemi

Yorumlayıcı Fenomenolojik Analiz kriterlerine gore katılımcıların homojen bir grup olması hedeflenmiş ve amaçlı örnekleme kullanılmıştır. Bu çalışmadaki kişiler de yedi ila on iki yaşları arasında otizm tanısı almış çocukları olan evli kadınlardır. Toplamda beş kişi çalışmaya dâhil edilmiştir.

2.4 Prosedür

Öncelikle, katılımcılara yöneltilecek olan araştırma soruları belirlenmiş ve bu sorular açık uçlu ve yarı yapılandırılmış olacak şekilde düzenlenmiştir. Görüşmeler 100 ile 140 dakika arası sürmüş, ses kaydı alınmıştır. Görüşmeler, İstanbul'daki çeşitli özel eğitim merkezlerinde gerçekleştirilmiştir. Katılımcıların kişisel bilgileri gizliliğin koruması açısından değiştirilmiştir.

2.5 Veri Analizi

YFA kriterlerine göre, her bir görüşmenin analizi bir diğeri tamamlandıktan sonra yapılmaktadır (Smith, Jarman, Osborn, 1999). Görüşme analizi yapılırken sayfanın sol sütunu, araştırmacının, katılımcıların ifadelerine dair çağrışımlarını ifade etmesi için kullanılır. Ortaya çıkan üst- temalar ise sayfanın sağ tarafında toplanır. Her bir görüşmeden sonra önceki görüşmelere dönülüp benzer temalar için tekrar değerlendirme yapılır. Bu analiz süreci sonunda bu çalışmada şu temalar ortaya çıkmıştır: *hamilelik ve doğum sırasında güçlükler yaşama, tanı öncesi çocuk yetiştirmeye dair tutum, tanı sonrası olumsuz duygular deneyimleme, çocuğun eksiklerini kapatmak için çaba gösterme, çocuğun babasına dair çelişkili atıflar ve sosyal yakınlığa bağlı yapılan yansıtmalar.*

2.6 Çalışmanın güvenilirliği

Bir nitel araştırmayı güvenilir kılan çeşitli kriterler vardır. Bunlar; sosyal geçerlililik, öznellik, verilerin yeterliliği ve yorumlamanın yeterliliğidir (Morrow, 2005). Nitel araştırmaların güvenirliğine dair bir diğer özellik ise, araştırmanın öznel konumunu ve bu konumun çalışmayı ne şekilde etkileyebileceğinin araştırmaya dâhil edilmesidir.

2.6.1 Özdönüşümsellik

Bu çalışmanın seçilmesinde araştırmacının mesleki geçmişinin, özel hayat geçmişinin ve şu anki yaşamındaki güncel konuların etkisi olmuştur.

BÖLÜM 3

SONUÇ

Bu çalışmanın sonucunda yedi üst tema ortaya çıkmıştır. Bu temalar YFA kullanılarak elde edilmiştir. Bunlar; *hamilelik ve doğum sırasında güçlükler yaşama, tanı öncesi çocuk yetiştirmeye dair tutum, tanı sonrası olumsuz duygular deneyimleme, çocuğun eksiklerini kapatmak için çaba gösterme, çocuğun babasına dair çelişkili atıflar ve sosyal yakınlığa bağlı yapılan yansıtmalar.*

3.1 Hamilelik ve doğum sırasında güçlükler yaşama

Bu üst temada katılımcıların hamilelikte ve doğumda yaşadığı sağlık problemlerinden bahsetmektedir. *Sağlık sorunları yaşama* ve *çocuğun durumu ile ilgili endişeli olma* bu üst temanın alt temasıdır.

3.1.1 Sağlık sorunları yaşama

Katılımcılar hamilelik ve doğumda yaşadıkları güçlükleri önemli ölçüde sağlık sorunlarının oluşturduğundan bahsetmişlerdir. Hale bu tema bağlamında, yaşadığı panik bozukluktan, ölüm korkusundan ve kan değerlerindeki dengesizliklerden bahsetmiş, bu sebeple hamileliğinde önemli kilo kayıpları yaşadığını anlatmıştır.

3.1.2 Çocuğun durumuyla ilgili endişeli olma

Bu alt temada katılımcılar çocuklarının sağlığı adına kaygılı olduklarını anlatmışlardır. Hamilelik ve doğum deneyimini stresli bir deneyim olarak tanımlamış ve onları büyük ölçüde endişe içinde bıraktığını dile getirmişlerdir. Özge kendini şu şekilde ifade etmiştir:

> Şeker testine gittim. Seni bir ntsye alalım dedi doktor tamam hocam dedim. Dedi kusura bakma seni de korkutmayayım kordon dolanmış bebeğin boynuna dedi seni de acilen sezeryana almak zorundayız. Tabi o an ani bir korku bir telaş çünkü daha erken daha 8 aylık hamileyim daha var normalden 45 gün önce geldi gibi bir şey oldu Koray. Korktum ağladım strese kapıldım neden erken geliyor

> çünkü doktor öyle bir konuştu ki az daha beklersek bebek ölebilir kordon iyice dolanmış diye söyledi. Bir yandan çok ağlıyorum bir yandan çok korkuyorum. Değişik bir duygu yaşadım.

3.2 Annenin tanı öncesi çocuğun yetiştirme tutumu

Bu tema içerisinde katılımcılar bir bebek sahibi olduktan sonraki düşünme biçimleri, tutumları hislerine dair bilgi verecek olaylar ve deneyimlerden bahsetmişlerdir. Bu üst tema; *ev dışında çalışmaya dair olumlu hissetme, çocukla zaman geçirmenin önemsizleştirilmesi, çocuk yetiştirmeye dair sorumlulukların başkalarına devredilmesi, bir bozukluğa dair erken belirtileri normalleştirerek inkar etme ve tanıyı kabul etmede güçlük* alt temalarını içermektedir.

3.2.1 Ev dışında çalışmaya dair olumlu hissetme

Birçok katılımcı mesleklerini ve daha önce yaptıklarını işleri sevdiğini ifade etmiş ve iş hayatı ile ilgili olumlu hisleri olduğunu dile getirmişlerdir. İş hayatından sosyalleşme, özgürleşme, kendini önemli ve değerli hissetme, saygı görme gibi kazanımlarının olduğundan bahsetmişlerdir. Katılımcılar ayrıca iş hayatına dair özlem duyduklarını ve geri dönmeyi dilediklerini anlatmışlardır.

3.2.2 Çocukla zaman geçirmenin önemsizleştirilmesi

Katılımcılar bu alt temada, çocuklarının uyanık olduğu zamanlarda, iş hayatını içeren yoğun bir programın içerisinde olduklarını ve beraber vakit geçirecek zamanlarının olmadığını anlatmışlardır. Çocukları ile biraraya gelebildikleri zamanları ise çocuklarının uyku saati sebebiyle değerlendiremediklerini söylemişlerdir.

3.2.3 Çocuk yetiştirmeye dair sorumlulukların başkalarına devredilmesi

Bu alt tema, katılımcıların, çocuklarının büyükannelerinin verdiği bakıma duyduğu güven ve rahatlığından bahsetmesini içermektedir. Katılımcılar bu şekilde, çocuklarına dair bir endişe duymadıklarını, çocuklarının ihtiyaçlarının karşılandığını bilmenin onlara iyi geldiğini dile getirmişlerdir.

3.2.4 Bir bozukluğa dair erken belirtileri normalleştirerek inkar etme

Katılımcılar bu alt temada, kendi deneyimlerine ve çevrelerinin yorumlarına dair, çocuklarındaki bir takım belirtilerin normal olduğunu savunduklarını, bu belirtilerin çocuklarının gelişimine özgü olduğunu ve her çocuğun farklı olabileceğini ve zamanla bazı şeylerin iyileşebileceğini düşündüklerini anlatmışlardır.

3.2.5 Tanıyı kabullenmekte güçlük

Bu alt temada katılımcılar, doktorun tanısıyla karşılaştıklarında yaşadıkları güçlüklerden bahsetmişlerdir. Şaşkınlık, çaresizlik, şok, kabullenememe gibi birçok duygu yaşadıklarını anlatan katılımcılar, bu deneyimin zorluklarını ifade etmişlerdir.

3.3 Tanı sonrası olumsuz duygular deneyimleme

Bu üst tema, annelerin otizmli bir çocuğa sahip olma ve onu yetiştirmeye dair duygularını kapsamktadır. Alt temalar; *çocuğun durumuna dair suçluluk ve şüphe, annelik becerilerine dair endişeler, çocuğun geleceğine ve bağımsızlık düzeyine dair kaygılar, çocuğun kayıp olacağından ve zarar göreceğinden korkma, otorite kuramama kaynaklı engellenmişlik hissi* olarak belirtilebilir.

3.3.1 Çocuğun durumuna dair suçluluk ve şüphe

Bu alt tema, annelerin çocuklarının neden otizmli olduğuna dair sorgulamalarını ve atıflarını içerir. Suçluluk hissettiklerini ve çocuklarının otistik olmasına yol açacak bir şey yapıp yapmadıklarını düşündüklerini ifade etmişlerdir. Kendi yeterliliklerini ve annelik becerilerini sıklıkla sorguladıklarını ve kendilerinden şüpheye düştüklerini dile getirmişlerdir.

3.3.2 Annelik becerilerine dair endişeler

Bu alt temada katılımcılar, kendi çocuklarına yetip yetemediklerini sorgulamışlardır. Ebeveyn olarak çocuklarının ihtiyaçlarını karşılayabilmeye dair endişler içinde olduklarını anlatmış, çocuklarının kendi annelik becerileri sebebiyle eksik veya geri kalmasından korktuklarını dile getirmişlerdir.

3.3.3 Çocuğun geleceğine ve bağımsızlık düzeyine dair endişeler

Bu alt temada, katılımcılar, kendileri çocuklarının hayatlarında olmadığında çocuklarının durumlarının nasıl olacağına dair endişeli oldukları ifade etmişlerdir. Çocukların, kendi kendilerine yetebilecekleri bir düzeye gelmesinin onlar için önemini vurgulamışlardır.

3.3.4 Çocukların kaybolacağından veya zarar göreceğinden korkma

Çocuklarının başına kötü bir şey gelmesine dair duydukları endişe, bu alt temayı oluşturmaktadır. Bu korku, çocuğun kaybolması veya bir şekilde zarar görmesiyle ilişkilidir. Çocuğu tekrar bulamama, araba çarpması, akran zorbalığı gibi olası durumlardan bahsetmişlerdir.

3.3.5 Otorite kuramama kaynaklı engellenmişlik hissi

Bu alt temada katılımcılar, çocuklarının onları dinlemediğinden, istediklerini yapmadıklarından ve onları sınırlandırmakta zorlandıklarından bahsetmişlerdir. Böyle durumlarda anneler yorulduklarını ve kızdıklarını dile getirmişlerdir.

3.4 Çocuklarının eksiklerini telafi etme çabaları

Bu üst tema, katılımcıların çocuklarını durumuna dair neler yaptıklarını içermektedir. Alt temalar*, bir baş etme yöntemi olarak otizmle ilgili araştırma yapmak, çocuğun gelişini takip etmek, çocuğun gelişimini akranlarıyla kıyaslama ve çocukla beraber olmadığında çevresini kontrol etmeye çalışma* şeklinde belirlenmiştir.

3.4.1 Bir baş etme yöntemi olarak otizmle ilgili araştırma yapma

Katılımcılar, çocuklarını çevredeki diğer çocuklarla kıyasladıklardan ve bu kıyas sonucu gördükleri farkın kendilerine hissettirdikleriyle ilgili ifadelerde bulunmuşlardır. Katılımcılar, kendi çocuklarının yapamadıkları şeyleri, diğer çocukların yapabildiğini gördüklerini dile getirmiş, buna dair hislerini; üzüntü, burukluk, eziklik gibi kelimelerle anlatmışlardır.

3.4.2 Çocuğun ilerlemesini takip etme

Bu alt temada katılımcılar, çocuklarının eskiye kıyasla gelişimsel olarak ne kadar ilerlediklerini ve ne hızla ilerledikleri hakkındaki düşüncelerini içerir. Katılımcıların yoğun olarak zihinlerini meşgul eden bu konu, kimi katılımcılarda kendini otizm tanısından çıkma umuduyle birlikte kendini göstermektedir.

3.4.3. Çocuğun gelişimini akranlarıyla karşılaştırma

Bu alt temada katılımcılar, çocuklar otizm tanısı aldığı andan itibaren, bu bozukluk hakkında kitaplar okumaya ve araştırma yapmaya başladıklardan bahsetmiştir. Katılımcıların neredeyse hepsi, üzgün olmayı bırakıp bir şeyler yapmaları gerektiklerini düşündüğünü ifade etmiştir.

3.4.4 Çocuklarıyla beraber olmadıklarında onları ve çevresini kontrol etme

Katılımcıları birçoğu çocuklarıyla beraber olmadıklarında kendilerini rahat hissetmediklerinden bahsetmişlerdir. Bu endişe ve kaygı sebebiyle çocuklarıyla ayrı oldukları zamanda neler olduğuna dair her şeyi bilmek istemektedirler. Öğretmen, gölge abla ya da diğer çocuklarından bu zamana dair her detayı anlatmalarını talep etmekte veya birçok durumda çocuklarıyla beraber olmaya çalışmaktadırlar. Sınıf gibi içeriye kabul edilmedikleri ortamda ise öfke duyduklarını ve güvensiz hissettiklerini anlatmışlardır.

3. 5 Çocuklarının hayatındaki yeri idealize etme

Bu üst tema, katılımcıların kendi annelik rollerini nasıl değerlendirdikleriyle ilgilidir. Alt temalar bu annelik kendilerini şu şekilde gördüğünü göstermiştir*: tamamen sorumlu, kendine çocuğu adamış ve çocuğu hayatın merkezi yapmış, kendine zaman ayırmayan, çocuğu iyileştirebilecek tek kişi, seçilmiş olan.*

3.5.1 Tamamen sorumlu

Bu alt temada katılımcılar, çocukların bakımından, çocuklarla ilgili alınacak kararlardan ve genel olarak çocuktan tek ve sadece kendilerinin sorumlu olduğunu dile getirmişlerdir.

3.5.2 Çocuğu iyileştirebilecek tek kişi

Katılımcıların birçoğu, hayatlarının merkezinde çocukları olduğunu ve bütün hayatlarını otizmli çocuklarının ihtiyaçları etrafında planladıklarını ifade etmiştir.

3.5.3 Çocuğu hayatın merkezine koyarak kendini ona adama

Bu alt temada katılmıcılar, kendileri için hiçbir şey yapmadıklarını ifade etmişlerdir. Yalnızca kendileri için ayırdıkları herhangi bir boş zamanın olmadığını, her hangi bir hobi ya da hoşlanacaklar bir etkinlikle uğraşmadıklarını dile getirmişlerdir. Kendileri için bir şeyler yapmak için çocuklarının iyileşmesini beklediklerini ifade eden katılımcılar, bir çok etkinliğin finansal yükünün olduğundan ve bu kaynaklarını çocuklarının eğitimine ayırmayı tercih ettiklerinden bahsetmişlerdir.

3.5.4 Öz bakım ve hobileri erteleme

Bu alt tema, annelerin çocuklarını kurtaracak tek kişi olduklarına dair inançlarını içermektedir. Çocuklarının tüm sorumluluğunu almış olduğunu ifade etmiş katılımcılar aynı zamanda, çocukları ile ilgilen aile bireyleri, eğitimciler ve sağlık elemanlarının katkılarını yetersiz görerek, çocuklarının- kendi ifadeleriyle- düzelmesini sağlayacak yegâne kişi olarak kendilerini görmektedirler.

3.5.5 Yüksek bir güç tarafından seçilmiş kişi

Bu alt tema katılımcıların neden çocuklarının otizmli olduğuna dair yaptıkları atıfları içermektedir. Katılımcılara yaşadıklarını anlamlandırmak için kader, Allah'ın takdiri veya başka bir güç tarafından seçilmek gibi sebepler öne sürmüşlerdir.

3.6 Çocuğun babasına dair çelişkili atıflar yapma

Bu üst tema katılımcıların çocuklarının babasıyla ilgili görüş ve değerlendirmelerini içermektedir. Alt temalar; *aileyi geçindiren, çocuklarla zaman geçiren, iyi eş ve çocukları konusunda yetersiz* şeklinde belirlendmiştir.

3.6.1 Ekonomik güce sahip olan

Katılımcıların, çocuklarının babasıyla ilgili öncelikli olarak yaptıkları yorum, çalışıp para kazanan ve evi geçindiren olmalarıyla ilgilidir. Katılımcılar, eşlerini işlerinde harcadığı zaman ve emeği takdir etmekte ve babanın temel rolünü para kazanarak bir takım olanaklar sağlayan kişi olarak ifade etmektedirler. Çocuklarının eğitiminde paranın önemini vurgulayan katılımcılar, ailelerinde bir rol paylaşımı olduğunu dile getirmişlerdir.

3.6.2 İyi bir baba

Katılımcılar, eşlerinin işlerinden arta kalan zamanında çocuklarıyla vakit geçirdiğini, onlarla oynadığını ve onları gezmeye götürdüğünü anlatmışlardır.

3.6.3 İyi bir eş

Bu alt temada katılımcılar, çocuklarının babalarının iyi bir eş olduğundan, iyi anlaştıklarından ve iyi bir ilişkilerinin olduğundan bahsetmiştir.

3.6.4 Otizmli çocuğun ihtiyaçlarını karşılamada yetersiz

Bu alt temada katılımcılar, otizmli çocuklarıyla ilgili konularda eşlerini yetersiz bulduklarından, babanın konumunun anneninki kadar önemli olamayacağını düşündüklerinden ve annenin konumunu eşsiz ve yeri doldurulamaz bulduklarından bahsetmişlerdir.

3.7 Sosyal yakınlığa göre değişen yansıtmalar

Bu üst temada katılımcıları çevrelerini nasıl gördüklerinden bahsetmişlerdir. .

3.7.1 Yetersiz kurumlar

Katılımcılar, çocuklarıyla ilgili çeşitli yasal düzenlemeleri, kurum ve kuruluşları yetersiz gördüklerinden bahsetmişlerdir. Özellikle devlet kurumları ve eğitmenler çocuklarının gelişimine destek vermesi açısından yetersiz bulunmaktadır. Katılımcılar çocuklarının devam ettiği okuldaki eğitime güvenmediklerini söylemiş, okul müdürü ve öğretmenler gibi kişileri de çocuklarına yetecek kadar donanımlı görmediklerini ifade etmişlerdir.

3.7.2 Yargılayıcı anneler

Çeşitli katılımcılar çevrelerindeki kişilerin onları anlamadığını ve anneliklerini yargıladığını düşündüklerini anlatmışlardır. Bu katılımcılar çocuklarının çeşitli davranışlarından dolayı anne olarak suçlanacaklarını düşünmektedirler.

3.7.3 Bencil öğretmenler

Bu alt temada katılımcılar, çevrelerindeki kişilerin çocuklarının durumuna karşı hassasiyetten yoksun, bencil ve anlayışsız bulduklarını dile getirmişlerdir.

3.7.4 Destekleyici akrabalar

Uzak çevreleriyle ilgili çoğunlukla olumsuz atıfları olan katılımcılar, aile üyeleri gibi akraba gibi daha yakın çevrelerini destekleyici olarak tanımlamış ve onlardan yardım alabildikleri için memnuniyetlerini dile getirmişlerdir.

BÖLÜM 4

TARTIŞMA

Bu bölümde temalardan elde edilen bilgilerin güncel alanyazın doğrultusunda tartışılması amaçlanmaktadır. Ayrıca bu bölüm, bu çalışmanın sınırlılıklarını ve sonraki çalışmalara yönelik önerileri de içermektedir.

4.1 Hamilelik ve doğum sırasında güçlükler yaşama

Lacanyen psikanalizde arzu çok merkezi, çok boyutlu ve bilinçdışı bir mesele olarak çalışılmaktadır (Lacan, 2004). Bir öznenin, bölünmüş nevrotik bir özne olması için annenin arzusu temeldir. Bir annenin arzusunu görüşme bağlamında incelemek güç olmakla beraber, katılımcıların çocuk sahibi olmakla ilgili ifadeleri tartışılacaktır.

Katılımcıların çocuk sahibi olmaya dair deneyimlediklerini ifade ettikleri korku, endişe ve özellikle kaygı; eksiği olan bir özne ve arzulayan bir özne olmanın sonucu olarark değerlendirilebilir (Fink,1997). Lacan'a da göre de, hamilelik kadınlar için çok arzu edilen bir deneyimdir çünkü bir doluluk ve tamlık deneyimi sağlar (2014). Bununla birlikte, doluluk ve tamlık hissi aynı zamanda kaygı uyandırıcıdır çünkü öznenin arzulamaya devam etmesi için eksik kalması gerekmektedir. Bu yüzden hamilelik döneminde kaygı, kadınlar tam da arzularına erişmek üzereyken ortaya çıkar.

Psikanalitik literature ek olarak, doğum öncesi çalışmalar, hamilelik ve doğum sırasında yaşananan bazı tıbbi komplikasyonların otizm riskini artırabileceğini önermektedir (Fombonne,1999).

4.2 Annenin tanı öncesi çocuğun yetiştirme tutumu

Lacanyen psikanaliz anne çocuk ilişkisini "anne timsah" benzetmesiyle tanımlar. Bu, bir öznenin bölünmüş özne olması için, annenin çocuğun dışında bir şeyleri arzulayabilemesi
gerekliliğini içerir (Fink, 1997). Katılımcılar, çalışmada iş hayatlarını özlediklerini, çalışırken kendilerini değerli ve işe yarar hissettiklerini, saygı gördüklerini ve bundan hoşlandıklarını anlatmışlardır. Bu ifadeler, bir arzunun ve bir eksiğin ifadeleri olarak görülebilir. Ancak yine de çocukları otistik bir yapıya sahiptir.

Laznik (1998)' göre, bebek annesinin varlığı ve yokluğunu deneyimleyip arzuya dair temsiller oluşturmaya başlamadan önce, ilk bakışa girmelidir. Annenin bebeğe yaptığı ilk libidinal yatırımla beraber çocuk fallik bir nesne halini alır. Anneden alınan zevk terk edilmeden önce bu evrenin gerçekleşmiş olması gerekmektedir. Melman (2004)'a göre yapısal veya durumsal bir takım sebeplerden dolayı otizmli çocuklarda bu deneyim gerçekleşemez. Daha ileriki çalışmalar anne bebek ilişkisinin ilk altı ayını ele alarak bu kavramları ele alabilir.

Çocuklarının gelişim süreci ile ilgili sorulan sorulara katılımcılar, çocuklarının durumuyla ilgili çevrelerinin uyarı ve önerileri dikkate almadıklarını söyleyerek yanıtlamışlardır. Bu dönemde katılımcıların inkârı bir savunma mekanizması olarak kullandığı ve bu inkârın otistiktik belirtilerin ilerlemesine ve kalıcı bir otistik yapının oluşmasına yol açtığı önerilebilir. Katılımcılar, çocukları otizm tanısı aldığında bu durumu kabul etmekte güçlük yaşamış ve birçok duyguyu deneyimlemişlerdir. Katılımcıların bu deneyime tepkisi ileriki bölümlerde tartışılacaktır.

4.3 Tanı sonrası olumsuz duygular deneyimleme

Çocuklarının aldığı tanıyla ilk defa karşılaştıktan sonra ebeveynler, kaygı, suçluluk, öfke ve yalnızlık gibi birçok duygu deneyimlemektedirler (Worden, 2004). Bu çalışmadaki katılımcılar da kendilerini sıklıkla sorguladıklarını, kararlarından şüphe duyduklarını ve kendilerini suçlu hissettiklerini anlatmışlardır. Suçluluk duyguları yıkıcı içsel dürtülerin bir çıktısı olarak görülebilir (Kübler-Rose ve Kessler, 2005). Yaşadıkları kayba karşı uyanan bu suçluluk aynı zamanda kendi erken dönem gelişimsel evrelerindeki psişik dinamiklerin tekrar harekete geçmesi olarak görülebilir (Klein, 2003).

Katılımcıların çocuklarıyla ilgili yaşadıkları yoğun kaygı ve korku, çocuklarını ve genel olarak çevrelerini kontrol etme çabası olarak kendini göstermiştir. Önceki çalışmalar, bu davranışı, belirsizlik durumu içerisinde kişinin kendisini güçlü hissetme çabası olarak değerlendirmektedir (Pusa et al,2012).

4.4 Çocuklarının eksiklerini telafi etme çabaları

Çocukları otizm tanısı aldıktan sonra katılımcılar hemen harekete geçmek istediklerini ifade etmişlerdir. Üzülmeyi bırakmaları gerektiğini ve bir an önce çocukları için bir şeyler yapmalarının daha önemli olduğunu söylemişlerdir. Bu örnek katılımcılar, yaşadıkları zor duyguları deneyimlemekten kaçındıkları şeklinde yorumlanabilir. Bununla beraber, yeterli bakımı ve eğitimi aldıktan sonra çocuklarının "normal" olabileceği umudunu katılımcılar arasında yaygın olarak görülmüşür.

Yas sürecinin bir parçası olarak görülebilecek bu umut aynı zamanda kendini çocuklarının güvenliği ve iyiliğinden emin olmak için çevrelerini kontrol etmeye dair büyük bir çaba olarak da kendini göstermiştir. Çocuklarıyla olmadıkları her an hakkında bilgi almaya çalışmaktadırlar. Çocukların gittiği okuldan ve eğitim aldığı öğretmenlerden memnun olmayan ve onları yetersiz bulan katılımcılar, derslerde çocuklarına eşlik etmek istemekte, sınıflara kabul edilmediklerinde ise öfke duymaktadırlar. Bu şekilde kişisel endişeleri, korkuları ve genel olarak duyguları ifade edilmemekte ve onları zayıf ve kırılgan bir konuma sokacak bir durumdan kaçınmış olmaktadırlar. Bu yüzden klinisyenler bu kişilerle çalışırken, yaşadıkların deneyimle ilgili altta yatan duygularını konuşmak önem arz etmektedir. Araştırmalara göre annelerin daha uyumlu baş etme yöntemleri edinmelerine yardımcı olmak, onların stresini azaltmakta, hem kendi hayatlarının hem çocuklarının ve ailelerinin hayatlarını iyileştirmektedir (De Gray, 1994)

4.5 Çocuklarının hayatındaki yeri idealize etme

Bu tema katılımcıların anne olarak aldıkları konuma dair yorumlar ışığında ortaya çıkmıştır. Katılımcılar kendilerini sorumluluğun tamamını üstlenen, tek karar verici ve yeri doldurulamaz olarak görmüşlerdir. Çocuğun her şeyi olmanın kaygı uyandırıcı olduğunu ifade etmekle beraber, çocuklarının ihtiyacı olan şeyin bu olduğunu dile getirmişlerdir. Bu açıdan bu katılmcıların anneliğini idealize ettikleri söylenebilir (Freud, 1905). Freud, idealizasyonun, ambivalan hislere karşı bir savunma olarak ortaya çıktığını önermektedir.

Katılımcıların kendini feda eden tutumları çevrenin desteğini almalarında zorluk oluşturma ve kendi ihtiyaçlarını ihmal etmelerine yol açmaktadır. Bu kendini adama durumunun ayrıca çocuklarının durumunu iyileştirmeye dair umutları ve bu umudu gerçekleştirme çabaları ile ilintili olabileceği söylenebilir (Bouchal et al.,2015). Ancak bu umut annelerin kendi hayatlarındaki özgürlüklerin kısıtlanmasına ve kişisel ihtiyaçlarının bastırılmasıyla sonuçlanabilir ((Beng et al., 2013; Gunnarson & Öhlen, 2006; Wong & Chan, 2007).

Çocuklarının otizmli olmasını anlamlandırmaya çalışan katılmcılar genellikle ruhani ya daha yüksek bir gücün varlığına dair inançları kullanmışlardır. Önceki araştırmalar göstermiştir ki, bir kayıpla karşılaşıldığında kişiler baş etme mekanizması olarak ruhani veya dini inaç ve pratikleri kullanabilmektedirler ((Wortmann &Park, 2008)

4.6 Çocuklarının babasına dair çelişkili atıflar yapma

Katılımcılara eşleri hakkında soru sorulduğunda öncelikli olarak onları evi geçindiren ve aileleri için para kazanan kişi olarak tanımlamışlardır. Babalar, aileleri için çok çalışan kişiler olarak takdir edilmektir. Bununla beraber babalar, çocuklarıyla oynayan, onlarla zaman geçiren ve onları gezdiren olarak görülmekte ve takdir edilmektedir. Katılımcılar, eşlerini iyi bir partner olarak görmekte ve tatmin edici bir ilişkiye sahip olduklarını ifade etmişlerdir

Bununla beraber, otizmli çocuklarının yetiştirilmesi ile ilgili olarak katılımcılar, eşlerini yetersiz gördüklerini dile getirmişlerdir. Babalarının çoğu zaman onların yanında olmadığını ve katılımcıların sorumlulukları yüklenmek durumunda olduğunu anlatmışlardır.

Lacan, timsah annenin çocuğu yutmasına mani olan kişinin baba olduğunu ifade etmiştir (Evans, 1996). Babanın yasayı ortaya koyması, anne ve çocuk arasındaki simbiyoz ilişkiyi bozar ve üçgenleşme yaratır. Bu baba işlevidir. Öncelikle simgeseldir ve kendini annenin dilinde gösterir (Lacan, 1957). Çocuk annenin dili doğrultusunda simgesel düzene girer ve bölünmüş bir özne olur.

Babanın yasasını belirleyen şeyin babanın fiziki varlığı veya yokluğu değil, annenin dilindeki işlevidir (Lacan, 2004). Bu katılımcıların dilinde ise baba, yetersiz görülmektedir. Temel ve vazgeçilmez bir rolleri yoktur ve anne kadar önemli olamazlar. Çocukları için onların yeri eşsiz ve doldurulamazdır. Katılımcıların anneliğe dair sahip oldukları idealize inançları çocuklarıyla ikili ilişkilerini sürdürme arzuları dillerinde belirgindir (Freud, 1940). Bu ifadeler babanın ayırıcı rolünün işlevselliğini sağlayamadığını gösterdiği söylenebilir.

4.7 Sosyal yakınlığa göre değişen yansıtmalar

Katılmıcılar aile ve akraba gibi yakın çevrelerini yardımcı ve destekleyici olarak değerlendirmiştir. Güncel literatür, yeterli destek görmenin bu tarz kişilerin sağlığına olumlu katkıda bulunduğunu göstermiştir (Burke et al., 2015; Hauksdottir, Steineck, Fürst, & Valdimarsdóttir, 2010).

Bununla beraber katılımcılar uzak çevrelerine karşı öfke ve kızgınlık hissetmektedirler. Öncelikle devletin kendisini daha sonra hastane, okul gibi kurumları yetersiz olarak atfetmekte ve bu kurum ve kurumlara bağlı kişilerin çocuklarının geri kalmasına yol açtıklarını düşünmektedirler. Devlet, okul, hastane gibi oluşumlar sosyal düzenin bir parçasıdır ve babalık işlevinin ve simgesel babanın bir parçasıdırlar. Yalnızca çocuklarının babası olan eşleri yetersiz görülmemekte, simgesel baba da bir çok açıdan katılımcıların dilinde işlevsiz bulunmaktadır.

Uzak çevrelerinde bulunan kimi insanları bencil ve anlayışsız bulmakta, ebevynliklerinin yargılandığını düşünmektedirler. Çocukları bir ortamda uygun davranmadığında, bu durumun onları kötü duruma soktuğunu ifade etmektedirler. Otizmli bir çocuk büyütmek kişilerde bir çok bilinçdışı çatışmayı tetikleyebilmektedir. Bu çatışmalarla çeşitli savunmalar kullanılarak baş edilir (Vaillant, 1994). Katılımcıların çevreleriyle yaşadığı bu deneyimin bir yansıtma mekanizması olduğu öne sürülebilir. Yansıtma kişiye ait olan ve katlanılması zor olan hisler ve dürtüler bölünür ve karşı tarafa atfedilir. Bu durumda da katılımcıların güçlü olma çabası, kendilerinin bir takıp saldırgan dürtülerinin ve yetersizlik hislerinin diğer kişilere yansıtılmasıyla sağlanma çalışılmış olabilir.

4.8 Çalışmanın sınırlılıkları ve ileriki çalışmalar için öneriler

Bu çalışma, yedi ila on iki yaşları arasında otizm tanısı almış çocukları olan annelerle gerçekleştirilmiştir. Katılımcıların çocuklarının otistik yapıya sahip olduğundan emin olmak için, katılımcılar çocukları ödipal dönemi tamamlamış anneler arasından seçilmiştir.

Katılımcıların güncel deneyimlerine dair derinlemesine bilgi edinmekle beraber, annelerin hamilelik ve yenidoğanla deneyimleri ancak geri dönük sorgulanabilmiştir. Dolayısıyla otistik özelliklerin ortaya çıkmasına ve otistik yapınının oluşmasına sebep olarak değişkenlerle ilgili yorum yapmak güçtür. Literatürde de etiyolojiye dair çelişkili sonuçlar bulunmaktadır(Maino, Viola&Donati, 2009). Bu açıdan, ileriki çalışmaların anne- bebek ilişkisini erken yaşlarda ele alması önerilebilir. Bu çalışma yalnızca anneleri içermekte ve çocukları dâhil etmemiştir. Dolayısıyla, otizm fenomenini anlamak açısından bebeğin aktif konumu ebeveynleri ile ilişkisi içinde incelemek faydalı olabilir.

4.9 Sonuç

Bu çalışma otizmli çocuğu olan annelerin deneyimleri derinlemesine çalışmayı amaçlamıştır. Otistik bir yapının oluşmasıyla sonuçlanan deneyimler geriye dönük tartışılmıştır. Katılımcıların ifadeleri psikanalitik alanyazından yararlanılarak tartışılmış ve babasal işleve vurgu yapılmıştır. Katılımcıların otizmli bir çocuk yetiştirmeye dair deneyimlerinin bulguları çok boyutludur. Suçluluk, kaygı ve öfke yoğun biçimde hissedilirken, katılımcılar yetersizlik duyguları içinde kendini feda etmiş bir moda bürünmüşlerdir. Baş etmek için kontrol ve yansıtma gibi savunmalar kullanmaktadırlar. Klinik açıdan bakıldğında öncelikle annenin dilindeki baba işlevi dikkat çekmekle beraber, katılımcıların deneyimleriyle daha iyi baş etmek için doğru müdahalelere ihtiyaç duyduğu da görülmektedir.

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