A QUALITATIVE STUDY ON THE EXPERIENCES OF MOTHERS HAVING A CHILD WITH DOWN SYNDROME

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PINAR EDACAN KANTEKİN

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submitted by **PINAR EDACAN KANTEKİN** in partial fulfillment of the requirements for the degree of **Master of Science in Psychology, the Graduate School of Social Sciences of Middle East Technical University** by,

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

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

Prof. Dr. Tülin Gençöz
Supervisor
Department of Psychology

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

Examining Committee Members:

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

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

Assist. Prof. Dr. Sinem BALTACI
Yalova University
Department of Psychology

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

Name, Last Name: Pınar Edacan KANTEKİN

Signature:

ABSTRACT

A QUALITATIVE STUDY ON THE EXPERIENCES OF MOTHERS HAVING A CHILD WITH DOWN SYNDROME

KANTEKİN, Pınar Edacan
M.S., The Department of Psychology
Supervisor: Prof. Dr. Tülin GENÇÖZ
Co-supervisor: Assist. Prof. Dr. Ayşen MARAŞ

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The current study aims to deeply understand the experiences of mothers having a child with Down syndrome. Qualitative research methods were employed in this study. Semi-structured interviews were conducted online with 5 mothers who have primary school-age children with Down syndrome. Interpretative phenomenological analysis was used to analyze the data and identify super-ordinate themes. In this thesis, 6 super-ordinate themes emerged, which were (1) the decision of giving birth, (2) enmeshed boundaries with the child, (3) struggle over education, (4) characteristics of the child, (5) the ideal image of the motherhood and (6) mothers' perception of the fathers. These emerging themes were examined in the context of existing literature.

Keywords: Down Syndrome, Mother Having a Child with Down Syndrome, Interpretative Phenomenological Analysis, Psychoanalytic View

ÖZ

DOWN SENDROMLU ÇOCUĞU OLAN ANNELERİN DENEYİMLERİ ÜZERİNE NİTEL BİR ÇALIŞMA

KANTEKİN, Pınar Edacan
Yüksek Lisans, Psikoloji Bölümü
Tez Yöneticisi: Prof. Dr. Tülin GENÇÖZ
Ortak Tez Yöneticisi: Dr. Öğr. Üyesi Ayşen MARAŞ

Ekim 2023, 102 sayfa

Bu çalışma Down sendromlu çocuğu olan annelerin deneyimlerini derinlemesine anlamayı amaçlamaktadır. Bu çalışmada nitel araştırma yöntemleri kullanılmıştır. İlkokul çağında Down sendromlu çocuğu olan 5 anneyle çevrimiçi, yarı yapılandırılmış görüşmeler gerçekleştirilmiştir. Verileri analiz etmek ve üst temaları belirlemek için yorumlayıcı fenomenolojik analiz kullanılmıştır. Bu tezde, (1) doğum kararı, (2) çocukla iç içe geçmiş sınırlar, (3) eğitim konusunda mücadele, (4) çocuğun karakteristik özellikleri, (5) ideal annelik imgesi ve (6) annelerin baba algısı olmak üzere 6 üst tema ortaya çıkmıştır. Bu ortaya çıkan temalar, mevcut literatür bağlamında incelenmiştir.

Anahtar Kelimeler: Down Sendromu, Down Sendromlu Çocuğu Olan Anneler, Yorumlayıcı Fenomenolojik Analiz, Psikanalitik Bakış

To My Dear Little Brother
and My Strong Mother

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CHAPTER 1

INTRODUCTION

The purpose of this thesis is to explain the experiences of mothers with children with Down syndrome. In line with this purpose, topics such as what Down syndrome is, how it is represented in the literature, the mother-child relationship, and having a child with a disability will be discussed. In the first section, what Down syndrome is, which factors play a role in its occurrence, the physical and intellectual characteristics of a child with Down syndrome, and finally, the potential challenges they may experience will be discussed. The second section will cover the studies conducted on children with Down syndrome and their parents. It will cover the nature of the mother-child relationship, what having a child means to mothers, and an evaluation from various psychoanalytic perspectives. The final section describes the experiences of families with a disabled child, what they feel and how they cope.

1.1. What is Down Syndrome?

First chapter of the thesis. Genetic conditions can impact the progression of fetal development and pregnancy, affecting both the mother and the baby (Blackburn, 2013). In a typical situation, all human cells, excluding the reproductive cells (egg and sperm), contain 46 chromosomes (known as the diploid number), comprising of one set of sex chromosomes and 22 sets of autosomes (Blackburn, 2013). Genes, located on chromosomes, play a vital role in shaping the fetus during pregnancy and determining the baby's growth after birth (Diamandopoulos & Green, 2018). Additionally, genes influence various physical traits like eye and hair color, as well as the likelihood of developing diseases later in life (Perkins, 2017).

Genetic disorders result from irregularities in an individual's genetic material, including genes or chromosomes (Jackson et al., 2018). These genetic disorders can be inherited from parents or occur spontaneously due to genetic mutations (Jackson et al., 2018). They have the potential to impact different aspects of a person's health and development, resulting in a diverse range of symptoms and medical conditions (Jackson et al., 2018). There are thousands of known genetic disorders, each with its own unique characteristics and impact on individuals and families, and one of these is Down syndrome (Jackson et al., 2018).

Down Syndrome was initially identified by John Langdon Down in 1866 (Diamandopoulos & Green, 2018). This genetic disorder, also known as trisomy 21, is characterized by the presence of an extra replica of the chromosome 21, either in its entirety or in partial form, as first described by Jerome Lejeune in 1959 (Diamandopoulos & Green, 2018; Sheets, et al., 2011). Although the exact reasons behind the occurrence of Down syndrome and the number of factors involved remain uncertain, it can originate from either parent, regardless of whether the error originated from the mother or father (Perkins, 2017). However, it is recognized that advanced maternal age is the most prevalent risk factor related with Down syndrome (Perkins, 2017). Even though the occurrence of Down syndrome can be influenced by advanced maternal age, it is important to note that there have been instances of mothers younger than 35 who have given birth to babies with Down syndrome (Perkins, 2017). The precise frequency of Down syndrome conceptions is uncertain, but the likelihood of conceiving a baby with Down syndrome varies, ranging from 1 in 1400 for a 20-year-old woman to as high as 1 in 32 for a 45-year-old woman (Diamandopoulos & Green, 2018). Apart from advanced maternal age, heredity is the only other identified risk factor, although this is exceedingly rare and affects only around 1% of all cases of Down syndrome (Perkins, 2017).

There are three different forms of Down syndrome: trisomy 21 or nondisjunction, Robertsonian translocation, and mosaicism (Diamandopoulos & Green, 2018). These conditions arise during the process of meiosis when either the sperm or the ovum fails to separate properly, resulting in an extra copy of chromosome 21 (Diamandopoulos & Green, 2018). As cells divide and reproduce, this additional copy of chromosome 21 is duplicated in every cell (Diamandopoulos & Green, 2018). Robertsonian translocation, which is a rare occurrence accounting for 4% of all cases, happens when the long arm of chromosome 21 turns into attached to another chromosome, typically chromosome 14 (Perkins, 2017). Mosaicism, the least common form, accounts for only 1% of all cases (Perkins, 2017). Mosaicism in Down syndrome is characterized by a post-fertilization process that leads to the formation of two different cell lineages (Diamandopoulos & Green, 2018). In individuals with mosaicism, the tissues and organs consist of a combination of cells with 46 chromosomes and cells with 47 chromosomes (including the extra chromosome 21). Compared to individuals with nondisjunction and Robertsonian translocation, those with mosaicism typically exhibit fewer characteristics of Down syndrome and the extent of these characteristics is thought to vary based on the number of affected cells in the individual (Diamandopoulos & Green, 2018).

Down syndrome is a disorder that can be diagnosed and identified during pregnancy while the baby is still in the womb. There are several different techniques used for prenatal diagnosis. Diamandopoulos and Green (2018) stated the first technique is that during the first trimester, a combined screening test is conducted, which involves both an ultrasound and a blood test. The blood test is typically administered between 9 to 12 weeks of gestation. If the fetus has Down syndrome, the blood test will indicate abnormal levels of certain markers. Around the 12-week pregnancy, a nuchal translucency scan is performed during the ultrasound. This scan evaluates the thickness of the nuchal fold, which is the fluid accumulation at the back of the baby's neck. By analyzing the data from the blood test along with maternal age and the nuchal translucency measurement, the probability of having a baby with Down syndrome can be determined. Another screening test option is the non-invasive prenatal test (NIPT), which requires a small blood sample taken from the mother's arm starting from 9 weeks of gestation. This blood sample is analyzed to detect fragments of DNA from the fetus. The NIPT is highly accurate, with a 99% success rate in determining whether the mother is at risk of having a baby with Down syndrome. The last one is that in the second trimester, the maternal serum screening test, also known as the triple or quadruple test, relies on blood tests conducted between 15 to 20 weeks of gestation (Diamandopoulos & Green, 2018). While prenatal diagnosis is possible, postnatal diagnoses of Down syndrome are also available. A crucial step in diagnosing Down syndrome is the physical examination conducted within the first 24 hours after birth (Bull, 2011). While the clinical presentation of babies with Down syndrome can vary, certain physical characteristics serve as strong indicators (Ivan & Cromwell, 2014). These include a short neck, small ears, a flat nasal bridge, epicanthal folds, brushfield spots, a single palmar crease, and a small mouth with a protruding tongue (ibid.). If the doctor observes enough of these features during the examination and Down syndrome was not previously diagnosed before birth, a blood sample is taken for chromosome evaluation to confirm the diagnosis (Bull, 2011).

Apart from a distinct physical appearance, infants with Down syndrome have a higher likelihood of experiencing various health complications, as well as intellectual and developmental disabilities (Diamandopoulos & Green, 2018). These disabilities can be such as learning difficulties, and delays in speech and language development and they often exhibit delayed overall development and may also face behavioral challenges (Perkins, 2017). According to Powell-Hamilton and Jefferson (2016), Down syndrome, like other conditions caused by chromosomal imbalances, affects multiple systems and leads to both structural and functional abnormalities. Down syndrome is linked to various medical conditions, with the most prevalent ones being cardiac defects, leukemia, gastrointestinal problems, vision and hearing impairments, dental issues, thyroid disease, obstructive sleep apnea, epilepsy, and Alzheimer's disease (Perkins, 2017).

1.2 Down Syndrome in Literature

First chapter of the thesis. Reid et al. (2009) conducted a meta-analysis study. The focus of this study was to examine how pregnant women make decisions regarding antenatal screening for Down syndrome and to identify the factors that impact pregnant women's choices in accepting or declining maternal serum and/or nuchal translucency screening for Down syndrome. In this study, four main themes emerged: destination unknown, to choose or not to choose, the risk is rarely pure and never simple, and treading on dreams. The first super-ordinate theme ‘destination unknown’ includes three sub-ordinate themes: anxiety, views on abortion and perceptions of having a child with Down syndrome. They approached anxiety from the following perspective: they highlighted the stress and worry experienced while waiting for screening results, the difficult decisions related to diagnostic testing, and the belief that anxiety may persist throughout pregnancy even if the results indicate low risk. The issue of whether women perceive screening as an option or not has brought forth the second main theme, which is "to choose or not to choose. It includes two sub-ordinate themes that are the routine nature of screening and expert authority. The notable consequence of women's perspectives regarding the routine nature of screening and the influence of experts was not an increase in choice, but rather a decrease. The interplay between the presentation of screening within a specific context and the emphasis placed on expert authority not only normalized the process of screening but also rendered choice mostly deceptive or illusory. The fact that screening tests are not without risks has influenced women's decision-making process and has brought forth the third main theme which is risk is rarely pure and never simple. Information about risk, contextualizing risk, and risk and diagnostic testing are the sub-ordinate themes. Women made choices regarding screening based on either intricate and inconclusive risk information, leading them to decline the screening, or due to feeling intimidated, leading them to accept it. Furthermore, their personal perceptions of risk played a significant role in their decision-making process. Consequently, women experienced risk in diverse ways, influenced by their unique life experiences and health conditions when approaching the screening process. The last super-ordinate theme is treading on dreams including three sub-ordinate themes: imaging the fetus, just in case and responsible motherhood. This theme describes how women focus on the image of the fetus through ultrasound screening, which makes the pregnancy feel real. It emphasizes the importance of learning whether the baby has Down syndrome as a precautionary measure and ensuring the baby's health to be a responsible mother (Reid et al., 2009).

A similar study has been conducted in Pakistan. Bryant et al. have investigated perspectives on prenatal screening tests and abortion (2011). The objective of this study was to examine the perceptions of Down Syndrome in Pakistan, as well as the attitudes towards testing and the decision to terminate pregnancies affected by this condition. In 2008, this study utilized Q-Methodology to identify various perspectives regarding Down Syndrome. Attitudes towards prenatal testing and the decision to terminate pregnancies affected by the condition were collected through a concise questionnaire. Q-Methodology integrates quantitative techniques and analyses with a more qualitative approach to sampling and interpreting patterns. Participants were instructed to read the statements provided and subsequently rank them on a scale ranging from +4 (strongly agree) to -4 (strongly disagree) in a sequential manner. They were encouraged to engage in discussions regarding the placement of the statements and to document any comments in the booklets. At the end of this study, the authors discussed three accounts: a child with DS is ‘the will of God’ and a valued human being, a child with DS is ‘the will of God’ but a burden to their family and a person with DS is a genetic anomaly in a stigmatizing society (Bryant et al., 2011).

In another qualitative study on the same topic, the focus was on the processes experienced by mothers who received a prenatal diagnosis and made decisions regarding childbirth (Loua et al., 2019). The aim of this study was to investigate the experiences of parents who received a prenatal diagnosis of Down Syndrome and their decision-making process regarding whether to proceed with the pregnancy. This study employed an exploratory research design, utilizing qualitative interviews. The only inclusion criteria were that the participants were parents of a child diagnosed with Down Syndrome before birth, and that the diagnosis occurred after the implementation of national screening guidelines in 2004. As a result, nine couples were selected and interviewed as part of the study. Seven couples participated in the study, and they had the option to choose between joint interviews (involving both the woman and her partner) or individual interviews (involving only the woman). In total, there were five joint interviews and four individual interviews, all of which took place in the couple’s homes. The interviews were semi-structured and aimed to investigate the couple’s perspectives on pregnancy, the diagnostic process, decision-making, and their interactions with healthcare professionals (HPs). The researchers employed thematic analysis to examine the transcribed data and identified recurring patterns and this analysis caused the identification of five themes: expectations, decision’s timing, reasons and concerns, information needs, and interactions with HPs. In the conducted study, there are also some common observations mentioned in addition to the emerging themes. Initially, all the couples experienced grief and sadness after receiving the diagnosis, leading them to undergo a mourning process where they had to relinquish their aspirations for a "typical" child and a conventional family future. Secondly, due to experiencing fertility issues, these five couples regarded this pregnancy as a once-in-a-lifetime opportunity. Thirdly, most of the couples emphasized the general uncertainties of life and highlighted those unexpected things can happen to a child or a family. Therefore, they underlined that Down syndrome is not the worst-case scenario. Lastly, although the families had concerns about the challenges that their child with Down syndrome and existing siblings might face in their lives, they all focused on the positive attributes of the child with Down syndrome (Loua et al., 2019).

In addition to experiences related to receiving a Down syndrome diagnosis during pregnancy and making decisions about childbirth or abortion, there are also studies available that explore what it is like to live with a child with Down syndrome. Durmaz et al. conducted a descriptive study in the Genetics Outpatient Service of the Ege University Hospital in 2010. The study included a group of 100 parents who had children with Down syndrome, aged between 1 and 18 years, participating in a follow-up program. To assess the family characteristics, an interview in Turkish was conducted, consisting of 16 questions. These questions covered topics such as the families' characteristics, their relationships with each other and other individuals, and their attitudes toward the child with Down Syndrome. This study yielded interesting findings concerning families with children with Down syndrome. The key findings can be summarized as follows: Down syndrome was predominantly observed in families with lower socioeconomic status, with mothers often experiencing feelings of guilt and being accused of causing this undesired condition. Overall, the parents expressed happiness with their marriage, and the birth of a child with Down syndrome did not create significant problems. However, the main challenge faced by these families was financial. Additionally, the families perceived that the children with Down syndrome were content living with them and did not disrupt the overall family unity. On the other hand, the mothers took on more responsibilities compared to the fathers. The rate of employment was found to be higher among fathers in the families, which is associated with the expectation that mothers take care of childcare responsibilities while fathers provide for the family's livelihood. It has been observed that 68% of families with a child with Down syndrome have a higher level of morale compared to families with other intellectually disabled children, and it has been noted that the diagnosis of Down syndrome during pregnancy causes greater stress for mothers. In the conducted interviews, mothers blamed themselves for having a child with Down syndrome 2.5 times more than fathers. Mothers were the ones who most frequently mentioned problems such as feeling tired, finding someone to stay with the child, and not getting enough sleep (Durmaz et al., 2010).

Using a qualitative approach, Steffensen et al. (2021) conducted semi-structured interviews with 25 parents who had children aged 4-12 years with Down syndrome. The parents who participated in the study were informed about their child's Down syndrome diagnosis only after the child was born. The objective of this study was to examine qualitatively the daily experiences of parents in families with a child with Down syndrome, with a specific focus on how parents perceive and make sense of their everyday routines and activities. Through reflexive thematic analysis, they identified two themes related to the parents' experiences. The first theme, titled 'Supporting our child,' illustrates how the parents viewed their child as a valuable individual and how this perception influenced their support for the child's development and social interactions. The second theme, titled 'Managing our family life,' highlights how the parents took action to navigate a family life that had become the "new normal." This involved being attentive to the needs of the child, establishing practical and logistical routines in daily life, and finding a balance between being present at home and engaging in activities outside of the home (Steffensen et al. 2021).

Another study investigating life with children with Down syndrome focused on the spiritual aspect of these experiences. Caring for a child with Down syndrome can pose challenges, and spirituality can serve as a dimension that relates to finding meaning in life and serves as a coping resource (Duarte et al., 2022). Spirituality encompasses personal values, is closely connected to the purpose and essence of life, fosters personal growth, facilitates reflection on life experiences, and aids in adapting to new life circumstances. In light of this, Duarte et al.'s study aimed to address the following questions: How is spirituality, as a resource, perceived by the families of children with Down Syndrome? Thematic analysis was conducted on all of these interviews using a deductive approach. The resulting themes were as follows: meaning and purpose in life of children with Down Syndrome; hope and family strength; trust and connection; spiritual practices, the concept of God or other higher Being (Divinity); personal beliefs and values; meeting the needs of love; and contribution to the transformation in life (Duarte et al., 2022). The initial theme discussed how the findings indicated that taking care of children with Down syndrome was seen as a "mission" that needed to be accomplished. People close to these families perceived the parents' caregiving role as a life purpose and referred to them as "very special people" and "chosen parents." The second topic pertained to the circumstances encountered while caring for children with Down syndrome that enhance the unity of the family and foster optimism about the future of their children with Down syndrome. In this study, the situations identified by the participants when expressing their feelings towards family members, the community, and healthcare providers were determined. In the third theme, it was explained that the trust in these individuals stems from their contributions to the care of children with Down syndrome or from the support provided to the participants to enable them to continue with this care. The fourth theme concerning personal beliefs and values focused on participants who have faith in God. They perceived God as a source of courage to confront the challenges of having a child with Down syndrome and believe that He is the one who "provides everything." Some even question, "Why was I blessed with a special child? Why did God choose this path for me? The fifth theme was associated with participants mentioning spiritual practices, such as engaging in religious rituals, prayer, meditation, attending church, and reading the bible. These practices were seen as coping mechanisms to deal with the challenges of having a child with Down syndrome (Duarte et al., 2022).

The theme called "Meeting the Needs of Love" involved segments that referred to individuals who played a role in fulfilling the emotional needs of the participants and/or the child with Down syndrome (Duarte et al., 2022). Caring for a child with Down syndrome enabled participants to acknowledge the positive impact these children have on the lives of others around them. The final theme focused on quotes that highlight the benefits perceived by participants as a result of living with the child, the newfound significance in their lives and family dynamic, and the valuable lessons learned through their caregiving experience (Duarte et al., 2022).

In the literature, most of the studies in this field have been conducted with mothers who have children with Down syndrome. In addition to the scarcity of studies conducted solely with fathers, in the studies involving fathers, there were also mothers included in most of them. Although these studies are referred to as studies with parents, the number of fathers involved was smaller compared to mothers. So, why have these studies mostly been conducted with mothers? In the next section, the mother-child relationship will be discussed.

1.3 Mother and Child Relationship

Mitchell and Black state that “Human beings, in Freud's account, are born at odds with their environment.” (1995, p. 163). From the moment we enter the world, we are not solitary beings. We are immediately engaged in relationships with others, primarily with our parents during the early years of our lives. The connection between a child and their parents holds significance for future relationships, as the manner in which we interact with our parents and communicate with others often exhibits similarities (Sarup, 1992). Therefore, many researchers have focused on individuals' relationships with their parents, especially the relationship between mother and child. The bond between a mother and child originates within the imagination of the hopeful mother well before the actual conception of the baby (Pubic & Dapic, n.d.). Expectant mothers frequently envision their future child during pregnancy, contemplating their gender, physical attributes, emotional qualities, and the profound connection they will develop and cultivate after birth (ibid.)

1.3.1 Psychoanalytical View of Mother and Child Relationship

The psychoanalytical perspective on mother-child relationships holds vital significance within the field of psychoanalysis, a psychological theory and therapeutic approach established by Sigmund Freud and later elaborated on by other psychoanalysts (Yaacob, 2006). This viewpoint posits that the initial bond between mother and child serves as a fundamental model for all subsequent relationships and exerts a substantial influence on an individual's psychological growth (Yaacob, 2006). Therefore, in this study, the perspectives of some psychoanalysts on the mother-child relationship will be presented.

1.3.1.1 Freudian Theory

Based on his sessions with patients, Freud believed that the current conflicts and symptoms of his patients were invariably linked to events in early childhood (Mitchell & Black, 1995). The person with whom the child interacts the most during early childhood is typically the mother. To understand the mother-child relationship in

Freud's theory, it is necessary to mention certain concepts and developmental processes.

1.3.1.1.1 Oedipus Complex

The focal point of Freud's developmental theory revolved around the concept of the Oedipus complex (Mitchell & Black, 1995). Freud defined the Oedipus complex as a set of unconscious desires, both affectionate and hostile, that an individual experiences towards their parents. Within this complex, the subject develops a desire for one parent, leading to a sense of rivalry with the other parent (Mitchell & Black, 1995). The Oedipus complex arises during the child's third year of life and diminishes by the fifth year (Evans, 1996). According to Freud, the resolution of the Oedipus complex materializes “through the threat of castration anxiety” (Mitchell & Black, 1995, p. 41). Freud asserted that any psychopathological structures could be attributed to a disruption or dysfunction within the Oedipus complex (Mitchell & Black, 1995).

1.3.1.1.2 Castration Anxiety

The castration complex, within Freudian psychoanalysis, represents a stage of psychosexual development (Evans, 1996). In 1908, Freud initially introduced the castration complex, proposing that when a child becomes aware of the anatomical disparity between genders, particularly the presence or absence of a penis, they may infer that the difference stems from the removal of the female's penis (Freud, 1908c). Initially, the child holds a belief that everyone possesses a penis; therefore, the castration complex represents the pivotal moment when a previous childhood theory is supplanted by a new belief, namely that females have undergone castration (Evans, 1996). The outcomes of this emerging theory regarding infancy have distinct effects on boys and girls. In the case of boys, they experience fear that their father will remove their own genitals (castration anxiety). Conversely, girls perceive themselves as already lacking genitals, which they believe occurred through their mother's actions (castration by the mother). The child relinquishes their sexual desires for their parents and identifies with the rival parent because of castration anxiety (Evans, 1996).

This is the initial occurrence of the concept of the object in Freud's work, followed by the subsequent exploration of the ‘uncanny absence of the penis’ (Lacan, 1957;

Hendrickx, 2017). According to Freud, the object is something that is lost, and its retrieval involves searching for it (Lacan, 1957). However, the object that is eventually found is not the exact object that was sought after. This leads to what Freud refers to as an "impossible repetition."(Lacan, 1957, p. 6). From this, we can infer that the object that is newly discovered is not and will never be the exact object that was originally being sought. Due to her assumption that she has been castrated by her mother, the absence of a penis becomes a lost object, causing the girl to continue searching for this lost object throughout her life (Evans, 1996). She tries to negate or make up for this by compensating a child as a substitute for the penis, a phenomenon known as penis envy (ibid.). This means that for a woman, a child can serve as a substitute for the object she believes she has lost, and she may perceive herself as being complete once she has the child.

1.3.1.2 Mahler’s Theory

According to Margaret Mahler, a Hungarian psychoanalyst, drawing attention to the fact that newborns and young infants are born "unadapted" to the external world, she argues that the biological birth of a human offspring does not coincide with their psychological birth (Pubic & Dapic, n.d.; Vahip, 1993). Mahler defines psychological birth as the process of becoming a separate individual and, at the most primitive level, acquiring one's own identity (Vahip, 1993). She likens the young baby to a psychotic child, stating that neither has undergone their psychological birth (Mahler, 1968). In the case of the young baby, this process has not yet occurred, while for the psychotic child, it has been interrupted and not successfully achieved (Mahler, 1968).

The initial period from birth until the second month of life is referred to as a normal autistic phase (Pubic & Dapic, n.d.). During this stage, the infant perceives no distinction between the external world and their internal reality, or between themselves and their surroundings (ibid.). In this period, the mother's care and attention protect the newborn from being overwhelmed by internal and external stimuli (Vahip, 1993). Towards the end of the second month, the child starts to develop a greater awareness of their environment, particularly focusing on the mother who provides nourishment and care, fulfilling their needs (Pubic & Dapic, n.d.). Gradually, the child begins to associate the visual features of the mouth, nose, and eyes with feeding, and they find comfort in the presence of a human face when hungry, even before receiving food, based on their recollection. The symbiotic relationship between mother and child is marked by the child's smile directed towards the mother. Following the period of symbiosis, during which the child perceives themselves and their mother as a unified entity, which, according to Margaret Mahler, typically persists until around six months of age, the phase of separation-individuation phase (Pubic & Dapic, n.d.). The differentiation subphase is the period between the fifth and ninth months. During this time, the infant exhibits alertness, continuity, and goal-directed behavior (Vahip, 1993). This behavior is a behavioral sign of the child "breaking out of its shell." When the baby individuates enough to recognize and identify its mother's face, it begins to visually and tactually explore the faces of other people and reacts to strangers (Vahip, 1993).

The baby compares the stranger's face both with its mother's face and the internal image of its mother (Vahip, 1993). During this early phase of separation-individuation, babies take their first steps away from their mother's embrace in a physical sense. However, at the same time, they try to stay as close to their mother's side as possible. The practicing subphase is between the ninth and fifteenth months. In the early practicing subphase, the child exhibits the first signs of physical distancing from the mother, such as crawling, pulling up to stand, climbing, and attempting to walk while holding on to support. In the practicing proper subphase, the child has begun to walk freely on two feet. The nature of the practicing subphase depends not only on internal factors but also on the mother's attitude. Some mothers encourage practice, independence, and autonomy. Others, however, create obstacles, preferring to maintain a close symbiotic relationship (Vahip, 1993).

1.3.1.3 Winnicott’s Theory

Donald Winnicott, an English pediatrician and psychoanalyst, coined the term "primary maternal preoccupation" to describe an intensified state of sensitivity that emerges over time, particularly towards the end of pregnancy (Pubic & Dapic, n.d.). This heightened state continues for several weeks after childbirth before gradually diminishing (ibid.). During the final trimester of pregnancy, the mother undergoes a profound biological and evolutionary preparation for her role (Mitchell & Black, 1995). Her natural focus on the baby leads to her being fully engaged with the growing life inside her, which results in the baby crowding her internal organs, affecting her mobility, digestive and eliminative processes, and even her ability to breathe. The concluding phases of pregnancy symbolically represent and serve as a direct preparation for the mother's provision of an environment in the early months of life that fosters the development of the infant's sense of self (Mitchell & Black, 1995).

According to Winnicott, the way infants experience the initial months of life is crucial for their development as individuals (Mitchell & Black, 1995). The environment provided by the mother plays a determining role in this outcome. From Winnicott's perspective, disorders related to the false self were considered as "environmental deficiency disease” which means a type of psychopathology where the very essence of subjectivity and the quality of being a person are somehow disrupted or disordered. When creating the nurturing environment for the infant, the mother experiences a shift where her own subjectivity, personal interests, rhythms, and concerns gradually recede into the background. She adjusts her movements, activities, and even her very existence to accommodate the wishes and needs of the baby (Mitchell & Black, 1995). Her undivided attention is solely focused on the baby, to the extent that she can recognize every movement even from another room (Pubic & Dapic, n.d.). She appears unconcerned about her own personal needs such as sleep or eating alone; only the well-being of the baby holds significance to her (ibid.). The mother's presence when required is of utmost importance, but it is equally important for her to step back when her presence is not necessary. Winnicott describes this state of mind as a ‘good enough mother’. (Mitchell & Black, 1995). In doing so, she establishes what Winnicott referred to as a "holding environment," a space both physical and psychological, in which the infant is protected without being consciously aware of it. This lack of awareness sets the stage for the emergence of subsequent spontaneous experiences (Mitchell & Black, 1995). In ideal circumstances, the mother gradually becomes more attentive to her own comforts, concerns, and personal sense of identity (Pubic & Dapic, n.d.). As a result, her response to her baby's needs and gestures may start to become slower or less immediate (Pubic & Dapic, n.d.).

1.3.1.4 Lacanian Theory

Upon the child's birth, they are in a state of vulnerability and rely on someone, often the mother, to provide nourishment and comfort (Owens & Almqvist, 2018). During this phase, the child is unable to differentiate between themselves and the external world, perceiving the mother as an extension of themselves, an inseparable part (Fink, 1997). The child forms representations of themselves through the mother's gaze. In other words, the mother's gaze assists the child in understanding their own identity (Fink, 1997; Hook, 2006).

1.3.1.4.1 Dual Relation Between Mother and Child

Lacan defined the fusion-like relationship that develops between the mother and the baby immediately after birth as "being in the imagery" (Hook, 2006). Lacan emphasizes the importance of understanding the concept of the phallus in conceptualizing this strong bond between the mother and the newborn. Freud posits that children, regardless of their sex, attach significant importance to the penis, and the realization that some individuals do not possess one has significant psychological consequences (Evans, 1996). However, the term "phallus" is infrequently mentioned in Freud's work, and when it is used, it is often synonymous with "penis” (ibid.). Lacan tends to favor the term "phallus" over "penis" to underline the psychoanalytic theory's focus on the role of this organ in fantasy rather than its biological reality. Therefore, Lacan typically reserves the term "penis" for referring to the physical organ itself, while using "phallus" to address its imaginary and symbolic functions (Evans, 1996).
In addition to the inherent vulnerability of the child in the mother-child relationship, Freud discusses the absence felt by the mother and notes that when girls become aware of the absence of a penis, they experience a sense of losing something valuable, in Lacanian term ‘lack’, prompting a desire to seek symbolic compensation for this absence through having a child (1924d; Fink, 1997). Following Freud, Lacan asserts that the child represents the substitution of the symbolic phallus for the mother who is the lack (Evans, 1996). Mother constantly tries to find what is missing, but none of the objects she finds can replace the original lost object, and she continues to search for the object she believes she has lost, what is lack (Hendrickx 2017). The mother's effort to replace this lack with her child and the child's dependent state after birth contributes

to the formation of this symbiotic relationship. The child as a substitute is unable to fully fulfill the mother’s desire, and as the mother's desire for the phallus endures, the child becomes aware that the mother's desire is beyond him or her (Hendrickx 2017).

Rather than framing this relationship solely as a dyad, Lacan characterizes the connection between the mother and child as a triad because there exists another element, namely the imaginary phallus, which functions as an imaginary object between the mother and the child (Owens & Almqvist, 2018; Evans, 1996).

Lacan describes the relationship between mother, child and imaginary phallus as an imaginary triad. (1957). The presence of a third element in this triad, as referred to by Lacan, arises from the mother's indication that her desire extends beyond the child (Owens & Almqvist, 2018). Through the dynamics of her absence and presence, it becomes evident that the mother's desire is directed toward the imaginary phallus (ibid.). The mother possesses a desire for this imaginary object, prompting the child to seek identification with this imaginary phallus in order to fulfill their mother's desires (Evans, 1996). The resolution of the Oedipus complex requires the child to relinquish the attempt to embody this imaginary phallus. It is necessary for the child and the mother to move beyond this state (Evans, 1996). The father is the figure who has the potential to prevent these particularities and influence the relationship between the mother and the child (Fink, 1997).

1.3.1.4.2 Name-of-The-Father

From the early stages of his work, Lacan places significant emphasis on the father's role in psychic structure (Evans, 1996). In his 1938 article on the family, Lacan ascribes great significance to the Oedipus complex due to its incorporation of two seemingly conflicting functions within the figure of the father: the protective function and the prohibitive function. At this stage, Lacan's depiction of the Oedipus complex aligns with Freud's, with the only distinction being his emphasis on its historical and cultural relativity (Lacan, 1938). In the 1950s, Lacan initiated the development of his unique understanding of the Oedipus complex. While he continued to acknowledge the Oedipus complex as the primary complex within the unconscious, he diverged from Freud on several significant aspects (Evans, 1996). The most noteworthy distinction is that, according to Lacan, the subject consistently desires the mother, while the father always assumes the role of the rival, regardless of the subject's gender. Therefore, the crucial role in the Oedipus complex is attributed to the FATHER, who serves as the important element that transforms the relationship between the mother and child into a symbolic structure. The symbolic father is also known as the Name-of-the-Father (Evans, 1996).

The father assumes the role of the law's embodiment, yet it is crucial for him to possess credibility in this symbolic capacity in order to be acknowledged as the 'nom-du-père' (name of the father) (Ruhs & Bernstein, 2015). The father mentioned here is not necessarily a physically present real father, but rather a symbolic father who fulfills the paternal function, which is essentially the imposition of the law and the regulation of desire within the Oedipus complex (Lacan, 1957; Fink, 1997).The terms 'Nom' (name) and 'Non' (no) share similar sounds, merging the father's function into a single word as the one who must assert his authority by using his own name when refusing the mother/child phallic relationship (Ruhs & Bernstein, 2015). In other words, it involves intervening in the imaginary dyadic relationship between the mother and child to establish a crucial "symbolic distance" between them (Lacan, 1957). The father keeps the child at a certain distance from the mother by preventing the child from becoming one with the mother or remaining with her indefinitely (Fink, 1997). This is achieved by either obstructing the child's attempts to merge with the mother or prohibiting the mother from obtaining specific satisfactions from the child, or both at the same time (ibid.).

The function of the father involved in the mother-child relationship may not be sufficient on its own because it is also necessary for the mother to accept the father's "no" and law (Fink, 1957; Ruhs & Bernstein, 2015). In other words, the Name-of-the-Father should function as an element within the discourse of the mother and it is necessary for the mother to involve the Name-of-the-Father in her dyadic relationship with the child (ibid.).

So far, the theories mentioned have discussed the relationship between a child and their mother in the context of a physically and mentally typical child's development. But what happens when the child has a disability? What experiences do families go through? The next section will focus on the experiences of families with a disabled child.

1.4 Having a Disabled Child

The World Health Organization has provided a definition for disability, stating that it refers to the incapacity or disadvantage that hinders a person's ability to lead a lifestyle that is considered typical for their age, gender, and social and cultural context (2007). Similarly, the American Health Association defines a disabled child as a child who is unable to engage in play, learn, or perform activities that are typically expected at their age (Sen & Yurtsever, 2007). In other words, it refers to a child who is unable to utilize their complete physical, mental, and social capabilities due to various reasons. Caring for children with disabilities requires unique attention and support due to their specific care requirements. These children often rely on others for assistance with their daily activities, so families with disabled children may face challenges in providing adequate care (Sen & Yurtsever, 2007). The disability of a child has a significant impact on the entire family system, affecting its different functions (Fereidouni et al., 2021). As a result, the family's unity and structure may be compromised, leading to adjustments in roles, performance, and adaptability; and these changes can have a deep effect on the overall well-being of the family (Sen & Yurtsever, 2007; Fereidouni et al., 2021).

1.4.1 Emotional Reactions of Parents

Upon receiving the news of their child's disability, parents go through a range of emotions. Having a child with a disability can evoke emotions such as guilt, blame, frustration, and a sense of being left out (Fereidouni et al., 2021). Ultimately, these emotions may manifest as grief or depression (ibid.). These emotional responses can be categorized into three primary groups which are primary, secondary, and tertiary reactions (Kearney & Griffin, 2001; Sen & Yurtsever, 2007). Primary reactions include shock, denial, suffering, and depression; secondary reactions include feelings of guilt, indecision, anger, and shame; tertiary reactions include bargaining, acceptance, and adaptation. According to Sen and Yurtsever (2007), the first reaction that parents feel when they learn that their children are disabled is being shocked. It arises from the fact that their family is confronted with an unexpected situation for which they were unprepared. This state of being is typically marked by tears, a lack of immediate reaction, and a sense of powerlessness. Certain parents struggle to acknowledge or accept their child's disability. The denial, which is a coping mechanism, arises from the fear of confronting something unfamiliar (Sen & Yurtsever, 2007). Parents, especially the woman, are forming a cognitive image of their child before the child is born (von Mohr et al., 2017). When parents have a child with a disability, it entails the shattering of their aspirations and expectations for an ideal child (Sen & Yurtsever, 2007). The suffering in such situations is in a class with the grief experienced after losing a loved one. It serves as a catalyst for the family to come to terms with having a disabled child. Depression, however, emerges towards the conclusion of this process of suffering. Feelings of guilt typically arise when parents believe that they are responsible for their child's disability or perceive it as a divine punishment for their past mistakes. While certain parents can swiftly adjust to the reality of having a disabled child, others struggle to do so. Uncertainty regarding the situation can lead to family members blaming each other or neglecting their responsibilities. Anger can significantly impede parents from accepting their disabled child. It typically manifests in two distinct ways. The first type involves parents questioning, "Why us?" This form of anger is commonly considered a natural and healthy reaction. However, the second type occurs when anger is directed at someone who is not responsible for the issue at hand. During the phase of acceptance and adaptation, the family endeavors to familiarize themselves with the disabled child, comprehend their challenges, and seek solutions. Adaptation emerges as an active extension of the acceptance phase. The adaptation process is greatly influenced by the individual traits of both parents and the child. It commences once the family acknowledges that they cannot alter the reality of having a disabled child (Sen & Yurtsever, 2007).

1.4.2 Challenges of Having a Disabled Child

Parents of typically developing children have the duty to fulfill their child's needs and create a suitable environment for their healthy growth and development (Barbosa et al., 2008). Conversely, parents of disabled children bear additional responsibilities alongside these obligations, such as teaching specific skills and providing physiotherapy (Sen & Yurtsever, 2007). Consequently, parents of disabled children require extra financial resources and time to fulfill these additional demands (Barbosa et al., 2008). Furthermore, due to the potential need for one parent to assume full-time care of the disabled child, that parent may have to cease their employment (Sen & Yurtsever, 2007). It has been observed that a larger proportion of mothers compared to fathers take on the primary caretaker role for their disabled children. As a result, those who are compelled to quit their jobs are predominantly mothers (Sen & Yurtsever, 2007). When one of the parents is unable to work due to the increased financial and emotional burden of caring for a disabled child, it can become an overwhelming burden that economically strained families may find difficult to manage (Şimşek et al., 2015).

Barbosa et al. (2008) reached two outcomes in their research. One initial observation was that the need for care extended beyond the child to encompass the entire family. Another observation was that the mother played a central role in family dynamics and the care of the child. She experiences the repercussions and social exclusion due to her child's disability and endures the inquisitiveness expressed through stares, comments, and behaviors when she and her child are present in various environments she visits. She notices a lack of engagement and the absence of essential support from professionals, which are vital for her adjustment to the situation and the implementation of appropriate actions related to child care Barbosa et al. (2008). Right from the start, parents who are caregivers require precise information regarding their child's health and medical condition (Morris et al., 2020). They need to comprehend what it entails and its implications. Moreover, they necessitate continuous support to enhance their comprehension, enabling them to make well-informed decisions regarding treatments and therapies (Morris et al., 2020). Research conducted on this topic reveals that healthcare professionals have been found to be insufficient in offering the necessary support and guidance to families during this highly distressing period (Sen & Yurtsever, 2007). One possible explanation for the limited number of families receiving external support could be the insufficiency of social assistance provided to families of disabled children and the absence of institutional care options that cater to home-based care for disabled children and their families in Turkey (Sen & Yurtsever, 2007).

1.4.3 Coping Styles

Despite the mother's efforts to seek support from healthcare professionals during this challenging period and to acquire the necessary skills for better caregiving, she can encounter a lack of available resources (Barbosa et al., 2008). The mother seeks some form of justification or explanation as to why this situation has befallen her, expressing concerns about the precise cause of the disability. The mother's anguish and personal journey tempt the quest for answers from a spiritual perspective. Through religion, they discover assistance that aids in their comprehension and enables them to confront and accept the truth (Barbosa et al., 2008). Research on coping primarily relies on empirical evidence, employing methods such as measurement and correlation (Eisen et al., 2008). Coping, as defined by psychologists, encompasses the various approaches individuals employ to either adapt or struggle in the face of challenging circumstances (Hood, 2012). These studies consistently indicate that religion can offer a valuable set of beliefs that allow individuals to reframe negative experiences in a positive manner (Eisen et al., 2008; Hood, 2012). A crucial aspect of religious coping revolves around the way individuals perceive their God (Hood, 2012). Possessing a benevolent depiction of God serves as a potent mechanism for finding purpose and accessing a source of solace and support during challenging periods (Hood, 2012).

According to Freud, religions were proposed as a means of safeguarding oneself from suffering through a ‘delusional remolding of reality’ (Freud, 1930a). From this perspective, religion serves as a means to assist individuals in bearing the weight of their social identities (Malone et al., 2000). In both religion and psychoanalysis, individuals believe they know "what" has occurred to them, typically experiencing a sense of loss. However, they are uncertain about the reasons behind "what" and its underlying causes (Malone et al., 2000). Religion emerges during the early phases of human development when individuals are unable to rely on their reasoning abilities to navigate external and internal forces (Fromm, 1950). Instead, they must either suppress or manage these forces with the aid of alternative emotional influences (Fromm, 1950). Lacan suggests that humanity will find a remedy for psychoanalysis by immersing it in meaning, specifically religious meaning (Richardson, 1992). This immersion would effectively suppress the symptoms, allowing people to overlook its shortcomings and disregard what is ineffective. Lacan's mention of "repressing the symptom" suggests that integrating religious meaning would act as a method to suppress or conceal the symptoms that psychoanalysis aims to uncover and address. This implies that when individuals concentrate on religious explanations or ideologies, they may shift their focus away from the fundamental psychological causes of their challenges or distress. The expression "so as to be able to ignore what does not work" implies that Lacan suggests that through immersing psychoanalysis in religious meaning, individuals can conveniently avoid facing the aspects of psychoanalysis that may be ineffective or lack (Richardson, 1992).

The way individuals cope can influence parental stress and reduce the occurrence of adverse outcomes such as depression, social isolation, and difficulties in spousal relationships (Javadian, 2011). As mentioned above, while religion is a commonly used coping style, it is not the only style. Parents who have children with disabilities require support in order to adapt and navigate the lengthy and challenging journey of caring for their children (Javadian, 2011). This support can come from relatives outside the nuclear family or from social connections (Lin et al., 2008). Parents actively seek and provide guidance and solace from sources beyond their immediate family circle, such as their coworkers, friends, and healthcare professionals. Support groups provides parents with various advantages, which include offering a platform for discussing challenges, exchanging coping strategies and achievements, connecting with other parents facing similar situations, and aiding in coping and stress reduction. (Lin et al., 2008).

1.5 The Purpose of The Study and Research Question

The purpose of this study is to examine the experiences of mothers with children who have Down syndrome. Based on the information provided above, when we look at the theories of mother-child relationships, the impact of this relationship on the child is generally discussed, while its effect on the mothers is less frequently mentioned. However, when it comes to having a disabled child, studies have primarily focused on the experiences of parents as a couple. Although there are numerous qualitative and quantitative studies on this topic, psychoanalytic interpretations are rarely encountered in the literature. Therefore, this study focuses on the question, "What are the experiences of mothers having children with Down syndrome?" Due to the nature of the question, a qualitative study has been conducted. The next section will focus on the qualitative research methodology.

CHAPTER 2

METHODOLOGY

This chapter describes the methodology of the current study. Firstly, information regarding the qualitative research method will be provided along with the reasons for choosing a qualitative method. A detailed description of the study participants, the sampling method, the data analysis, and the trustworthiness of the study will be provided next.

2.1 Qualitative Research

For several years, traditional experimental psychology predominantly used quantitative methods based on a theoretical model. This model involved testing theories by creating hypotheses from them, which could then be verified through experiments or observations. The researcher aimed to disprove or falsify the theory by eliminating inaccurate claims, which was considered a way of approaching the truth (Pietkiewicz & Smith, 2014). However, there are some critiques that could be directed towards quantitative studies include: the tradition of hypothesis testing not encouraging the emergence of new theories and phenomena; statistical relationships established between quantitative variables overlooking the intermediate processes; reducing individual differences to group averages; the researcher's assumption of objectivity masking existing biases; and limitations in the data collection process (Pietkiewicz & Smith, 2014; Tanyaş, 2014). In this way, qualitative research methods have been gaining prominence, which rely on a different epistemological perspective. (Pietkiewicz & Smith, 2014; Tanyaş, 2014).

As a result of its reactive relationship with the quantitative tradition, qualitative research has developed an internal structure in which it critiques and opposes it, especially in the early periods. Qualitative researchers typically prioritize the exploration of meaning, focusing on how people interpret and give significance to the world and their experiences. They argue that the process of interpretation cannot be considered independent of the subject and context and their goal is to comprehend the subjective nature of individual experiences and to gain insight into what it is like to go through specific situations or conditions (Willig, 2013; Tanyaş, 2014). Meaning-making is the primary focus of qualitative researchers, such as how individuals interpret and interpret the world around them, their experiences, and the meanings they ascribe to phenomena. Their interest lies in the quality of the experience rather than establishing causal relationships (Pietkiewicz & Smith, 2014). This approach allows participants to express themselves more freely, resulting in a more profound research process.

2.2 Interpretative Phenomenological Analysis

Husserl's work highlights the significance of studying subjective experiences and how we perceive them (Smith, Flowers & Larkin, 2009). Heidegger, Merleau-Ponty, and Sartre expand upon Husserl's ideas and present a view of humans as being deeply connected to and impacted by the world around them. They emphasize the importance of our relationships with objects, culture, and language, as well as the projects and concerns that shape our experiences (Smith, Flowers & Larkin, 2009). The goal of Interpretive Phenomenological Analysis (IPA) is to understand the phenomenon under study from the perspective of individuals who have experienced it firsthand. IPA is entirely focused on individual perceptions and narratives and seeks to investigate experience from the perspective of the "insider" (Tanyaş, 2014). The IPA approach has the key characteristic of being idiographic, meaning that it focuses on the analysis of individual cases or experiences.

Furthermore, IPA is phenomenological, which means that it emphasizes how individuals experience and make sense of the world around them rather than trying to establish an objective reality that exists independently of human perception (Tanyaş, 2014). This approach involves situating participants within their specific contexts, exploring their personal perspectives, and conducting a detailed examination of each case before making more general claims (Smith, Jarman & Osborn, 1999; Smith, Flowers & Larkin, 2009).

The IPA method is effective when studying subjective topics and does not disregard the researcher’s subjective perspective. Rather, it takes the researcher's personal involvement into account, acknowledging their subjective role in the research process. The unique interaction between the researcher and participants is also a significant aspect of this subjectivity (Smith, 2004). The other primary theoretical foundation of IPA arises from hermeneutics, which pertains to the study of interpretation, serving as the underlying framework for understanding (Smith, Flowers & Larkin, 2009).

This study investigates the subjective experiences of mothers who have children with Down syndrome are, so qualitative research is more suitable for investigating these subjective experiences. Interpretative phenomenological analysis (IPA) was selected for this study among several qualitative approaches because it allows for an in-depth examination and enables unexpected themes to emerge (Barker, Pistrang, & Elliott, 2002). Furthermore, IPA recognizes the subjective influence of the researcher.

2.3 Participants and Sampling Method

Following IPA guidelines, this study utilizes purposive sampling with a homogeneous sample (Smith, Flowers & Larkin, 2009). The participants were mothers who had a child with Down Syndrome who was attending primary school. The age of the children is between 7 and 9 years old. The announcement of the study was made through social media tools such as Instagram and Facebook, and 5 mothers volunteered to participate in the study. As part of the IPA approach, a small sample size allowed for deeper analysis of the mothers' subjective experiences within their specific contexts (Smith, Flowers & Larkin, 2009). Ethical permission was obtained from the ethics committee of the Middle East Technical University. Participants were provided with the informed consent form both written and verbally at the beginning of the study. To protect participants’ privacy, letters were used in the research.

2.4 Procedure

The study questions were developed in consultation with the research team involving the researcher and two advisors. Semi-structured interviews with open-ended questions were conducted to collect data (see APENDIX A). The interviews were conducted online via Skype and Zoom. The interviews lasted approximately 60-90 minutes. The study promoted free expression among participants and communicated that they had the freedom to withdraw from the research if they felt uneasy. The interviews were recorded in audio format and later transcribed. In order to maintain anonymity, participants' names were replaced with letters, and the data collection process took nearly two months.

2.5 Data Analysis

The conversations were recorded on audio and later converted into written form. To initiate an IPA analysis, the initial stage is to carefully go through the data multiple times. The analyst keeps a receptive perspective and records any noteworthy information present in the transcript. In order to adhere to its idiographic approach, IPA necessitates that the analyst analyze the initial case comprehensively before moving onto the subsequent case (Smith, Flowers & Larkin, 2009). Based on this information, the analysis process began with reading the first case, and while reading, everything that came to mind was noted on one side, while the emerging themes were written on the other side. The existing themes were arranged and categorized as superordinate and subordinate themes. Once the analysis of the first case was completed, the same process was used to analyze the second case. After completing the analysis process, a cross-case analysis was conducted to compare and link all the identified themes. The research team, consisting of the researcher, her advisor, and her co-advisor, read the transcripts reviewed and verified the themes that emerged. The superordinate themes were *the decision of giving birth, enmeshed boundaries with the child, struggle over education, characteristics of the child, the ideal image of the motherhood and mothers' perception of the fathers.*

2.6 Trustworthiness of The Study

The qualitative researcher takes into account several specific issues such as social validity, subjectivity, reflexivity, adequacy of data, and adequacy of interpretation (Morrow, 2005). Social validity emphasizes the significance of authenticity and societal worth in social science research. It relates to how qualitative research addresses subjectivity, as all research has some level of researcher bias. Qualitative methodology aims to investigate data without imposing constraints or limitations on it (Morrow, 2005). Various terms such as "bracketing," "self-monitoring," and "rigorous subjectivity" have been used to describe methods of dealing with subjectivity. To manage subjectivity in the research, qualitative researchers achieve several crucial concerns and one of them is reflexivity, which describes the act of an individual revisiting and reflecting on their own involvement in shaping a particular comprehension or carrying out an action. (Morrow, 2005; Fischer, 2009). Qualitative research employs various tools such as being personally connected to the data, being impacted by it, and recognizing connections. Through reflexivity, researchers can be more receptive to the data by being fully aware of how it intersects with their lives (Fischer, 2009). Ensuring the adequacy of data involves taking measures to ensure proper sampling, sufficient data collection, and obtaining adequate evidence for the research as a whole. Qualitative sampling is always purposive sampling, where the selection of participants is deliberate to obtain the most informative data possible. The process is also criterion-based, meaning specific criteria are used, such as age, demographics, or experience of a particular phenomenon, based on the research questions (Morrow, 2005). Apart from ensuring the adequacy of data, ensuring adequacy of interpretation during the stages of data analysis and interpretation is crucial to complete the requirements for trustworthiness (Morrow, 2005).

2.6.1 Self-Reflexivity

The inspiration for my research on this subject originates from my personal experience. I also have a sibling with Down syndrome, who is currently 15 years old. Unlike the mothers in the study, my mother learned that my sibling had Down syndrome during her pregnancy, but it was a risky period for abortion. Although I cannot remember my mother's experiences clearly, I could not comprehend why she reacted in that way at the time. I remember that my mother went through quite challenging times, and I only wanted my sibling to be born, not understanding why there was so much sadness in the house. Even though I witnessed what was happening, I think not fully comprehending it sparked curiosity in me. By conducting this study, I might be trying to find that missing piece from my childhood, which I could not fully grasp back then, through the experiences of other mothers.

CHAPTER 3

RESULTS

The result of Interpretative Phenomenological Analysis revealed six super-ordinate themes. These themes are *the decision of giving birth, enmeshed boundaries with the child, struggle over education, characteristics of the child, the ideal image of the motherhood and mother's perception of the fathers* (see Table 1).

Table 1. Emerging Themes of The Study

1. The decision of giving birth	
a. Given by God	Mrs. A, Mrs. B, Mrs. E
b. Prior abortions of handicapped babies	Mrs. D
2. Enmeshed boundaries with the child	
a. Using 'we' language	Mrs. B, Mrs. C, Mrs. E
b. Always together	Mrs. A, Mrs. B, Mrs. D
c. Understanding without speaking	Mrs. A, Mrs. C
3. Struggle over education	
a. Mother as the educator	Mrs. A, Mrs. B, Mrs. C
b. Extra money needed for education	Mrs. A, Mrs. C, Mrs. E
c. Unwanted child in class	Mrs. B, Mrs. C
d. Wrong information from the school	Mrs. D
4. Characteristics of the child	
a. Positive characteristics of the child	Mrs. A, Mrs. B, Mrs. C, Mrs. E, Mrs. D
b. Negative characteristics of the child	
5. The Ideal Image of the Motherhood	
a. Powerful mother	Mrs. A, Mrs. B, Mrs. E
b. Devoted mother	Mrs. B, Mrs. A, Mrs. C
c. Merciful mother	Mrs. C, Mrs. E

Table 1. Emerging Themes of The Study (cont'd)

6. Mothers' perception of the fathers	
a. Emotional father	Mrs. A, Mrs. E
b. Angry father	Mrs. C
c. Father without boundaries	Mrs. C, Mrs. D
d. Uninvolved father	Mrs. A, Mrs. B, Mrs. C

3.1 The Decision of Giving Birth

The first super-ordinate theme was the decision of giving birth. Although mothers learned of their children's diagnoses after birth, they talked about what they thought about giving birth if they had known beforehand. In this theme, they described their decision to give birth to children with Down syndrome. The sub-ordinate themes are *given by God* and *prior abortion of handicapped babies.*

3.1.1 Given by God

Türkiye is a predominantly Muslim country. Muslims usually hold the notion that Allah's will determines one's life destiny, and the name "Islam" derives from the act of surrendering to God's will (Murata & Chittick, 1994). Mothers of children with Down syndrome often emphasized their religious beliefs that they would give birth to a child sent by God in any case. The majority of mothers said that they did not know their children had Down Syndrome until birth, but even if they did know, they considered the child a gift from Allah and would give birth to him.

Mrs. B. explained that she had undergone a test immediately after giving birth and she had seen a dream that night. Based on her dream, she had determined that her kid has Down syndrome before learning the results of the tests:

> In my dream, I live in Kayseri. There are actually 2 balconies in our house, yet there is a third balcony in my dream. There is an extra ledge, like an excess at the edge of our balcony. When you go there, on the edge of my balcony, you see the word "Allah" written on the Mount Erciyes. At that moment, I woke up anyway. When I woke up, well, it was a lot like, I had a great power in me, I felt very powerful. I felt that I had a power that could overcome whatever

> happens. Well, the balcony's thing… I have 3 sons and a daughter, my third son, that is how I interpreted it. Y. is my third son. However, things I went through with Y will make me closer to my God, it will be a blessing for me, he will be a blessed child. I mean, I personally interpreted these. The fact that the word "Allah" was written on Mount Erciyes, completely, I mean, it was with will of Allah it was sent to me, I thought these.

> Ben rüyamda ben Kayseri'de yaşıyorum. Bizim evimizde 2 balkon var 3. bir balkon varmış evimizde balkonun kenarında böyle fazladan bir çıkıntı varmış bir fazlalık var yani. Balkonumun kenarında oraya çıktığın zaman Erciyes dağında Allah yazısını görüyorsun. … O esnada uyandım zaten uyandığımda ıı çok böyle kendimi içimde müthiş bir güç vardı yani çok güçlü hissettim hani ne olursa olsun her şeyi karşılayabilecek bir güce sahip hissettim kendimi. … Yani balkonun şeyi 3 oğlum bir kızım var, 3. Oğlum öyle yorumladım yani Y. 3. Oğlum. Fakat Y. ile yaşadığım şeyler beni rabbime daha çok yaklaştıracak benim için hayırlı olacak hayırlı bir evlat olacak hani bu yorumlara ulaştım. Erciyes dağının üzerinde Allah yazmasının tamamen hani Allah'ın dilemesiyle onu bana gönderdiğini bunları düşündüm.

Mrs. E. stated that she learned about the 50% probability of Down syndrome in a test she had taken during pregnancy. Nevertheless, she did not want to have any further tests done. According to Mrs. E, who has three other children, the health of her other children was not guaranteed, and she could not terminate the pregnancy since it is God's will:

> I went it through like an ordinary pregnancy. We waited for the end of it, we focused on what we should do and what could be done, with respect to the result at the end. I accepted it, to be honest. Doctor, I mean, doctor was the one we knew already. Miss E. said that there was a test in USA, that it showed 90% accuracy and that we should have done it and terminate the pregnancy. I said "I cannot accept this. Can you guarantee me my other 3 children? If you do, let me terminate it, but if not, why would I terminate it? It is Allah's blessing to me that I protect, after all. I said, "I don't want it".

> Normal hamilelik süreci gibi geçirdim sonunu bekledik sonunda çıkan sonuca göre de ne yapılabilir ne yapmamız gerekiyor oraya odaklandık. Ben kabul ettim açıkçası. Doktor hani tanıdığımız bir doktordu E. Hanım dedi Amerika'da bir test var o yüzde 90 net olarak gösteriyor bunu yaptıralım dedi bebeği aldıralım. Ben de dedim ki ben böyle bir şeyi kabul etmiyorum ben, diğer 3 çocuğumun garantisini bana verebilir misiniz dedim. Verirseniz ben o zaman aldırayım ama veremezseniz ben bunu niye aldırayım yani o da bana Allah'ın bir emaneti sonuçta ben dedim istemiyorum.

Mrs. A told that her doctors wanted to perform more tests on the baby due to her age but she did not. Even though she had reasons such as being pregnant for the last time and wanting the last pregnancy to go smoothly, the fact that the baby was too big for the abortion and she did not want any situation to disrupt the pregnancy process, Mrs. A. said that regardless of the results of the tests, she would not have an abortion because God gave her baby, so she decided to give birth:

> Nothing abnormal came up in my tests during pregnancy. Then, of course, since I was pregnant at age 33; they wanted to do other tests and I did not do any of them because it was my last pregnancy in my life. I did not want to find out what it was. Since I could not abort my 7-month-old baby no matter what, I did not take any tests. I said, “It was given by Allah”. I went on, I mean there is not any issue, Allah decided it so, it is over, there is nothing more to talk about. I am someone who believes that everything happens for a good reason. Since I am a person of faith, I handled it very easily.

> Hamilelik sürecinde testlerimde hiçbir şey çıkmadı. Sonra tabii 33 yaşında hamile olduğum için başka testler de yapalım istediler ve hiçbirini yaptırmadım çünkü bu benim hayatımda son hamileliğimdi. Ne olduğunu öğrenmek istemedim. Ne olursa olsun 7 aylık bebeğimi de aldırmayacağım için hiçbir teste girmedim. … Allah verdi dedim yürüdüm sıkıntı yok yani Allah böyle kararlamış bitti, onun üzerine konuşacak bir şey yok her şeyde bir hayır olduğuna inanan biriyim inançlı biri olduğum için çok rahatlıkla kaldırdım.

3.1.2 Prior Abortions of Handicapped Babies

Mrs. D. told that her second child was born with Down syndrome, and that she had terminated her previous two pregnancies when she learned that they were disabled. While she did not refer to the possibility of abortion if the baby had Down syndrome, her previous abortion experiences suggest that she might have faced with a dilemma for giving birth if the diagnosis had been made during her pregnancy. She said that prenatal tests did not show any problems, so she gave birth to her child with Down syndrome. She said:

> We had no information, I mean, regarding that she would have Down syndrome. It happened with normal conditions; the delivery was a caesarean section due to my age. Later, we started, like, going to doctors, we had tests done. The test results showed that she had Down syndrome, there were postpartum signs… I have aborted 2 sick children; they were sick. They were

> severely disabled, they had severe disabilities, it was seen while in my womb. They made me abort them, they said that it was the healthiest choice was to abort. Of course, I regretted it, but I had to abort them. They ended it, I mean, while in my womb.

> Hiçbir bilgimiz yoktu yani Down sendromlu olacağına dair. Normal şartlar şeyinde oldu sezaryenle oldu yaşımdan dolayı. Ondan sonra işte doktorlara filan başladık tahlil yaptırdık tahlilin sonucunda Down sendromlu olduğu ortaya çıktı, doğumdan sonra belirtileri vardı. … 2 tane ben rahatsız çocuk aldırdım rahatsızdılar. Çok özürlüydüler çok özürleri vardı karnımda belli olmuştu onlar. Onları aldırttılar bana hani en sağlıklısı aldırmanız dediler tabii ki.

3.2 Enmeshed Boundaries with The Child

The second super-ordinate theme is enmeshed boundaries with the child. Enmeshment can manifest in various family dynamics, such as between parents and children, siblings, or multiple family members collectively. These connections inevitably entail a blending of boundaries, a disruption of typical relationships, and a sense of experiencing each other's emotions on an intuitive level. In this study, mothers spoke about their experiences and relationships with their children in a way that showed they had strongly identified with them. They even talked like they are the same and recounted their children's experiences as if they were experiencing themselves. This theme explains in what ways the mothers had enmeshed boundaries with their children.

The sub-ordinate themes were *using 'we' language, always together* and *understanding without speaking.*

3.2.1 Using 'we' language

When describing the difficulties and developmental processes experienced by their children, the mothers expressed themselves using the pronoun 'we' without separating themselves and their children as individuals.

Mrs. C explained the development, and critical milestones of her child's development. As well, she shared her daughter's school experience and talked about her daughters's transition into school. When referring to her child, Mrs. C frequently used the pronoun ‘we’ instead of mentioning her individually. In addition to these, she also talked about her daughter's father, and grandmothers as if they belonged to both her daughter and herself:

Our preschool process started, **we** had a very, very nice time during the preschool period. During preschool, E. as an integration student, because **we** had our report, **we** started it this way. Now, **we** have passed to the second grade, it is very good, she is very successful in her grades, **we** had a theatre fear… She started taking her first steps when 10-months-old and **we** were completely walking while she was 21-month-old. **We** used that milk until preschool. E. sees the dad as a means of socialization little bit, because **our** dad does not know how to say no. Both **our** maternal and paternal grandmothers are alive.

Ana okul süreci**miz** başladı, ana okul sürecinde çok çok güzel bir süreç geçir**dik**. … Anaokulu sürecinde E’yi kaynaştırma öğrencisi olarak çünkü raporu**muz** olduğu için bu şekilde başlattık. … Şu anda ikinci sınıfa geç**tik** gayet güzel notlarında gayet başarılı, tiyatro korku**muz** vardı. … 10 aylıkken adım atmaya başladı 21 aylıkken tam yürüme noktasına gel**dik**, anaokuluna başlayana kadar o sütleri kullan**dık**. … Babayı da sosyalleşme aracı olarak görüyor E. biraz çünkü baba**mız** biraz **bizim** hayır demeyi bilmiyor. ... **Bizim** hem anneanne**miz** hem babaanne**miz** sağ.

In a similar way, Mrs. B also referred to her son's educational and developmental process using the pronoun ‘we’:

> **We** had to enroll in an intense physical therapy program… During that period, when the diaper was put back on again, **our** potty training got interrupted… **We** are doing our schoolwork; having done **our** schoolwork, **we** play a little in the remaining time…Before primary school, **we** have a 3-year preschool past. When Y. was going to preschool, the preschool and primary school were in neighboring gardens. When **we** got out of the preschool, **we** used to go out early with Y…. At preschool, when **we** first started, we did not have many problems.

> Yoğun bir fizik programına girmek zorunda kal**dık**. … O süreçte tekrar bez takılınca **bizim** tuvalet eğitimi**miz** aksadı. … Dersleri**miz**i yapıyoruz, dersleri**miz**i yaptıktan sonra kalan zamanda da biraz oyun oynuyoruz. … İlkokuldan önce 3 yıl bir anaokulu geçmişi**miz** var. … Y. anaokuluna giderken anaokuluyla ilkokul yan yana bahçelerdeydi **biz** anaokulundan çıktığı**mız** zaman erken çıkıyor**duk** Y. ile. … Anaokulunda ilk başladığı**mız**da da çok sorun yaşamadık.

Mrs. E. also switched between saying ‘we’ and saying ‘I’ when talking about her child’s education and development:

> B. is already very mild; her perception, like, is very good. Now, **we** have a little problem with **our** speaking… B. walked while 8-months-old, it happened very quick since **we** had immediately started physiotherapy… She started individualized education, **we** were taking private lessons at home, then I started for the institution too… **We** were having individualized education, she had individual lessons… If you had told me 5 years ago whether she could do it, maybe then I could approach it as worried, but now, at the point **we** reached, when I watch her old videos, I see that **we** have come a very long way, I mean especially, I see B. coming a very long way.

> B. çok hafif zaten algısı falan çok iyi şu an konuşma**mız**da biraz sıkıntı var. … 8 aylıkken yürüdü B., zaten hemen fizyoterapiste başladığı**mız** için çok çabuk oldu … Bireysel eğitime başladı, evde özel alıyor**duk** sonra kuruma da başladı**m ben** … Bireysel eğitim alıyor**duk** bireysel dersleri vardı. … 5 sene önce deseydiniz ki yapabilir mi belki o zaman kaygılı yaklaşabilirdim ama şu an geldiği**miz** noktada eski videolarını da izleyince çok yol kat ettiği**miz**i görüyorum yani B’nin özellikle çok yol kat ettiğini görüyorum.

3.2.2 Always Together

Mothers explained that they spent the majority of their days with their children. They explained that this is mainly due to the fact that a typical child is already dependent on their parents from birth, but a child with Down syndrome requires special attention. They said that these special attention-requiring situations involve physical exercises to facilitate walking, efforts to enable speech, and additional lessons and studies necessary for their education. They mentioned that because they could not leave their children alone during school hours, they accompanied them to school. Additionally, they stated that outside of school, they spent most of their time together to attend educational activities or to supervise their children’s behavior.

Mrs. D. explained that she cannot leave her daughter alone because she misbehaves when left alone:

> We are always together; we are always together. You can’t entrust them anything as normal children, you certainly have to be with them in the

> bathroom and in the washroom as well… You need to be with her in the bathroom too, while eating too, I mean, you can never leave her alone. She is always with me, like, except maybe one hour, maybe two hours without me; because it is when I am obliged, maybe if I have something to do at hospital or with doctor, then I go. Even then, I always encounter with something unpleasant when I come back, I mean. It is not the same as when she is with me. We encounter different things, you see, she had misbehaved… Since I left her and went out, she particularly does everything opposite.

> Sürekli beraberiz, sürekli beraberiz. … Normal çocuklar gibi emanet edemiyorsun bir şeyi, muhakkak tuvalette de yanında olman gerekiyor lavaboya gittiğinde de. … Tuvalette de yanında olman gerekiyor yemek yerken de yanında olman yani kesinlikle tek başına bırakamıyorsun. Sürekli benle yani benim dışımda belki bir saat belki iki saat çünkü onu da onu mecbur kalıp belki bir hastane bir doktor işim olursa giderim. Onda da geldiğimde ille ters bir şeyle karşılaşırım yani. Benimle olduğu gibi olmuyor. Farklı şeylerle karşılaşıyoruz işte ya yaramazlık yapmış oluyor. … Ben onu bırakıp gittim diye ille her şeyin tersini yapıyor.

Mrs. A said that she quit her job after her son was born and she learned that he had Down syndrome. As the owner of a workplace, Mrs. A, during this process, trained employees to work at the workplace, stating that she no longer needed to work herself and dedicated her life to her son. She mentioned that she spent the majority of her day with her son:

> I had a baby with Down syndrome at the age of 33, you see, I took a break from my career at that moment and now I am only taking care of the child. Right now, my life is my son, I've been taking care of my son for 7 years. We go on the road at 9, we are at school every day until 5. I am never separate from him, of course he is with me when I am cooking too, at the dining table of course, we all have individual plates, we sit, I mean we are always together, not separate I mean… I was working full time before Y., now I am only taking care of Y.

> 33 yaşında Down sendromlu bir bebeğim oldu işte, iş hayatıma burada ara verdim ve sadece şu an çocukla ilgileniyorum. … Hayatım oğlum şu an oğlumla ilgileniyorum 7 yıldır. … 9'da yola çıkıyoruz 5'e kadar okullardayız her gün. … Ben hiç ayrı kalmıyorum tabii ki yemek yaparken de yanımda, sofrada tabii ki hepimizin ayrı bir tabağı var oturuyoruz yani hep beraberiz ayrı falan değiliz yani. … Y.'den önce full çalışıyordum şimdi sadece Y. ile ilgileniyorum.

Mrs. B. told that she and her son spent most of their time together during the day, mainly focusing on lessons and playing games because her son needed constant and continuous education in order to learn:

> We first do our schoolwork, having done our schoolwork, we play a little in the remaining time, we do puzzles together. He is with me most of the time, if I am busy with something else, he plays by himself. He is a child who shows very slow progress. You make an effort, give your all for months and years for things which others learn without any effort. There is an incomparable amount of time spent, that is for sure, but it is what it is, there is nothing to do… You give up from your own time for a lot of times, you leave no time for yourself, because there is no time left for you.

> Önce derslerimizi yapıyoruz derslerimizi yaptıktan sonra kalan zamanda da biraz oyun oynuyoruz birlikte yapboz yapıyoruz. … Çoğunlukla benimle, ben başka işle uğraşıyorsam kendi halinde de oynar. … Çok yavaş ilerleyen bir çocuk, diğerlerinde hiçbir çaba harcamadan öğrendikleri şeyler için siz aylarca yıllarca böyle çaba harcıyorsunuz, gayret gösteriyorsunuz. … Kıyaslanamayacak kadar fazla vakit harcanıyor kesinlikle orası öyle ama böyle yani yapacak bir şey yok. … Kendine ait zamandan veriyorsun birçok zaman kendine vereceğin zamanı bırakmıyorsun kendine zaman kalmıyor çünkü.

3.2.3 Understanding without Speaking

Speech is one of the vital elements of communication, which is an integral part of life. Through speaking, people can share their emotions and thoughts with each other, and understand one another. However, in this study, mothers stated that they communicated with their children even without speaking. They understood their children's desires and thoughts through nonverbal communication, such as body language or just through eye contact, without the need for any verbal conversation.

Mrs. A explained that during toilet training, she understood her son without the need for him to speak, and she provided him with this training:

> He was already expressing his problem through body language. He used to let me know when he needed to go to the bathroom, he would tell me. I understood him when he looked into my eyes. There was no problem, I didn't have any trouble. I potty-trained him at the age of 1.

> Beden diliyle derdini anlatıyordu zaten. Tuvaletin geldiğini hissettiriyordu, bana söylüyordu. Gözümün içine baktığı zaman ben anlıyordum artık onu sıkıntı yok, sıkıntı yaşamadım. 1 yaşında kurtarmıştım bezden yani.

Additionally, Mrs. C mentioned that at school, her daughter constantly tried to go to another classroom, which the teachers misinterpreted as her inability to remember her own class. Despite not discussing this issue with her daughter, Mrs. C explained that she actually knew that the situation was not as the teachers perceived it, and she understood what her daughter was trying to do. According to Mrs. C, her daughter was simply seeking support by trying to find someone familiar in a foreign environment:

> At first, E. had a friend from preschool there, who started first grade. They were not in the same class, but they were in the same school. Later, they transferred that student to another school and E. used to go to their class constantly. Teachers interpreted it as E did not know their own class. Actually, I was aware of what E was trying to do, because in a very foreign, and I mean, very crowded environment, they were seeking support.

> E'nin ilk önce anaokulundan gelen bir arkadaşı vardı orda 1. Sınıfa başlayan. Aynı sınıfta değillerdi ama aynı okuldalardı, sonra o öğrenciyi farklı okula geçirdiler ve E sürekli onun sınıfına gidiyordu. Öğretmenler bunu E kendi sınıfını bilmiyor diye yorumladılar. Aslında ben E'nin ne yapmaya çalıştığının farkındaydım çünkü çok yabancı ve yani çok kalabalık bir ortamda kendine destek arıyordu.

3.3 Struggle over Education

The third super-ordinate theme is the struggle over education. The participants discussed that children with Down syndrome needed education in many areas, such as physical and individual, very shortly after birth. Although the education provided by the government starts shortly after birth, according to the mothers' accounts, it is not sufficient. Therefore, they have either supported their children's education themselves or arranged for additional training. However, these additional trainings were not readily accessible to everyone or affordable in terms of fees. They also encountered numerous challenges when their children reached school age. In this theme, the mothers' struggles over education are explained. The sub-ordinate themes are *mother* *as the educator, extra money needed for education, unwanted child in class and wrong information from the school.*

3.3.1 Mother as The Educator

Due to the fact that children with Down syndrome must begin learning at a young age, mothers actively participate in their children's education. Many of these mothers acted as teachers because they recognized that the education provided to them was inadequate. Additionally, the mothers frequently emphasized that even if the education were sufficient, their children would still need continuous learning and ample repetition to grasp a concept. Therefore, they explained the need to continue this education at home, in addition to the school environment.

Mrs. C described how she became her child's educator in this way and then decided to study child development:

> Because I believe in and trust my child's capacity. Also, since age 0, I dedicated myself to constantly improving myself in this regard, already. I fulfilled my duties as a mother, but besides this, I have undertaken the duty of teaching as well, like completely, I have taken it upon myself. We started special education. For lessons and materials, I search the internet, website by website; I search for books, materials… If there were not such a diagnosis for E, what would I do? I mean, what do mothers and daughters do? Of course, I would do certain activities, but would I do them as intensively? Would I work with beans, peanuts, how can I say, a room full of academic materials? Of course, not… I said I started studying child development for E., now I am in third grade. About her, and different seminars, or about this, what can be done regarding her special education - I continue to improve myself about this topic.

> Çünkü ben çocuğumun kapasitesine inanıyorum ve güveniyorum bir de 0 yaştan itibaren sürekli kendimi bu konuda geliştirmeye adadım zaten. … Annelik görevlerimi yerine getirdim ama ekstra bunun dışında öğretmenlik görevini de ben bir böyle üstüme tamamen sırtlanmışım yani üstlenmişim. … özel eğitime başladık derslerde materyallerde ben site site araştırıyorum kitap araştırıyorum materyal araştırıyorum. … Böyle bir tanı olmasaydı E'de ben ne yapacaktım yani anne kızlar ne yapar yani tabii ki de belli etkinlikleri yapardım ama bu kadar yoğun yapar mıydım? Fasulyelerle, fındıklarla, nasıl deyim bir oda dolusu akademik materyallerle çalışır mıydım? Tabii ki hayır. … E. için çocuk gelişimi okumaya başladığımı söylemiştim 3. Sınıftayım şu anda. Onunla ilgili ve daha farklı hani seminerler veya hani bununla ilgili, özel eğitimi ile ilgili neler yapılabilir, hani bu konuda kendimi geliştirmeye devam ediyorum.

Mrs. B told that she took care of her child's education herself at the beginning of primary school because she was not satisfied with the education at school. She wanted her child to attend an inclusive classroom for better and faster education, but permission was not granted. Although she initially registered her child into a special class and sent him for a while, she found that the education provided progressed quite slowly and was not suitable for her own child. As a result, she decided not to continue sending her child to that class. While providing education to her child until school age. Mrs. B continued to do so by adapting her education to her child’s learning style:

> He goes to primary school, but we can say that he did not go, we can say that he did not go at all, we are not satisfied with the education process. … Y went to school for like 20, 25 days, we didn't continue after that, I mean. Since I was taking care of Y from the beginning already, we continued in the same way. … I try to teach the skill I want to teach by trying different methods, for example. … For example, if Y. takes visuals, I try visuals, I try auditory. I prepare different things in the visual form and present with them, I turn them into a game, I mean I do my best so that Y. can learn.

> İlkokula gidiyor ama gitmedi diyebiliriz hiç gitmedi diyebiliriz, memnun kalmadık eğitim sürecinden. … 20 25 gün falan gitti okula Y. ondan sonra devam etmedik yani. Zaten baştan beri ilgilendiğim için aynı şekilde biz devam ettik. … Ben farklı farklı yöntemler deneyerek o öğretmek istediğim beceriyi öğretmeye çalışıyorum mesela. … Mesela görsel alıyorsa görsel deniyorum işitsel deniyorum. Görselde farklı farklı şeyler hazırlayıp onlarla sunuyorum, oyuna döküyorum yani öğrenebilmesi için elimden geleni yapıyorum.

Mrs. A stated that she took her son for an extended period of physical therapy but did not see any improvement in terms of walking. She explained that due to his inability to walk, his feet and legs would not develop properly, leading to potential body imbalances. In an effort to prevent this, she wanted to enroll her child in swimming lessons, but she was informed that the child needed to be at least 7-8 years old for that. Therefore, she was taking care of her child's physical development:

> Y. was born with muscle weakness. Of course, we constantly applied physical therapy to tighten the muscles, I took him to physical therapy constantly, constantly, constantly; and he did not respond in any way. … I threw him into a 1.80-tall pool from the age of 2 as a mother, I made him swim as a mother, so that his muscles would not fall behind, there would be no disproportion in

> his body. … I made him swim all the time, fixed it as 2 days a week and made him swim. Although no teacher agreed, I did it myself.

> Y. kas gevşekliğiyle beraber doğdu. Tabii ki kasları sıklaşması için sürekli fizik tedavi uyguladık, fizik tedaviye götürdüm sürekli sürekli sürekli ve hiçbir şekilde cevap vermedi. … ben 2 yaşından itibaren onu bir 1.80'lik havuza attım bir anne olarak, bir anne olarak onu yüzdürdüm yani sürekli kasları geride kalmasın, vücudunda bir orantısızlık olmasın diye. … Onu sürekli yüzdürdüm, haftada 2 gün sabitledim onu yüzdürdüm. Hiçbir öğretmen kabul etmemesine rağmen bunu kendim yaptım.

3.3.2 Extra Money Needed for Education

The mothers explained that because the government schools do not provide sufficient education, they had to provide many private lessons for their children and hire caregivers or 'gölge öğretmen'. They said that these courses were expensive and that they could afford it, but not everyone would be able to do.

Mrs. A. mentioned that she has been providing private lessons for her child since the age of 1, and that she has received more education than the education provided by the state:

> After the age of 1, we started special education, after the age of 1, I continued special education fully from 8 (a.m) to 5 (p.m) … He finished the 1st grade and will now go to the 2nd grade. He is there until noon, and in the afternoon, we come to rehab. Of course, I make him take additional and private lessons here. The state was providing 13 hours of lessons per month, but I extended it to 60-70 hours. Y will attend lessons at 9, he will stay at school with his caregiver until half past 12. We are in private rehabilitation right now; we are in private lessons. … I didn't send him to a public school, of course; because as I knew from my other daughter, Y had to be able to read and write in 2 months. How could I get him into public school? I sent him to a special education school, of course, so that he could be with his peers. I only sent him to the school for people with Down syndrome. They are 5 people, 2 teachers… He continues to receive special education, I mean.

> 1 yaşından sonra özel eğitimlere başladık, 1 yaşından sonra 8-5 olarak özel eğitimlere full devam ettim. … 1. Sınıf bitirdi şu an 2. Sınıfa gidecek. Öğlene kadar orda, öğlenden sonra da rehabilitasyona geliyoruz. Tabii ki burada ek ve özel dersler aldırıyorum. Devletin verdiği 13 saati ayda 60 70 saat verdirttim.

> … Y de 9’da ders yapacak 12 buçuğa kadar okulda bakıcısıyla beraber duracak, şu an özel rehabilitasyondayız özel dersteyiz. … Devlet okuluna onu yollamadım tabii ki; çünkü diğer kızımdan bildiğim için 2 ayda okuma yazma bilmesi gerekiyordu Y’nin. Nasıl ben devlet okuluna veriyim? Özel eğitim okuluna verdim tabii ki kendi akranlarıyla olsun diye yani. Down sendromlu okuluna verdim sadece. 5 kişiler, 2 tane öğretmen özel eğitim almaya devam ediyor yani.

Mrs. C. explained that they afforded education on their own because their child's report was delayed, so they have paid for many of the trainings until the necessary reports were issued. In addition, they received many education services that were not covered by the government after the report was released:

> We started paid physiotherapy when we were 13 months old because you can't get state aid without a report. Apart from that, we started with individualized training, and after the report was out, these lessons started to be covered by the state. Apart from these trainings, from outside sources, of course, massage supports, oils, organic oils or something called mental shower; since it is severely mental, since it affects development in children; we continued with such methods. There is a problem in our country. While the state gives free shadow teachers to children with autism, unfortunately we do not have such a thing with Down syndrome. We have implemented this ourselves with our own money, yet there occurs a problem, like OK, we have the power to afford it, but what will others who do not have power do, so it is really sad.

> Biz 13 aylıkken ücretli olarak fizyoterapiyle başladık çünkü rapor almadan devlet yardımı alamıyorsunuz. Onun dışında bireysel eğitimle başladık, rapor çıktıktan sonra yine bu dersler devlet tarafından karşılanmaya başladı. Bu eğitimleri dışında dışardan da tabii ki de masaj destekleri yağlarla, organik yağlarla veya mental banyo denilen bir olayla, ağır mental olduğu için çocuklarda gelişimi etkilediği için, böyle yöntemlerle de devam ettik. … Ülkemizde sıkıntı var. Otizm tanısı olan çocuklara devlet ücretsiz gölge öğretmen verirken maalesef Down sendromlu olan bizde böyle bir şey yok. Biz bunu ücretli olarak kendimiz hayata geçirdik ama şöyle bir sıkıntı çıkıyor, tamam bizim bunu karşılayabilecek gücümüz var ama peki olmayanlar ne yapacak yani gerçekten çok üzücü.

Mrs. E. also said that her daughter received many private lessons until she started school:

> When B was 2 months old, we started a private physiotherapist, 3 days a week, and it benefited us a lot. B. started walking when she was 1.5 years old, she is in very good physical condition, but there are thousands of families who do not have that opportunity. … She started individualized education at the age of one, we were taking those lessons at home privately, and then I started the institution. … She had private lessons, she had too many private lessons, we had to give up them, it was like that, I mean we used to go to the lessons. We were trying to do all kinds of things, whether it was motor skills related to her condition or regarding behavioral disorders.

> 2 aylıkken B, fizyoterapiste başladık özel, haftada 3 gün ve o bize çok kazandırdı. B. 1.5 yaşındayken yürümeye başladı fiziksel olarak çok iyi durumda ama o imkânı olmayan binlerce aile var. … Bir yaşında da bireysel eğitime başladı, o da evde özel alıyorduk sonra kuruma da başladım. … Özel dersleri vardı, fazlasıyla özel dersleri vardı onları mecburen bırakmak zorunda kaldık, o şekilde geçiyordu yani derslere gidiyorduk. İşte onun durumuyla ilgili motor becerileri olsun, işte davranış bozuklukları üzerine olsun, her türlü şey hani yapmaya çalışıyorduk.

3.3.3 Unwanted Child in Class

The majority of the mothers said that they have experienced similar problems regarding their children's teachers when the children started elementary school. According to them, teachers did not want their children in the class. Children were considered unwanted for a variety of reasons, such as behavioral problems or being unsuitable for inclusive curriculums.

Mrs. B shared that when her son started school, she felt extremely upset and cried for three days due to the complaints from the teachers. She stated that the teacher who claimed that her child had behavioral problems actually did so because she did not want the child in the classroom. Since she used the word ‘we’ instead of focusing solely on her son, it suggests her feelings may be about herself as much as her son being unwanted:

> We started in the lower grade once; we went for 3 days. The first day we went there, the teacher called me like two hours later. She said; Mrs. B, Y has behavioral problems. He got up and sat down and stood up repeatedly and looked out the window, she said. … It saddens me that behaviors that should be considered very, very normal for a lower grade student were told to me as behavioral problems, to be honest. The next day, the teacher said he has no

> self-care skills. On the 3rd day, the other teacher called me again and said that Y. wet his pants. His own teacher called this time, saying, Ms. B. I don't know if it would suit you as well, but there is another lower grade class in the neighborhood, there is only one student there, and this might be better for Y. It turns out that this was what laid behind the things, you know, what was expressed as, you know, a behavioral problem or peeing problem. Due to completely different thoughts, I can call it a policy of intimidation or a policy of harassment, with a different policy, they called me like that for 3 days for things that would not really be considered as a behavior problem. I said, OK. I mean, we don't stay where we are not wanted.
>
> Alt sınıfa bir başladık, 3 gün gittik. Orada ilk gittiğimiz gün, öğretmen iki saat falan sonra aradı beni. B. Hanım Y'nin davranış problemleri var dedi. Kalkıp kalkıp pencereden aşağıya baktı dedi. … Bir alt sınıfı öğrencisi için çok çok normal kabul edilmesi gereken davranışların davranış problemi olarak bana anlatılması üzdü beni yani açıkçası. Ertesi gün öğretmen öz bakım becerisi yok dedi. 3. gün tekrar diğer öğretmen beni aradı Y. çiş kaçırdı dedi. Kendi öğretmeni aradı bu sefer B. Hanım size de uygun gelir mi bilmiyorum ama mahalledeki başka bir alt sınıf varmış orda tek öğrenci varmış, bu Y için daha iyi olabilir dedi. Meğerse hani davranış problemi olarak veya çiş kaçırdı olarak ifade edilen şeylerin altında tamamen bu varmış. Ya tamamen hani farklı düşüncelerle, yıldırma politikası mı deyim size bezdirme politikası mı deyim, farklı bir politikayla gerçekten davranış sorunu olarak değerlendirilmeyecek şeyler için, 3 gün boyunca beni böyle aradılar. Dedim tamam istenmediğimiz yerde biz de durmayız yani.

It was difficult for Mrs. C to get elementary school teachers to accept her child as an inclusive education student, even though all the necessary institutions had stated that the child could be enrolled as one:

> They presented unbelievable things to me in order not to keep E. in school. They said; the child was given a lot academically, right, but the child was not sufficient for first grade behaviorally and you should have done something about them. They said this child needed to go to a special lower-grade class and receive cognitive education. They claimed, I mean, that our child could not be an inclusion student. During the time I was there, I experienced such interesting things, I mean, the lack of understanding shown to our children and other children just because of their diagnosis is truly heartbreaking.
>
> Bana yani E'yi okulda tutmamak için yani inanılmaz şekilde şeyler sundular. Çocuğa evet akademik olarak bir sürü şey verilmiş ama davranış olarak çocuk birinci sınıfa başlayacak yeterlilikte değil, bununla ilgili yapmanız gereken şeyler var dediler. Bu çocuğun özel alt sınıfa gitmesi gerekiyor, bilişsel eğitim alması gerekiyor. Kaynaştırma öğrencisi olamaz diye yani bir iddiada bulundular. Orda olduğum süre içerisinde o kadar enteresan şeyler yaşadım ki

> yani sadece tanısı olduğu için bizim çocuklarımıza, diğer çocuklara gösterilen anlayışın gösterilmemesi hakikaten içler acısı.

3.3.4 Wrong Information from The School

Ensuring the accuracy of the information communicated by educational institutions to students and their families is highly important. Misinformation can result in confusion, misunderstandings, and potentially undesirable outcomes. One of the mothers shared her experience based on the incorrect information she received from a special education center.

Mrs. D frequently mentioned her daughter's muscle weakness during the interview and talked about trying various methods to strengthen her muscles. She told that one of the teachers at a special education and rehabilitation center, particularly for strengthening her leg muscles, suggested that they should let the child use a trampoline, emphasizing its benefits. However, when they visited a doctor after her daughter's fall on a trampoline, it was actually stated that it could be harmful to a child with Down syndrome. Mrs. D explained that due to the school's wrong guidance, her child suffered physical harm:

> She was about 5-6 years old, probably 6, we had a park accident. She had a slip in her leg, in her growth plate, a disability started to appear in her leg. They had told us in the special education that take her to a trampoline, let her jump, let her leg bones harden. We took her but of course could not get her out of course, it was a very large area. When we could not take her out, she lost her balance there badly, her foot got stuck to the stairs when she was going out. There were ruptures there, she got stuck into the ruptures, there was a slip in her growth plate. Children with Down syndrome apparently tend to have too many fractures, bending, and tearing because their bones are so soft. We started taking her to a lot of doctors again for her foot and leg, we even went to professors. Finally, one doctor said, 'Be thankful that her spine is not broken,' and she said that these children had very soft bones and anything could happen at any moment, so she said "be careful about that".

> 5 6 yaş civarındaydı 6'ydı herhalde, bir park kazası yaşadık. Onda da bacağında, büyüme kemiğinde kayma oldu, bacağında sakatlık oluşmaya başladı. Bize özel eğitimden şey dediler tramboline götürün zıplasın bacak

> kemikleri sertleşsin. Biz bunu götürdük ama biz bunu çıkartamadık tabii ki çok büyük bir alandı, çıkartamayınca iyice orda dengesini kaybetti çıkarken ayağı merdivene takıldı. Orda yırtıklar vardı yırtıklara takıldı büyüme kemiğinde kayma oldu. Down sendromlu çocuklarda kemikleri çok yumuşak olduğu için kırılma bükülme yırtılma çok fazla oluyormuş. Biz bunu artık tekrar ayağı, bacağı için doktor doktor gezdirmeye başladık, profesörlere gittik. En son bir doktor dedi ki siz dua edin sırtı kırılmadı dedi bu çocuklar dedi çok yumuşak kemikleri dedi bunlarda her an her şey olabiliyor dedi ona dikkat edin dedi.

3.4 Characteristics of The Child

In this study, the mothers frequently mentioned their children's characteristics. This super-ordinate theme includes *positive characteristics of the child* and *negative characteristics of the child* sub-ordinate themes.

3.4.1 Positive Characteristics of The Child

Positive characteristics are qualities, traits, or attributes that individuals have that are seen as desirable or beneficial. They are valued for their contribution to personal growth, relationships, and overall well-being. These traits encompass a range of qualities, such as kindness, honesty, empathy, resilience, optimism, and more, which are considered advantageous in different areas of life.

Mrs. A mentioned what her son can do. Her son was accustomed to education, so she mentioned positive things about how his teachers are pleased with him. She also emphasized the positive aspects of Down Syndrome on its own:

> He can play with his friends, tell his problems, put 2 words together, I mean, when we say do this, bring the ball, bring the remote, bring tea, he is able to bring them all by himself. It's very good, so the only thing his teachers say is that we have never seen such a person with Down. … Beautiful, he is love anyway, ball of love, ball of love, love me, kiss me, like, have fun with me, laugh with me, that's what Down means. … Teachers admire Y. because the ready child is in front of them, the ready child who has received continuous education is in front of them.

> Arkadaşlarıyla oyun kurabiliyor, derdini anlatabiliyor, 2 kelimeyi bir araya getirebiliyor yani ama şunu yap bunu yap topu getir kumandayı getir çay getir dediğimizde bunları kendi gider alır getirir hepsini. Çok iyi yani

> öğretmenlerinin de dediği tek şey biz böyle bir Down'lı görmedik. … Güzel, aşk zaten, sevgi yumağı sevgi yumağı, sev beni öp beni yani benimle eğlen benimle gül, Down bu demek. … Öğretmenler Y.'ye hayran çünkü hazır çocuk önlerinde, sürekli eğitim almış hazır çocuk önlerinde.

Mrs. B explained that having a child with Down Syndrome is a challenging process, but she talked about how the positive characteristics her son possessed made it much easier. She expressed how her son alerts her to prevent any harm to herself and how this makes her happy:

> It is a very difficult process, I definitely cannot say it is easy, it is tough, but there is also ease with its difficulty. Sometimes, they sometimes let you embrace them, they let you embrace them, they act cute. Like, they come and immediately, I mean, very thoughtful. Y is like that for example, very thoughtful. For instance, a moment ago, I was putting red pepper flakes in my sandwich, and Y. said, 'your mouth will burn mom, don't put too much, just put a little'. … He is not a child who is introverted. Immediately, he quickly adapts and engages with the environment he enters.

> Çok zor bir süreç kesinlikle kolay diyemeyeceğim zor fakat zorluğuyla birlikte kolaylığı da var. Yani bazen sevdiriyorlar, kendilerini sevdiriyorlar, cilveli davranıyorlar. İşte gelip hemen yani çok ince düşünceli Y öyle mesela çok ince düşünceli. Az önce mesela pul biber atıyordum ben ekmeğimin arasına, anne diyor ağzın yanar çok fazla atma az at diyor. … İçe kapanık bir çocuk değil hemen girdiği ortama çabucak alışan çabucak kaynaşan bir çocuk.

Mrs. C. explained that she had to have one of her tubes removed as a result of a medical condition, which reduced her chances of getting pregnant to 50%. She mentioned being very surprised when she became pregnant and attributed it to a miracle even before the baby was born. This attribution of miracle became something she emphasized after witnessing what her daughter was capable of. Additionally, Mrs. C. mentioned that during the conversation, she realized her daughter had fulfilled one of her own dreams:

> It was a surprising and miraculous pregnancy because my chances of getting pregnant had decreased to 50% due to one of my tubes being removed. … You know, I can say that we are in a better condition, well, compared to other children with Down Syndrome… With their ability to imitate, they can really

> do everything the other person does, so they have such a perception. … Our children are also a bit inclusive; I mean, E. includes everyone in the game. I sometimes think, 'Am I wasting my effort?' but a month later, the child pours out those pieces of information to me, and it's like experiencing a miracle. … She opened the doors of a different world to me, the needs of different people. E. enabled me to fulfill a dream of mine that I had when I was very young, and now I'm realizing this with you, because I always wanted to study anthropology, and I with E, while talking to other families about their problems one by one not judging anyone... Can I make myself clear? I mean, E made me experience this.

> Sürpriz ve mucize bir hamilelikti çünkü tüpümün biri alındığı için hamilelik şansım %50'ye inmişti. … Hani diğer Down'lu çocuklara bakaraktan daha ııı güzel durumdayız diyebilirim. … Taklit yeteneği ile hakikaten karşı tarafın yaptığı her şeyi yapabiliyorlar yani böyle de bir algıları var. … Bizim çocuklarımız da biraz bütünleştirici çocuklar yani E herkesi oyuna dahil ediyor. Boşa mı emek veriyorum diye düşünüyorum ama bir ay sonra çocuk bana patır patır patır yani o bilgileri bir döküyor ki ya böyle işte mucize yaşamak gibi bir şey oluyor. … Bana farklı dünyanın kapılarını açtı, farklı insanların farklı ihtiyaçların. Benim çok gençken yaşamak istediğim bir hayalimi gerçekleştirdi E., şu anda seninle fark ediyorum bunu çünkü ben antropoloji okumak isterdim hep ve bunu ben E ile tek tek o ailelerin sorunlarıyla konuşurken hiç kimseyi yargılamadan anlatabiliyor muyum yani E bana bunu yaşattı.

Mrs. E. frequently talked about the empathy her daughter instilled in her. She explained that she started to perceive life in a completely different way with her daughter, experiencing emotions she wouldn't have felt if her daughter hadn't been born or didn't have Down Syndrome:

> Naturally, you're worried, and also, you hear about it but you don't really know what Down syndrome is, to be honest. B. opened a very different window for us, and we gained very different knowledge through that window. A very different environment was formed around us, and of course, when you first hear about it, you feel bad and uneasy, but over time, the things that are done, the experiences that are lived, take a person to a different dimension. We already had sensitivity towards people in that situation, feeling empathy towards them, but now, for instance, we try to help them. We understand them, and different connections have been formed. … Without B., I wouldn't have known about them, since I have experienced their educational deficiencies through her, I know. When you go out to the garden, the child is accepted in a different way. Now, since I have experienced them myself, I can understand them much better. If I hadn't lived through it, I could have felt sorry for them, but I wouldn't have felt it at the same depth and dimension. Yes, I can understand all of them very well now because I have experienced it myself.

> Endişeleniyorsunuz haliyle dediğim gibi bir de hani duyuyorsun ama Down sendromu nedir bilmiyorsun açıkçası B. bize çok farklı bir pencere açtı o pencereyle çok farklı bilgiler edindik. Çok farklı bir çevremiz oluştu hani onu ilk duyduğum anda haliyle kötü hissediyorsunuz, tedirgin oluyorsunuz ama zamanla yapılan şeyler o yaşanmışlıklar insanı farklı bir boyuta taşıyor. O durumda olan insanlara karşı empati duya ya zaten bu konuda hassasiyetimiz vardı ama şimdi mesela onlara yardımcı olmaya çalışıyoruz. Onları anlıyorsunuz, başka başka bağlantılarımız oluştu. … B. olmasa ben onlardan haberdar olamayacaktım şimdi kendim onunla ilgili yoksunlukları yaşadığım için eğitimsel anlamda, biliyorum. Bahçeye çıkıyorsunuz farklı şekilde kabul görüyor çocuk. Şimdi onları ben yaşadığımdan onları daha iyi anlayabiliyorum hani yaşamış olmasaydım hiçbir şekilde hani üzülebilirdim ama aynı derinlik boyutunda hissedemezdim. Şu an hepsini çok iyi anlayabiliyorum evet ben onu yaşadığım için kendim.

3.4.2 Negative Characteristics of The Child

A negative characteristic refers to a trait or quality that is generally perceived as undesirable or unfavorable. It can vary depending on the context and perspective. Some examples of negative characteristics may include selfishness, dishonesty, laziness, arrogance, impatience and so on. The perception of what is considered negative can vary from person to person and across different cultures and societies.

Mrs. D., unlike other mothers, emphasized more on her daughter's mischievousness and stubbornness. She described the challenges she faced due to her daughter's various misbehaviors, not listening to her or her teachers, and doing the opposite of what was told. Mrs. D described this situation as a struggle between ‘winning’ and ‘not being able to win’ due to stubbornness and conflict:

> What is she doing? For instance, she knows that it is mischievous behavior, but she still does it. When I ask why did you do that, she hides, she knows that it is mischievous. … In the beginning, she had a habit of throwing things, around 5-6 years old, she used to have the habit of throwing things on the table, she was throwing and spilling. For example, when you said don't do something, she would do it, as if saying "don't do it" was like telling her to do it. Even now, it is like that, when you tell her not to do something, she insists on doing it. … She seemingly was very mischievous in school; she wouldn't attend classes and would lie on the floor. She stays in regular schools that are provided by the national education system as well, and she loves her teachers there, but she still

> misbehaves there too sometimes. Some days she can be very fussy … You can never succeed with stubbornness; I mean, you succeed but you wear yourself out and also exhaust her. It is more for children with Down syndrome now, previously when she was a bit younger, I could manage her a bit more, but now I can't.

> Ne yapıyor, mesela biliyor ki onun yaramazlık olduğunu ama yapıyor. Ne için yaptın dediğimde saklanıyor, biliyor yaramazlık olduğunu. … İlk zamanlar zaten atma huyları vardı şöyle 5 6 yaşında, masadaki şeyleri atma huyları vardı atıyordu, döküyordu. Mesela bir şey yapma dediğinde onu yapıyordu, yapma deyince ona yap demek gibi oluyordu. Şu anda da öyle yapma dediğin şeyi inadına yapıyor. … Okulda çok yaramazlık yapıyormuş, derse girmiyormuş, yerlere yatıyormuş. Normal milli eğitimin verdiği okulda da duruyor, orda öğretmenlerini seviyor ama orda da yapıyor bazen. Bazı günler çok huysuzluklar yapabiliyor. … İnatla asla başarılı olamıyorsun yani başarılı olursun, onu da yıpratırsın kendin de yıpranırsın. Down sendromlarda şimdi daha fazla var, önceden birazcık daha küçükken biraz daha yenebiliyordum ama şimdi yenemiyorum.

3.5 The Ideal Image of The Motherhood

The perception of motherhood within the minds of mothers is influenced by a blend of societal norms, personal encounters, cultural impacts, and individual convictions. This perception can differ significantly among individuals. The mothers in the current study seemed to have an idealized image of motherhood that they behaved accordingly. The sub-ordinate themes were *powerful mother, devoted mother* and *merciful mother.*

3.5.1 Powerful Mother

In family, there are often established roles and hierarchies that can be influenced by cultural, traditional, or individual factors. Power dynamics exist within families, where parents typically hold authority and make significant decisions. However, the distribution of power can vary based on cultural and individual circumstances. According to the mothers who participated in the study, mothers are the ones who should be regarded as strong and listened to. As revealed by this subordinate theme, mothers believed they were the decision-makers regarding childbearing, possess the strength to care for a child with Down syndrome, and were the more 'listened-to members' of the family.

Mrs. B. described feeling quite strong after having a dream and how it helped her accept and raise her child. After giving birth, tests were conducted on Mrs. B due to doctors suspecting that the child may have Down syndrome. On the evening of the day, she took the test, before receiving the results, she had a dream. In the dream, she saw the word "Allah" (God) written on Mount Erciyes, which is not actually visible from an imaginary third balcony in her house. When she woke up, she described feeling a power within herself to embrace everything:

> Like, I had a tremendous power within me, I mean, I felt very strong, I felt like I had a power within me that could handle anything. When I accepted it internally, that acceptance thing didn't feel difficult for me. Thanks to God, it didn't turn into a difficult process for me.

> Böyle içimde müthiş bir güç vardı yani çok güçlü hissettim, hani ne olursa olsun her şeyi karşılayabilecek bir güce sahip hissettim kendimi. Onu içte kabullendiğim zaman bana zor gelmedi o kabulleniş şeyi, bende sıkıntılı bir süreç olarak geçmedi elhamdülillah.

Mrs. E mentioned that she decided to give birth to her child by herself. Mrs. E. stated firmly that she would not follow the doctor's recommendation to terminate the pregnancy if she learned that her child had Down Syndrome. She asserted that as the one carrying the child, she had the authority to make that decision. Taking birth and pregnancy into consideration, she expressed that mother was the one who holds strength in such situations:

> I mean, why would I terminate it? After all, it is entrusted to me by Allah. I said I don't want it, but he said you can't make that decision, your husband can also make the decision. I said I'm the one carrying the child, I will make the decision. … You know how they say 'men are strong, women are weak'; if you ask who is strong, I can say that it is mothers who are strong. During childbirth, and during pregnancy, women show a great, like, deal of serious effort.

> Ben bunu niye aldırayım yani? O da bana Allah'ın bir emaneti sonuçta. Ben dedim istemiyorum ama sen buna karar veremezsin eşin de karar verebilir dedi. Ben taşıyorum çocuğu ben karar veririm dedim. … Erkek güçlü, kadın güçsüz diye hani; güçlü kim derseniz ben annelerin güçlü olduğunu söyleyebilirim. Doğum anında, hamilelik anında çok yani ciddi efor sarf ediyor kadın.

Mrs. A. shared that her son was born with a heart condition and described the challenging process that required her to be strong until her child underwent surgery. Despite the difficulties, she expressed that as a mother, she felt it was her responsibility to go through this process and that it did not cause her any distress:

> A heart condition, due to his being severely ill with a heart condition, it was forbidden to breastfeed the child in order to prevent exhaustion. They taught me how to insert a tube from his mouth into his stomach. Every three hours, I emptied a whole cup of formula directly into his stomach. I took care of him like this for three months, after three months, he underwent surgery. After the surgery, all the heavy medications and everything ended, went away. … It was stressful and challenging, but we managed to get through it with a routine. I set an alarm on my phone every three hours. I consistently gave him his feedings at regular intervals, and even his crying was not allowed, so I did even make him cry. ... I also had other children, of course, but I always did it. I did it as a mother, instinctively, and it wasn't a problem.

> Kalp hastası, ileri derece kalp hastası olduğu için, yorulmaması için emzirmek yasaktı. Ağzından midesine kadar boru sokmayı öğrettiler bana. 3 saat arayla düzenli bir koca bir bardak mama boşalttım direk midesine. 3 ay böyle onunla ilgilendim, 3 aydan sonra ameliyat oldu. Bütün ağır ilaçları ve her şeyi bitti geçti bitti gitti kalp ameliyatıyla beraber. … Stresli oldu, zor oldu ama düzenle bunu atlattık. Telefonumu 3 saat arayla kurdum. 3 saat arayla düzenli mamasını verdim ve çocuğun ağlaması dahi yasaktı, ağlatmadım dahi. … Diğer çocuklarım da vardı tabii ama hep de yaptım. Anne olarak yaptım yani içgüdüsel olarak yaptım sıkıntı yok.

3.5.2 Devoted Mother

Being devoted refers to a strong commitment, loyalty, and dedication to someone or something. Being devoted often involves a sense of selflessness and a willingness to make sacrifices for the sake of what or whom one is devoted to. A devoted mother is someone who is deeply committed to the well-being, nurturing, and growth of her child or children. In the interviews, the mothers in this study emphasized that within the family, it is expected for the mother to be the one who makes sacrifices.

Mrs. B expresses what motherhood means to her and shared her thoughts on motherhood:

> Being a mother is a unique feeling that involves a lot of sacrifice, love, and compassion. ... And he (Ms. B's spouse) tries his best to support me, but as much as a mother, for a child, especially if they have a special child, I think that the greatest sacrifice should be made by the mother. I cannot imagine anyone else thinking about what is ahead of the child and their future as much as a mother does.

> Anne olmak demek bol bol fedakârlık, bol bol sevgi, bol bol şefkat içeren farklı bir duygu. … Ya o da (Bayan B’nin eşi) elinden geldiğince bana destek olmaya çalışıyor ama anne kadar, bir çocuk için, özellikle özel çocuğu varsa, en çok büyük fedakarlığı annenin yapması gerektiğini düşünüyorum. Hiç kimsenin anne kadar onun ilerisini, geleceğini düşüneceğini düşünemiyorum.

Mrs. A expressed her desire of being a good mother. While she was working in a job with her first two children, she made the sacrifice of quitting her job when she had a child with Down syndrome. She explained that by leaving her job, she was able to spend more time with her children, be a good mother, and that was why she was very happy:

> When I was 33 years old, I had a baby with Down syndrome. I took a break from my career at that point, and I am currently just taking care of the child right now. … I became happy because I became very happy when I quit my job. I used to want to become a mother when I grew up, I didn't want to pursue further education anyway. Being a mother is wonderful. I struggled to finish high school, but I said to myself that I would become a mother when I grew up. Then I became a very good mother. I have three beautiful children, like precious diamonds, and I am taking care of them, this is my job.

> 33 yaşında Down sendromlu bir bebeğim oldu, iş hayatına burada ara verdim ve sadece şu an çocukla ilgileniyorum … Çok mutlu oldum çünkü işi bırakınca çok mutlu oldum. Büyüyünce anne olmak istedim, okumak istemedim zaten. Anne olmak çok güzel. Liseyi zor bitirdim ama ben dedim ki büyüyünce anne olacağım. Sonra çok güzel bir anne oldum. Çok güzel 3 tane pırlanta gibi çocuğum var, onlarla ilgileniyorum işim bu.

After Mrs. C had a daughter with Down syndrome, she quit her job and started taking care of her daughter. In fact, she began studying child development because she was already interested in her daughter's development. According to her, the mother is crucial for a child, especially for a child with a diagnosis. Mrs. C believes that the ideal image of a mother is someone who takes care of and nurtures the child's development, and she herself has made sacrifices for this purpose:

> I used to work with my spouse, but I'm not working at the moment. What do I do after E. come home from school? When I say I'm not working, I said, I had started studying child development for E., now I am in third grade. About her, and different seminars, or about this, what can be done regarding her special education - I continue to improve myself about this topic… Indeed, a mother is very important in a child's life, it is important in the life of every child. However, in the life of a child with a diagnosis, the mother and well, the family, are very important.

> Eşimle birlikte çalışıyordum, şu anda çalışmıyorum. Efnem okuldan geldikten sonra he ne yapıyorum kendim çalışmıyorum derken, Efnem için çocuk gelişimi okumaya başladığımı söylemiştim 3. Sınıftayım şu anda onunla ilgili ve daha farklı hani seminerler veya hani bununla ilgili özel eğitimi ile ilgili neler yapılabilir, hani bu konuda kendimi geliştirmeye devam ediyorum. … Yani anne çok önemli bir çocuğun hayatında her çocuğun hayatında önemli ama tanısı olan çocuğun hayatında anne ve yani hani aile çok önemli.

3.5.3 Merciful Mother

Being merciful entails demonstrating compassion, forgiveness, and kindness towards others, particularly when circumstances may call for punishment or judgment. Some mothers described motherhood as being characterized by mercy.

Mrs. E. describes motherhood as being merciful:

> Because motherhood is very different; mothers experience the feeling of mercy very intensely. Fathers are not like that; you worry because there is too much compassion. … What does it mean to be a mother? Being a mother, there is a lot of compassion. I have four children, and you become one with all of them, each one is different. To try to meet all their needs, I don’t know, you need to create a Voltron or something.

> Annelik çünkü çok farklı, merhamet duygusunu çok yoğun yaşıyor anneler. Babalar öyle değil, merhamet duygusu fazla olduğu için endişeleniyorsunuz. … Anne olmak ne ifade ediyor? Anne olmak, merhamet duygusu çok fazla. 4

> tane çocuğum var, hepsiyle bir oluyorsunuz, hepsi farklı. Hepsine yetmeye çalışmak için ne biliyim böyle voltranı falan oluşturmanız gerekiyor.

Mrs. C says that she feels a sense of mercy not only towards her own child but towards all children with Down syndrome. Mrs. C. shared that she did not initially have a strong desire to become a mother, but when she became one, she loved it deeply. She mentioned that having a child with Down syndrome led her to experience motherhood with many other children as well. However, Mrs. C. also emphasized that excessive mercy can be more harmful than beneficial:

> I have had hundreds of children. And this is a really beautiful feeling because I don't really differentiate any of them from 'E'. But when they asked me to be involved in the management of the association, I didn't agree to it. Why? Because we are trying to blunt our sense of compassion. … There is a very beautiful quote from Mustafa Kemal Ataturk: 'Excessive mercy is treachery to the homeland. … We also need to withdraw this from E because our sense of compassion is doing more harm than good to her.

> Benim yüzlerce çocuğum oldu. Bu da çok gerçekten çok güzel bir duygu çünkü ben hiçbirini E'den gerçekten ayırmıyorum ama dernekte hani yönetimde olmamı istediler buna katılmadım. Neden? İşte merhamet duygumuzu törpülemeye çalışıyoruz. … Mustafa Kemal Atatürk'ün çok güzel bir sözü vardır 'Fazla merhamet vatana ihanettir' diye. … E'de de bizim bunu geri çekmemiz gerekiyor çünkü bunun E'ye yararı değil zararı oluyor bu merhamet duygumuzun.

3.6 Mothers' Perception of The Father

The last super-ordinate theme was mothers' perception of the father. Mothers' perceptions of fathers can range from positive, seeing them as supportive and actively involved in parenting, to negative, perceiving them as less involved or lacking in parenting abilities. Mothers spoke in various ways about fathers when discussing the time, they spent with their children and the period when they learned about their child's Down syndrome. The sub-ordinate themes were *emotional father*, *angry father, father without boundaries* and *uninvolved father.*

3.6.1 Emotional Father

The notion of an emotional father refers to a father who actively and openly expresses his emotions and engages in emotional connections with his family members. An emotional father recognizes and embraces his own feelings, allowing himself to be vulnerable and empathetic. Some of the participants described their spouses' sensitivity, their emotional nature and inability to accept the diagnosis of Down Syndrome.

Mrs. E stated that the process of accepting her child's diagnosis and condition was challenging for her spouse due to his emotional nature:

> I'm someone who has always acted like this from the beginning, I haven't had any problems bigger than me. Her father had a really hard time accepting it, her father is very emotional, it was a little difficult for him, but then he also accepted it.

> En baştan beri böyle hareket eden bir insanım boyumdan büyük sorunlar olmadı. Babası çok zor kabul etti, baba çok duygusal onun biraz zor geçti ama sonra o da kabullendi.

When asked to Ms. A how her spouse reacted to their child's diagnosis, she said that he cried a lot due to his emotional nature and expressed that being a mother was challenging for him because of this situation:

> He cried, cried and cried. Thank goodness they did not become a mother. … He cried a lot, felt very sad, got shocked a lot and couldn't accept it. That's why I'm saying it's good that he is not a mother, he wouldn't be able to handle it if he was one.

> Ağladı, ağladı, ağladı. İyi ki anne olmadı o. … O çok ağladı, çok üzüldü, çok şok oldu, kabul edemedi o. O yüzden diyorum ki iyi ki anne olmadı, anne olsaydı o başa çıkamazdı.

3.6.2 Angry Father

Anger is an inherent human emotion that emerges when people encounter perceived threats, injustices, frustrations, or difficult circumstances.

Mrs. C learned that her child had Down syndrome after giving birth, and her doctor stated that he did not notice anything abnormal in her tests or ultrasound images during pregnancy. She describes her husband's reaction to the doctor who could not notice Down syndrome before birth:

> My spouse had a harder time with this process. You know, how could the doctor not know something like this... He wanted to file a lawsuit or something, and I told him that it wouldn't work with a lawsuit or anything, a lawsuit would only wear us out more.

> Eşim bu süreci daha ağır geçirdi. Doktorun bunu bilememesinin nasıl bir şey olduğunu falan hani… Dava falan açmak istedi, ben de dedim ki davayla falan olmaz, dava bizi daha çok yıpratacak.

3.6.3 Father without Boundaries

Boundaries within a family refer to the guidelines, limits, and expectations that family members establish to maintain healthy relationships and their well-being. These boundaries might involve emotional and physical boundaries, personal space and privacy. Some mothers mentioned that their spouses were not successful in setting these boundaries effectively for their children.

Mrs. C described her spouse's difficulty in saying "no" to their daughter and how this has started to be harmful for their daughter:

> She sees the father as a means of socialization too, because our father doesn't know how to say no. I try to manage the father in most matters now because it's time to start saying no since it has started to harm E. Thinking that you can get everything you want, I mean, no matter whom you do it to, they will show the same reaction. I mean, it's not valid for 'E'. So now we are trying to step the father back a bit at this point.

> Babayı da sosyalleşme aracı olarak görüyor E biraz çünkü babamız biraz bizim hayır demeyi bilmiyor. Çoğu konuda babayı yönetmeye çalışıyorum çünkü artık hayır deme zamanı geldi. Çünkü bu E'ye zarar vermeye başladı. Her şeyi elde ettiğini düşünmek yani bunu kime yapsanız aynı şeyi yani reaksiyonu

> gösterir. Bu E için geçerli değil yani şimdi bu noktada babayı biraz geri çekmeye çalışıyoruz.

Also Mrs. D similarly stated that her spouse had difficulty in setting boundaries for their daughter under the guise of not to be dictatorial:

> She doesn't listen to her father much either. When I go somewhere, for example, I leave her with her father, and she wears the person out. She wears them down until they are drained away, she keeps doing things that they don't want and things that they asked her not to do. She does the opposite of everything in that way. … They are not enforcing dictatorship on her too much, and because they don't, she uses them.

> Babasını da çok dinlemez. Ben bir yere gittiğim zaman mesela babasına emanet edeyim artık bıktırır onları böyle. İyice can boğaza gelene kadar bıktırır, hep onların istemediği şeyleri, onların yapma dediği şeyleri yapar. O şekilde her şeyin tersini yapar. … Onlar çok fazla buna diktatörlük yapmıyorlar, yapmadıkları için de onları kullanıyor.

3.6.4 Uninvolved Father

An uninvolved father refers to a parent who has minimal or limited involvement in the upbringing and care of their child. Mothers described spending a day with their children as if it was just them and their children. They mentioned that since the father was the one working, he primarily spent time at work, and he did not participate in responsibilities such as taking the child to and from school, attending to the child's self-care needs, or helping with homework. They frequently reported that the father spent only a brief amount of time playing with their children when he returned from work. Although it was portrayed as if the father could not be involved, one mother stated that she did not want the father to be involved.

Mrs. B explained that she was more involved in her child's education and worried about it more, while her spouse was more relaxed in this regard. Although she generally handled it on her own, she expressed that she did not want her spouse's support:

> I mean, in general, as I said, a child's education mostly affects the mother. When a child cannot learn something, the father can be more relaxed and leave it to time, but I try different methods to teach the skill I want to teach, for example. He does support me, of course, but let me say to you that it is enough for me that he does not stop me.

> Hani genel anlamda dedim, çocukların eğitimi en çok anneyi etkiliyor. … Ya hani bir şey öğrenemediği zaman çocuk, baba daha çok zamana bırakıp daha böyle rahat olabilirken ben farklı farklı yöntemler deneyerek o öğretmek istediğim beceriyi öğretmeye çalışıyorum mesela. … Beni destekler tabii ama hani engel olmasın yeter gibi diyeyim ben size.

Mrs. A stated that when asked about her son's relationship with his father and the time they spend together, they do not spend much time together, and during this time, they usually play games:

> Onunla da işte top oynarlar, araba oynarlar, televizyon film bakarlar, öyle eğleniyorlar yani onunla da. … Yok o (Bayan A'nın eşi) gündüz çalışıyor, akşamları da biz genelde parkta oluyoruz. O ancak işte pazar günleri denk geldikleri sürece. Çünkü o çalışıyor ben çalışmıyorum.

> They play ball, cars, watch TV shows, and have fun together. ... No, he (Mrs. A's husband) works during the day, and in the evenings, we are usually at the park. It's only on Sundays if they coincide. Because he works, and I don't.

Similarly, Mrs. C explained that because her husband also works, he cannot spend much time with their child, so they try to make up for it on weekends because their daughter misses her father:

> Babasıyla işten geldikten sonra daha kısa vakit geçiriyor çünkü 7'de eşim işten geliyor. Yemek yiyoruz ancak ondan sonra uyku saati geliyor. Babasıyla hafta sonu daha fazla kaliteli zaman geçirerek doldurmaya çalışıyoruz bu boşluğu da yani çünkü babayı çok özlüyor.

> She spends less time with her father after he comes home from work because my husband gets off work at 7. We have dinner, but then it's time for sleep for

her. During the weekends, we try to fill this gap with more quality time with her father because she misses him a lot.

CHAPTER 4

DISCUSSION

This section entails an examination of the current study's results in the context of existing literature. This study aims to understand the subjective experiences of mothers with children with Down syndrome. Interpretative Phenomenological Analysis was used to examine the present data, as the goal was to gain a profound comprehension of the distinctive experiences of mothers with a child diagnosed with Down Syndrome. This study consists of questions about what mothers experienced after having a child with Down syndrome and the impacts of this situation on their lives.

The analysis revealed multiple super-ordinate themes: *the decision of giving birth, enmeshed boundaries with the child, struggle over education, characteristics of the child, the ideal image of the motherhood* and *mother's perception of the fathers,* respectively.

4.1 The Decision of Giving Birth

The first super-ordinate theme was the decision of giving birth and included the subordinate themes of *given by God* and *prior abortions of handicapped babies.*

All of the participating mothers learned that their children had Down syndrome after giving birth. The decision about childbirth here is related to how and in what manner they would decide whether to give birth to the baby if they had learned about it during pregnancy. The majority of mothers stated that even if they had learned about their children having Down syndrome during pregnancy, they would not choose to terminate the pregnancy. The assumption of not terminating the pregnancy and the aspect that mothers mostly emphasized during the process of learning about the diagnosis after birth came from a religious belief.

In the literature, religion stands out as one of the primary coping mechanisms for families with a disabled child. In this study, consistent with the literature, the most frequently expressed coping strategy for dealing with this situation and finding the strength to cope was 'given by God'. Commonly, Muslims believe in the concept that Allah knows everything, Allah's will shape one's life fate, and the term 'Islam' originates from the act of submission to God's will (Murata & Chittick, 1994). Here, mothers talked about the presence of a higher power over themselves, and because of their belief that pregnancy is also with Allah's permission, they said they would not go against this power and choose to terminate the pregnancy. Actually, this situation has somewhat relieved the mothers by taking the burden of decision-making responsibility from them. It must be something that can make the process easier for these mothers because they frequently mentioned that they did not struggle much when talking about the period after the diagnosis. The researchers observed that mothers tend to search for some kind of rationale or clarification for the circumstances they find themselves in, expressing anxieties about the exact cause of the disability (Barbosa et al., 2008). At this point, religion gives meaning to the uncertainty experienced by mothers; it becomes an answer to mothers' 'Why?' question as 'Because Allah willed it to be so,' which appears to facilitate the mothers' decision-making process.

Lacan proposes that this religious meaning would effectively mask the symptoms, enabling individuals to overlook limitations and dismiss what proves to be ineffective (Richardson, 1992). While having a child with Down syndrome can be challenging on its own, mothers discussed the additional difficulties arising from their children's other health issues due to the nature of the diagnosis. When asked about their experiences during the period after receiving the diagnosis, almost none of the mothers described it as a difficult process. The belief of 'given by Allah' in mothers serves as a function to prevent them from perceiving these issues as problems or difficulties, and it also acts as a barrier against potential symptoms that could arise in mothers. While religion functions as a protective factor and coping mechanism here, it also appears to make it difficult for mothers to experience and express their emotions openly. Therefore, when working with this kind of a group, the clinician should create a space where mothers feel comfortable discussing this topic.

Another topic is related to ‘prior abortions of handicapped babies’. A mother shared that she terminated her previous two pregnancies before giving birth to her daughter with Down syndrome because prenatal screenings indicated certain disabilities. She based on the reason for giving birth to her child with Down syndrome as the fact that it was not detected in any tests and screenings during pregnancy. If the diagnosis of this child had been detected during pregnancy, it would be possible to say that the mother might have chosen to terminate the pregnancy. This mother did not make any religious references related to her child's birth. She also did not mention any coping mechanisms, such as the social support mentioned above. From this perspective, considering that this mother could not cope with the situation, her decision to terminate the pregnancy seems reasonable. Although the situation may appear this way, the mother expressed regret for her previous two abortions, stating that doctors had advised her to terminate the pregnancies. It appears that the ease provided by the notion of 'given by God' in decision-making for other mothers is fulfilled by doctors in this case. Acting upon the advice of someone believed to know better, the mother chose to terminate her pregnancy, thereby lightening the burden of responsibility.

4.2 Enmeshed Boundaries with The Child

The second super-ordinate theme was enmeshed boundaries with the child and included the subordinate themes of *using ‘we’ language, always together* and *understanding without speaking.*

In psychoanalysis, the mother-child relationship during the early days after childbirth is explained as a symbiotic relationship. When a baby is born, it is completely dependent on someone else for care. It needs someone's assistance to meet its own needs, and most often, that someone is the mother. In such a way that even if the baby does not speak, the mother can understand and fulfill the baby's needs. However, this symbiotic-like relationship changes over time. As the baby grows, they begin to express their needs and take care of them independently. The mother also starts to step back from always being there to meet the child's needs. The child may still seek the mother's attention, and the mother may treat the child as her phallus. At this point, the symbolic father needs to intervene in this dual relationship. Thus, the mother and child can become separate from each other and become subject (Lacan, 1957).

During the interviews with mothers, it was noted that despite the children's ages ranging from 7 to 9, this dual relationship continued to persist. An example of this is mothers referring to both their children and themselves as 'we' while speaking about situations related to the child. Additionally, spending almost constant time together throughout the day and the continuation of the newborn period, where the mother understands the child without the need for the child to speak, can be cited as evidence of this. It seems that the mother and child have not achieved separation, and the boundaries within this relationship remain closely enmeshed.

Two significant factors that could contribute to the continuation of this dual relationship have been observed. The first one could be the nature of Down syndrome, which may require the child to rely on the mother for a longer period to meet their needs. While a typically developing baby learns to walk and start speaking a few words around 1-1.5 years old, a child with Down syndrome may have a much more variable learning process, and it can take them until the ages of 5-6 to achieve these milestones. Similarly, toilet training also occurs later compared to the normal developmental period. The prolonged dependency on the mother to meet their needs because they cannot fulfill them independently extends the duration of reliance on the mother. This seems to make it difficult for a boundary to be established in this dual relationship. Of course, besides the nature of Down syndrome, it is also true that mothers create an environment to continue meeting these needs. In the interviews, some mothers mentioned that their children could not do certain things alone, such as dressing or going to the toilet, but later in the conversation, they actually said that their children do these things alone. Some mothers also mentioned that actually, children with Down syndrome can do many things themselves, but it is necessary to allow them to do so. They said that when mothers continue doing things for them, the children find it easier, and as a result, they do not learn the behavior. In this case, whose need is it to continue this dual relationship and not set boundaries? Considering the mother's feeling of lack and her attempt to substitute her child for the phallus, these behaviors of the mothers appear to be consistent with the literature.

At this point, the father needs to intervene in this dual relationship, which leads us to the second factor. In the interviews, it was observed that in families with a child with Down syndrome, the family dynamics were structured in a way where the mother is the caregiver for the child, and the father is the provider for the family. Almost all of the participating mothers described the father's relationship with the child as merely playing together in the study. This indicates that fathers, the function of Name-of-the-Father, are insufficient in intervening in the relationship between the mother and child. As a result, the enmeshed boundaries in the mother-child relationship can become inevitable. Lacan (1957) emphasizes that the separation of this dual relationship is crucial for both the mother and the child to become a subject. Due to this, when working with this group, clinicians should focus on intervening in this dual relationship and drawing attention the mothers' subjectivity.

4.3 Struggle over Education

The third super-ordinate theme was struggle over education and included the subordinate themes of *mother as the educator, extra money needed for education, unwanted child in class* and *wrong information from the school.*

The mothers in the study identified the period and topic they struggled with the most, apart from their children's health issues, as the process of starting school and education. Children with Down syndrome need to start their education almost immediately after birth. As they are born with muscle weakness, their first form of education is usually physiotherapy. However, in order to receive this and other necessary education for free, they need to obtain a disability report. Without the report, these educations become paid services. Even with the report, the education hours are generally limited, varying between 2 to 4 hours per week, which is not sufficient in most cases. Mothers expressed their dissatisfaction with the lack of similar opportunities for children with Down syndrome, as they mentioned the existence of special schools and education programs for autism or other disabled children. While "gölge öğretmen" who can support autistic children in schools are provided free of charge, it seems that this opportunity is not offered to children with Down syndrome. The mothers' view is that the provided opportunities are not sufficient for the development of children with Down syndrome, and as a result, they need additional education. As a result of this insufficiency, the burden falls on families who want to promote their children's development.

Families have tried to compensate for this in two ways, one being the mother taking on an educational role, and the other being enrolling the child in paid extra lessons.

Mothers study with their children at home on what is taught at school or in the private education centers they attend. Moreover, there was a participant among the mothers who chose not to send their child to school because they found the education provided there insufficient and preferred to provide education at home by herself. Mothers have also sought external education by paying extra fees in areas where they felt they could not manage on their own. Mothers generally stated that this inadequacy in education is related to the opportunities provided by Turkey. They mentioned that they faced such issues because the different educational options and facilities they had heard of in European countries are not available in Turkey. Although they are currently able to afford extra education for their children, they pointed out that not every family in the country has such a chance. In addition to the lack of sufficient educational opportunities, one mother also shared her experience of her child developing a permanent health problem due to misinformation from teachers. It is observed that in Turkey, where opportunities for children and individuals with Down syndrome are already limited, the existing educators and professionals also have limited or incorrect knowledge in line with the literature, which can be considered as areas that need to be developed.

Another problem that mothers face regarding education was that when their children start primary school, teachers do not want to have these children in their classrooms. This can be either the teacher of a special education class specifically designated for disabled children or the teacher of the inclusive class where children considered suitable for inclusion will attend. At this point, mothers pointed out that the teachers' lack of knowledge about children with Down syndrome and their inadequacies in knowing how to provide education are the reasons behind the experiences they have faced. Although the mentioned lack of opportunities provided by the country exists, from a psychoanalytic perspective, there seems to be another significant deficiency, particularly concerning the mothers. Until primary school, despite facing their own problems, the educational institutions they visited for their children did not mention any deficiencies about their children to the mothers and provided education without seeing the diagnosis. However, with the start of primary school, teachers began to inform mothers about the things their children could not do. This can be interpreted as a more symbolic environment in which the mother encounters her child's disability and deficiency or lack. Although it was a situation concerning this child, mothers kept referring to their experiences of their children not being wanted, using the pronoun 'we' constantly. The intertwined boundaries with their children caused some mothers to experience the state of their children being unwanted as if they themselves were unwanted. It can be interpreted that they believe the deficiency experienced is caused by themselves, and they make extra efforts to complete it. From this perspective, the mothers' role as educators and the extra expenses they incur for education to compensate for this lack, and the experiences when teachers do not want their children in the classroom can be considered as the reactions mothers give when they encounter the lack.

4.4 Characteristics of The Child

The fourth super-ordinate theme was characteristics of the child and included the subordinate themes of *positive characteristics of the child* and *negative characteristics of the child.*

During the interviews, mothers frequently mentioned their children, what they could do, and what they could not do while answering the questions. While the majority of mothers talked about their children with positive references like "miracle," "child who rewards our efforts," and "happiness of the family," one mother emphasized the negative traits of her child, such as mischievousness and stubbornness. This situation can be considered in terms of the mother's acceptance of having a child with Down syndrome. According to studies in the literature, families with a disabled child go through various phases. This process begins with denial, progresses through grief and depression, and ultimately concludes with acceptance and adaptation.

Mothers who talked about their children's positive characteristic traits did not mention the phases mentioned in the literature, such as denial, grief, etc., when discussing the time, they learned about their child's Down syndrome and the subsequent process. Instead, they focused more on accepting the situation and what can be done for the future. They described focusing on the solution rather than dwelling on the problem, as engaging in the search for solutions is part of the adaptation process following acceptance. This state of acceptance appears to help mothers to concentrate on their children's more positive characteristics. These mothers also mentioned that, in addition to their children's positive traits, having a child with Down syndrome has added many things to themselves and their families. They spoke of it as opening a new window for them. They were very content with the time they spent with their children.

It can be said that the mother who frequently talked about her child's negative traits may be experiencing difficulty in accepting the situation. The mother, who had terminated her previous two pregnancies due to the babies being disabled, gave birth this time assuming there were no issues during pregnancy but then encountered that her baby had Down syndrome. The mothers who mentioned positive characteristics stated that learning about it during pregnancy would not change anything, and they would still give birth to their babies. In this case, it is possible to say that the mother who terminated her previous two pregnancies might have difficulty accepting that her daughter has Down syndrome. Although other mothers did not exhibit the phases observed in the literature, this mother's statements could potentially be included in the grief process. Children with Down syndrome experience delays in functions such as walking and speaking due to muscle laxity, and even as newborns, they may face difficulties in holding their heads up. The mother, who is trying to strengthen her child's muscles, described this process as trying to revive her child. One of the first things that come to mind when to revive is mentioned is the attempt to revive a person who is dead. Although she didn't directly say it in terms of death, it can be said that the mother went through a grief-like process and may not have reached the stage of acceptance yet.

4.5 The Ideal Image of The Motherhood

The fifth super-ordinate theme was the ideal image of the motherhood and included the subordinate themes of *powerful mother*, *devoted mother* and *merciful mother.*

In Lacan's work, identification holds a significant place (Evans, 1996). He highlights the role of the image and describes identification as "the transformation that occurs within an individual when they take on an image." (Evans, 1996). Taking on an image means recognizing oneself within that image and making it a part of one's own identity (Evans, 1996). This notion sheds light on how individuals construct their identity and sense of self through identification with certain images or representations, contributing to their understanding of themselves and their place in the world.

In the interviews, mothers were asked about what "motherhood" and "being a mother" meant to them. When answering this question, mothers actually talked about images of how a mother should be according to their own perceptions. Interestingly, the mothers portrayed themselves in a manner consistent with their descriptions of motherhood and family dynamics while narrating their relationships with their children. The mothers who advocate that they should be the ones who need to be strong are presented as the decision-makers regarding their children and as individuals who can navigate the process after the diagnosis more easily within the family. When looking at the statements related to the image of the devoted mother, it was noticeable that the mothers left their jobs to take care of their children. Additionally, one of the mothers explicitly stated that the most devoted parent among the parents is the mother because she can think about a child's future the most. One of the other most mentioned images related to motherhood was the merciful mother. The mothers who spoke about the merciful mother image mentioned that they struggled to set boundaries for their children due to their merciful behaviors.

As parallel to Lacan, it is observed that mothers have an ideal image of motherhood and they identify with this image to create a maternal identity that aligns with this ideal image. Additionally, the reason for these ideal images to emerge so prominently can be attributed to having a child with Down syndrome. For instance, for mothers with typically developing children, there may not be a need to leave their jobs, and if they do, the return-to-work period might be shorter. However, it seems different for a mother with a child with Down syndrome. Apart from the diagnosis, dealing with additional health issues and other challenges falls mainly on the mother, as she plays a fundamental caregiving role. Therefore, it is quite possible for the mother to have a stronger and more compassionate image in this context.

4.6 Mothers’ Perception of The Father

The last super-ordinate theme was mothers’ perception of the father and included the subordinate themes of *emotional father, angry father, father without boundaries* and *uninvolved father.*

Just as a mother holds significant importance in a child's life, the father is quite crucial. However, at this point, in addition to the father's own importance, the father's presence in the mother's language also holds great significance for the child (Lacan, 1957). During the interviews, mothers described their spouses' fatherhood in various ways. The first two are related to their reactions after learning that their children have Down syndrome. Mothers described their spouses as very emotional, and one of them recounted that her partner cried upon learning about their children's diagnosis of Down syndrome. Another mother also mentioned that her partner got angry with the obstetrician for not understanding anything about Down syndrome during pregnancy and wanted to sue the doctor. These reactions are actually normal responses that a person might have when facing a challenging situation, and they are also among the emotions that parents of disabled children may experience, as observed in studies in the literature. In this context, a different and significant aspect is the mothers' statements about fathers' reactions, such as 'It's a good thing that he's not the mother; otherwise, he wouldn't have been able to handle it,' or the mothers' explanations that fathers are not as strong as they are. It is mentioned that the role of the father in the mother-child relationship may not be fully effective by itself, as it is also essential for the mother to acknowledge and accept the father's "no" and authority (Fink, 1957; Ruhs & Bernstein, 2015). When considering mothers' statements about fathers from this perspective, it appears that children may perceive fathers as lacking authority, as they do not fully acknowledge the father's role. This could potentially diminish the father's position in the eyes of the children.

Similarly, some mothers mentioned that fathers have difficulty setting boundaries for their children, saying "no," and in the context of the father-child relationship, they seem to be more like playmates rather than authority figures. Some mothers stated that they are the ones who are listened to at home and that they are working on setting boundaries with fathers as well. Considering the mothers' statements about fathers, the issue of fathers not being able to set boundaries is actually about whom? One mother hardly mentioned her child's relationship with his father. In the parts she mentioned, she described the father as someone who is not very involved in the child's education, someone who does not try different ways if the child is not learning something, and just waits for time to pass. However, later on, the same mother actually said that it would be better for the father to remain in the position of being there, without being an obstacle. While she mentioned that the father is not involved, the person who does not want the father to intervene actually seems to be the mother herself.

In conclusion, while working with this group, attention can be given to the ongoing dyadic relationship between mothers and children, the lack of intervention from fathers in this relationship due to mothers’ discourse, and whether mothers accept their children's conditions or not.

CHAPTER 5

LIMITATIONS AND FURTHER IMPLICATIONS

The current study was conducted with mothers of children with Down syndrome. The study only required that the children with Down syndrome attend primary school. The reason for this was that children who had already started primary school had passed milestones such as speaking, walking, and the beginning of school. However, when looking at it, homogeneity of the sample is an important criterion in interpretative phenomenological analysis. Therefore, future studies can make the sample more homogeneous by adding criteria such as mothers' age at childbirth, children's age, and gender. Furthermore, in this study, some of the children with Down syndrome were only children, while others had sisters or brothers. This could be another criterion to consider in future studies. Although there was no criterion such as mothers learning about their children having Down syndrome after birth, all the participating mothers were in this situation. However, there are also families who learn about this condition during pregnancy and make the decision to give birth. Working with participants in this way in future studies can contribute to the literature.

CHAPTER 6

CONCLUSION

To conclude, this study reveals the experiences of mothers with children with Down syndrome. One of the most common experiences of mothers who participate in the study can be described as the dual relationship they establish with their children, and the inability to involve the father or a third party in this relationship. While it is a known fact that children with Down syndrome inherently require longer-term care, mothers appeared to sustain their children's need for them through various behaviors. Additionally, because mothers spend a lot of time with their children with Down syndrome, the time allocated to their other children and spouses also decreased. For these reasons, clinicians can emphasize who the excessive attention to the child is needed for or consider the subjectivity of the mother when working with such a group.

Another experience encountered is the acceptance of having a child with Down syndrome. The mothers in this study learned about their children's condition after birth. While the majority of mothers who generally described it as an unexpected situation stated that they accepted the situation, there were also some mothers who could not accept it. The process of acceptance can be addressed when working with these mothers in therapy. Besides acceptance, almost all mothers explained that they were not provided with any opportunities to facilitate the process they were going through by the state. While discussing this, they also described the opportunities provided in developed countries and generally stated that such a situation does not exist in Turkey. It is anticipated that the efforts and opportunities developed for these groups will make the lives of mothers and these families easier.

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APPENDICES

A. APPROVAL OF THE METU HUMAN SUBJECTS ETHICS COMMITTEE

UYGULAMALI ETİK ARAŞTIRMA MERKEZİ
APPLIED ETHICS RESEARCH CENTER

ORTA DOĞU TEKNİK ÜNİVERSİTESİ
MIDDLE EAST TECHNICAL UNIVERSITY

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

Sayı: 28620816 /

20 MAYIS 2022

Konu : Değerlendirme Sonucu

Gönderen: ODTÜ İnsan Araştırmaları Etik Kurulu (İAEK)

İlgi : İnsan Araştırmaları Etik Kurulu Başvurusu

Sayın Prof. Dr. Tülin GENÇÖZ

Danışmanlığını yürüttüğünüz Pınar Edacan Karakaş'ın "Down Sendromlu Çocuğu Olan Annelerin Öznel Deneyimleri" başlıklı araştırması İnsan Araştırmaları Etik Kurulu tarafından uygun görülmüş ve **0260-ODTUİAEK-2022** protokol numarası ile onaylanmıştır.

Saygılarımızla bilgilerinize sunarız.

Prof.Dr. Mine MISIRLISOY
İAEK Başkan

B. INFORMED CONSENT FORM

Bu araştırma, ODTÜ Psikoloji Bölümü Yüksek Lisans öğrencisi Pınar Edacan Karakaş tarafından Prof. Dr. Tülin Gençöz danışmanlığındaki yüksek lisans tezi kapsamında yürütülmektedir. Bu form sizi araştırma koşulları hakkında bilgilendirmek için hazırlanmıştır.

Bu çalışmanın amacı Down Sendromlu çocuğu olan annelerin öznelliklerine odaklanılarak yaşadıkları deneyimleri ve bu deneyimleri nasıl aktardıklarını analiz etmektir.

Araştırmaya katılmayı kabul ederseniz, sizden bir görüşmeye katılmanız beklenmektedir. Yaklaşık olarak 60-90 dakika sürmesi beklenen bu görüşmede sizlere bir dizi açık uçlu sorular yöneltilecektir. Görüşme esnasında sonrasında değerlendirilmek üzere cevaplarınızın ses kaydı alınacaktır.

Araştırmaya katılımınız tamamen gönüllülük temelinde olmalıdır. Çalışmada sizden kimlik veya kurum belirleyici hiçbir bilgi istenmemektedir. Cevaplarınız tamamıyla gizli tutulacak ve sadece araştırmacılar tarafından değerlendirilecektir. Katılımcılardan elde edilecek bilgiler toplu halde değerlendirilecek ve bilimsel yayımlarda kullanılacaktır.

Görüşme, genel olarak kişisel rahatsızlık verecek sorular veya uygulamalar içermemektedir. Ancak, katılım sırasında sorulardan ya da herhangi başka bir nedenden ötürü kendinizi rahatsız hissederseniz görüşmeyi yarıda bırakıp çıkmakta serbestsiniz. Böyle bir durumda görüşmeyi yapan kişiye çalışmadan çıkmak istediğinizi söylemek yeterli olacaktır.

Görüşme sonunda, bu çalışmayla ilgili sorularınız cevaplanacaktır. Bu çalışmaya katıldığınız için şimdiden teşekkür ederiz. Çalışma hakkında daha fazla bilgi almak için Psikoloji Bölümü öğretim üyelerinden Prof. Dr. Tülin Gençöz ya da yüksek lisans öğrencisi Pınar Edacan Karakaş ile iletişim kurabilirsiniz.

Yukarıdaki bilgileri okudum ve bu çalışmaya tamamen gönüllü olarak katılıyorum.

(Formu doldurup imzaladıktan sonra uygulayıcıya geri veriniz).

İsim Soyad	Tarih	İmza
	---/----/-----	

C. SEMI-STRUCTURED INTERVIEW QUESTIONS

1. Kendinizi tanıtabilir misiniz?
2. Hamilelik sürecinizden bahsedebilir misiniz? Bu süreç sizin için nasıldı?
    - 2.1. Hamile olduğunuzu öğrendiğiniz zamandan bahsedebilir misiniz?
3. Bebeğinizin Down sendromlu dünyaya geleceğini nasıl öğrendiniz?
    - 3.1 Bu haber sizi nasıl etkiledi?
    - 3.2 Bu bilgi öncesi ve sonrasında hamilelik sürecinizi kıyaslarsanız, farklar oldu mu?
4. Hamileliğinizin tanı konulduktan sonraki döneminden bahsedebilir misiniz?
5. Doğumu gerçekleştirme kararını verme sürecinizden bahsedebilir misiniz?
    - 5.1 Eşinizin bu süreçteki tutumu nasıldı?
6. Eşinizle ilişkiniz nasıldır?
7. Çocuğunuzun gelişiminden bahsedebilir misiniz?
8. Çocuğunuzun aile bireyleri ile ilişkilerinden bahsedebilir misiniz?
9. Anne olmak sizin için neler ifade ediyor?
10. Çocuğunuz ile ilişkinizden bahsedebilir misiniz?
    - 10.1. Çocuğunuzla birlikte nasıl vakit geçiriyorsunuz?
    - 10.2. Çocuğunuzla birlikte ne kadar vakit geçiriyorsunuz?
    - 10.3. Çocuğunuzla birlikteyken bulunduğunuz sosyal ortamlardan bahsedebilir misiniz?
    - 10.4. Çocuğunuzdan ayrı olduğunuz zamanlarda nasıl hissedersiniz?
11. Down sendromlu çocuğunuz olması yaşamınızı etkiledi mi? Nasıl?
12. Çocuğunuzun ilkokula başlamasıyla çocuğunuzun hayatında değişiklikler oldu mu? Nasıl?
13. Çocuğunuzun ilkokula başlamasıyla sizin hayatınızda değişiklikler oldu mu? Nasıl?
14. Okul yaşamı çocuğunuzu nasıl etkiledi?
15. Okul görevlileri ve diğer velilerle etkileşiminiz var mı? Nasıl?
16. Görüşmede benim sormadığım ama sizin eklemek istedikleriniz var mı?

D. TURKISH SUMMARY / TÜRKÇE ÖZET

1. GİRİŞ

1.1 Down Sendromu Nedir?

Genetik bir bozukluk olan Down sendromu, trizomi 21 olarak da bilinir ve 21. kromozomun ekstra bir kopyasının, tamamen veya kısmen var olmasıdır (Diamandopoulos & Green, 2018; Sheets, et al., 2011). Ortaya çıkma sebebindeki faktör sayısı tam olarak bilinmemekle birlikte, sadece anne ya da baba veya hem anne hem babadan kaynaklanabilir (Perkins, 2017). En sık rastlanan risk faktörü ilerlemiş anne yaşı olarak belirlenmiştir.

Down sendromu, bebek anne karnındayken çeşitli kan ve tarama testleriyle teşhis edilebileceği gibi doğumdan sonra da teşhis konulabilir (Diamandopoulos ve Green, 2018). Down sendromuna özgü bazı belirli fiziksel özellikler bulunmaktadır, bunlar arasında kısa boyun, küçük kulaklar, düz burun köprüsü gibi özellikler yer almaktadır. Down sendromlu bireyler, bu fiziksel özelliklerin ötesinde konuşma ve dil gelişiminde gecikmeler, kalp hastalıkları, görme ve işitme sorunları ve tiroid hastalığı gibi sağlık ve gelişimsel sorunlar da yaşarlar (Ivan & Cromwell, 2014; Perkins, 2017).

1.2 Literatürde Down Sendromu

Down sendromu üzerine literatüre özellikle nitel araştırmalar açısından bakıldığında, genellikle ailelerle yürütülen araştırmaların hâkim olduğunu görülüyor. Bu araştırmaların amaçları hamilelikte yapılan tarama testlerine ve kürtaja olan bakış açısı, hamilelikte tanı alma ve doğum kararı, Down sendromuna dair tutumlar veya Down sendromlu bir çocukla yaşamanın nasıl olduğu şeklinde ifade edilebilir.

1.3 Anne ve Çocuk İlişkisi

İnsan dünyaya geldiği an itibariyle yalnız bir varlık değildir ve hayatın ilk yıllarında özellikle anne ve baba ile bir ilişki içine girer (Mitchell & Black, 1995). Bir çocuğun ebeveynleriyle olan bağı, gelecek ilişkileri için önem taşır (Sarup, 1992). Bir anne ile çocuk arasındaki bağ, bebek dünyaya gelmeden önce bir annenin çocuğunu hayal etmesiyle başlar (Pubic & Dapic, n.d.). Bebek bekleyen anneler sık sık hamilelik sırasında gelecekteki çocuklarını, cinsiyetlerini, fiziksel özelliklerini, duygusal özelliklerini ve doğumdan sonra geliştirecekleri ve besleyecekleri derin bağlantıyı düşünür.

1.3.1 Anne ve Çocuk İlişkisine Psikanalitik Bakış

Psikanaliz alanında, anne-çocuk ilişkisine psikanalitik bakış büyük öneme sahiptir; bu, Sigmund Freud tarafından kurulan ve daha sonra diğer psikanalistler tarafından detaylandırılan bir psikolojik teori ve terapötik yaklaşımdır (Yaacob, 2006).

1.3.1.1 Freud’un Teorisi

Freud'un hastalarıyla yaptığı seanslara dayanarak, Freud hastalarının mevcut çatışmalarının ve semptomlarının neredeyse her zaman erken çocukluk dönemindeki olaylarla bağlantılı olduğuna inanıyordu (Mitchell & Black, 1995). Erken çocukluk döneminde çocuğun en çok etkileşimde bulunduğu kişi genellikle annesidir. Freud'un teorisinde anne-çocuk ilişkisini anlamak için belirli kavramlar ve gelişimsel süreçlerden bahsetmek gereklidir.

1.3.1.1.1 Oidipus Kompleksi

Freud, Oidipus kompleksini, bireyin ebeveynlerine karşı yaşadığı hem sevgi dolu hem de düşmanca olan bilinçdışı arzular olarak tanımlar. Bu kompleks içinde, birey bir ebeveyne yönelik bir arzu geliştirir ve diğer ebeveyne karşı rekabet duygusu oluşturur (Mitchell & Black, 1995). Oidipus kompleksi, çocuk üç yaşındayken ortaya çıkar ve beş yaşına kadar azalır (Evans, 1996). Freud'a göre, Oidipus kompleksinin çözülmesi, "kastrasyon kaygısı tehdidi" yoluyla gerçekleşir (Mitchell & Black, 1995, p. 41).

1.3.1.1.2 Kastrasyon Kaygısı

Freud'un kuramında, kastrasyon kompleksi, psikoseksüel gelişimin bir aşamasını temsil eder (Evans, 1996). Başlangıçta, çocuk herkesin bir penise sahip olduğuna inanır; bu nedenle kastrasyon kompleksi, önceki çocukluk teorisinin yeni bir inançla, yani dişilerin kastrasyona uğradığı inancıyla değiştirildiği dönemin dönüm noktasını temsil eder (Evans, 1996). Erkekler, kendi cinsel organlarının babaları tarafından alınacağı korkusunu yaşarlar (kastrasyon kaygısı). Buna karşılık, kızlar kendilerini zaten genital organlardan yoksun olarak algılarlar, bunun annelerinin eylemleri sebebiyle gerçekleştiğine inanırlar (anne tarafından kastrasyon). Çocuk, kastrasyon kaygısı nedeniyle rakip ebeveyne özdeşleşir (Evans, 1996).

1.3.1.2 Mahler'in Teorisi

Macar psikanalist Margaret Mahler, yeni doğanlar ve küçük bebeklerin dış dünyaya "uyumlu" olmadıkları gerçeğine dikkat çekerek, bir insan yavrusunun biyolojik doğumu ile psikolojik doğumunun örtüşmediğini savunur (Pubic & Dapic, n.d.; Vahip, 1993). Mahler, psikolojik doğumu ayrı bir birey olma süreci olarak tanımlar ve en ilkel düzeyde kendi kimliğini kazanmayı içerir (Vahip, 1993).

1.3.1.3 Winnicott'ın Teorisi

Winnicott'a göre, bebeklerin hayatın ilk aylarını nasıl deneyimlediği, birey olarak gelişimleri için kritiktir (Mitchell & Black, 1995). Bu sonucu belirlemede annenin sağladığı çevre belirleyici bir rol oynar. Annenin gerektiğinde varlığı son derece önemlidir, ancak gereksiz olduğunda geri çekilmesi de o kadar önemlidir. Winnicott, bu ruh halini 'yeterince iyi anne' olarak tanımlar. Anne bunu yaparak bebeğe, bebeğin bilinçli olarak farkında olmadığı hem fiziksel hem de psikolojik bir korunma alanı oluşturur (Mitchell & Black, 1995).

1.3.1.4 Lacan'ın Teorisi

Çocuk doğumla birlikte savunmasız bir durumdadır ve beslenme ve rahatlama sağlamak için genellikle annelerine güvenirler (Owens & Almqvist, 2018).

1.3.1.4.1 Anne ve Çocuk Arasındaki İkili İlişki

Lacan, doğumdan hemen sonra gelişen anne ile bebek arasındaki kaynaşma benzeri ilişkiyi "imgeselde olma" olarak tanımlar (Hook, 2006). Lacan, anne ile yeni doğan bebek arasındaki bu güçlü bağı kavramlaştırırken fallus kavramını anlamanın önemini vurgular. Freud, cinsiyetlerine bakılmaksızın çocukların penis üzerine önemli bir vurgu yaptığını ve bazı bireylerin buna sahip olmadığını fark etmelerinin önemli psikolojik sonuçlar doğurduğunu öne sürer (Evans, 1996).

Freud, annenin hissettiği eksiği tartışır ve kızların penisin eksikliğini fark ettiklerinde, Lacan'ın terimleriyle ifade edildiği gibi, bir şeyi kaybetme duygusu yaşadıklarını ve bu eksiğin simgesel telafisi için bir çocuk sahibi olma isteğini tetiklediğini belirtir (1924d; Fink, 1997). Freud'un ardından, Lacan çocuğun, annenin eksiği olan simgesel fallusun yerine geçtiğini iddia eder (Evans, 1996). Anne ile çocuk arasında kurulan bu ikili ilişkiye müdahale edilmesi gerekir ve bunu da baba figürü yapar (Fink, 1997).

1.3.1.4.1.1 Baba'nın-Adı

1950'lerde Lacan, bilinçdışındaki temel kompleks olarak Oidipus kompleksini kabul etmeye devam etmesine rağmen, Freud'dan birkaç önemli açıdan ayrıldı (Evans, 1996). En dikkate değer farklılık, Lacan'a göre özne her zaman annesini arzularken, baba her zaman öznenin cinsiyetine bakılmaksızın rakip rolünü üstlenir. Bu nedenle Oidipus kompleksi içindeki kilit rol, annenin ve çocuğun ilişkisini simgesel bir yapıya dönüştüren önemli bir öğe olarak BABA'ya atfedilir. Simgesel baba aynı zamanda Baba'nın-Adı olarak da bilinir (Evans, 1996).

1.4 Engelli Bir Çocuğa Sahip Olmak

Engelli çocukların bakımı, özel bakım gereksinimleri nedeniyle özel dikkat ve destek gerektirir (Sen & Yurtsever, 2007). Bu çocuklar genellikle günlük aktivitelerinde yardım için başkalarına güvenirler, bu nedenle engelli çocukları olan aileler, yeterli bakım sağlama konusunda zorluklarla karşılaşabilirler (Sen & Yurtsever, 2007).

1.4.1 Ebeveynlerin Duygusal Tepkileri

Engelli bir çocuğa sahip olmak suçluluk, suçlama, hayal kırıklığı ve dışlanmışlık hissi gibi duyguları tetikleyebilir (Fereidouni et al., 2021). Sonuç olarak, bu duygular yas veya depresyon olarak ortaya çıkabilir (Fereidouni et al., 2021). Bu duygusal tepkiler, üç temel gruba ayrılabilir: birincil, ikincil ve üçüncül tepkiler (Kearney ve Griffin, 2001; Sen ve Yurtsever, 2007). Birincil tepkiler şoku, inkârı, acıyı ve depresyonu içerir; ikincil tepkiler suçluluk, kararsızlık, öfke ve utanma hissini içerir; üçüncül tepkiler ise pazarlık, kabul ve uyum içerir.

1.4.2 Engelli Bir Çocuğa Sahip Olmanın Zorlukları

Yapılan bir çalışmada zorluklarla en çok annelerin karşılaştığı görülmüş (Barbosa et al., 2008). Bu çalışmaya göre engelli bir çocuğa sahip anneler gittikleri ortamlarda bakışlara, rahatsız edici yorumlara maruz kalıyor ve dışlanma gibi durumlar yaşayabiliyorlar. Sağlık çalışanlarından yeterli ilgi ve bilgi desteğinin gelmemesi de annelerin ve ailelerin bu duruma uyum sağlamasını zorlaştırıyor (Barbosa et al., 2008).

1.4.3 Başa Çıkma Yolları

Annelerin acısı ve kişisel yolculuğu, onları manevi bir şekilde cevapları aramaya yönlendirir (Barbosa et al., 2008). Din aracılığıyla, gerçeği anlamalarına yardımcı olan ve onları gerçekle yüzleşmeye ve kabul etmeye olanak sağlayan bir destek bulurlar (Barbosa et al., 2008). Freud'a göre, dinler, kendini "gerçeğin hayali yeniden şekillendirilmesi" yoluyla acıdan korunma aracı olarak önerilmiştir (Freud, 1930a). Bu bakış açısından, din, bireylere sosyal kimliklerinin yükünü taşıma konusunda yardımcı olma aracı olarak hizmet eder (Malone et al., 2000).

1.5 Çalışmanın Amacı ve Araştırma Sorusu

Bu çalışmanın amacı, Down sendromlu çocukları olan annelerin deneyimlerini incelemektir. “Down sendromlu çocukları olan annelerin deneyimleri nelerdir?" sorusuna odaklanmaktadır.

2. METODOLOJİ

2.1 Nitel Araştırma

Nitel araştırmalar genellikle anlamın keşfini öncelikli olarak görürler, insanların dünyayı ve deneyimlerini nasıl yorumladıklarına ve anlam verdiklerine odaklanırlar (Pietkiewicz & Smith, 2014). Bu yaklaşım, katılımcıların kendilerini daha özgürce ifade etmelerine olanak tanır ve daha derinlemesine bir araştırma sürecine yol açar (Pietkiewicz & Smith, 2014).

2.2 Yorumlayıcı Fenomenolojik Analiz

Yorumlayıcı fenomenolojik analizin (YFA) amacı, araştırma konusu olan olguyu bu deneyimi doğrudan yaşayan bireylerin bakış açısından anlamaktır (Smith, Flowers ve Larkin, 2009). Bu tezde de katılımcıların öznel deneyimleri çalışıldığı için yorumlayıcı fenomenolojik analiz kullanılmıştır.

2.3 Katılımcılar ve Örneklem Yöntemi

IPA yönergelerini takip ederek, bu çalışma homojen gruplar ve amaçlı örnekleme yöntemini kullanmaktadır (Smith, Flowers ve Larkin, 2009). Çalışmaya Down sendromlu çocuğu olan beş anne katılmıştır. Çocukların yaşları 7 ve 9 arasında değişmektedir. Görüşmeler çevrimiçi şekilde yapılmıştır.

2.4 Prosedür

Görüşmelerde yarı-yapılandırılmış sorular kullanılmıştır. Bu görüşmeler yaklaşık 60-90 dakika arası sürmüştür. Yarı-yapılandırılmış sorularla katılımcıların serbestçe konuşmalarına olanak sağlanmıştır. Gizliliğin korunması amacıyla katılımcıların isimleri harflerle değiştirilmiştir.

2.5 Veri Analizi

Görüşmelere ses kaydına alınmış, sonrasında deşifre edilmiştir. Deşifre edilen görüşmeler YFA'ya uygun şekilde analiz edilmiştir ve bu analiz sonucu oluşturulan temalar, üst ve alt temalar şeklinde gruplandırılmıştır. Bu çalışmada altı tane üst tema çıkmış olup şu şekildedir: *doğum kararı, çocukla iç içe geçmiş sınırlar, eğitimdeki mücadele, çocuğun karakteristik özellikleri, ideal annelik imgesi ve annelerin baba algısı.*

2.6 Çalışmanın Güvenilirliği

Nitel çalışmalar sosyal geçerlik, öznellik, veri yeterliliği ve yorum yeterliliği gibi yöntemler kullanarak çalışma güvenilirliğini sağlarlar (Morrow, 2005).

2.6.1 Özdönüşümsellik

Bu çalışmanın yapılma amacı kendi deneyimlerime dayanmaktadır. Benim de şu anda 15 yaşında olan Down sendromlu bir kardeşim var ve doğduğunda henüz olayları ve özellikle annemin yaşadıklarını anlamlandıramayacak yaştaydım. Bu durum da beni, kendi annemin yaşadıklarına olan merakım sebebiyle benzer durumdaki annelerin neler yaşadığı hakkında düşündürmeye başladı.

3. SONUÇ

Bu çalışma altı tane üst temadan oluşmaktadır. Bunlar: *doğum kararı, çocukla iç içe geçmiş sınırlar, eğitim konusunda mücadele, çocuğun karakteristik özellikleri, ideal annelik imgesi ve annelerin baba algısı.*

3.1 Doğum Kararı

Bu üst tema *'Allah' tarafından verildi* ve *önceki engelli bebek kürtajları* şeklinde iki alt temadan oluşmaktadır.

3.1.1 'Allah' tarafından verildi

Annelerin çoğunluğu, çocuklarının Down Sendromu olduğunu doğum anına kadar bilmediklerini söylediler, ancak bilseler bile çocuğun Allah tarafından verildiğine inandıkları için bu çocukları aldırmayacaklarını ifade ettiler. A. Hanım yaşı gereği istenen testleri yaptırmak istemediğini çünkü ne olursa olsun çocuğunu aldırmayacağını belirtti:

> Ne olursa olsun 7 aylık bebeğimi de aldırmayacağım için hiçbir teste girmedim. … Allah verdi dedim yürüdüm sıkıntı yok yani Allah böyle kararlamış bitti, onun üzerine konuşacak bir şey yok her şeyde bir hayır olduğuna inanan biriyim inançlı biri olduğum için çok rahatlıkla kaldırdım.

3.1.2 Önceki engelli bebek kürtajları

D. Hanım Down sendromlu çocuğundan önce 2 kez engelli bebek kürtajı yaptırdığını anlattı ve bunun sebebini de teşhislerin hamilelik öncesi belli olması olarak açıkladı. Down sendromlu çocuğunda ise hamilelikte hiçbir şeyin belli olmadığını ve bu sebeple doğum yaptığını söyledi. D. Hanım'ın çocuğunun durumu hamilelikte belli olsaydı önceki kürtajlara bakıldığında doğum kararı almayabileceği yönünde olabilirdi.

3.2 Çocukla İç İçe Geçmiş Sınırlar

Bu üst tema, *'biz' dilini kullanmak, her zaman birlikte* ve *konuşmadan anlaşmak* alt temalarını içermektedir.

3.2.1 'Biz' dilini kullanmak

Çocuklarının deneyimlediği zorlukları ve gelişim süreçlerini anlatırken, anneler kendilerini ve çocuklarını bireyler olarak ayırmadan "biz" zamiri kullanmışlardır. Bu konula ilgili olarak C. Hanım şöyle anlatmıştır:

> Ana okul süreci**miz** başladı, ana okul sürecinde çok çok güzel bir süreç geçir**dik**. … Anaokulu sürecinde E'yi kaynaştırma öğrencisi olarak çünkü raporu**muz** olduğu için bu şekilde başlattık. … Şu anda ikinci sınıfa geç**tik** gayet güzel notlarında gayet başarılı, tiyatro korku**muz** vardı. … 10 aylıkken adım atmaya başladı 21 aylıkken tam yürüme noktasına gel**dik**, anaokuluna başlayana kadar o sütleri kullan**dık**. … Babayı da sosyalleşme aracı olarak görüyor E. biraz çünkü baba**mız** biraz **bizim** hayır demeyi bilmiyor. ... **Bizim** hem anneanne**miz** hem babaanne**miz** sağ.

3.2.2 Her zaman birlikte

Anneler, günlerinin büyük bir kısmını çocuklarıyla geçirdiklerini açıkladılar. Çocuklarını okul saatlerinde yalnız bırakamadıklarını belirterek, onları okula yanlarında götürdüklerini ifade ettiler. Ayrıca, okul dışında, eğitimsel etkinliklere katılmak veya çocuklarının davranışlarını denetlemek için birlikte vakit geçirdiklerini belirttiler. D. Hanım şöyle anlattı:

> Sürekli beraberiz, sürekli beraberiz. … Normal çocuklar gibi emanet edemiyorsun bir şeyi, muhakkak tuvalette de yanında olman gerekiyor

> lavaboya gittiğinde de. … Tuvalette de yanında olman gerekiyor yemek yerken de yanında olman yani kesinlikle tek başına bırakamıyorsun.

3.2.3 Konuşmadan anlaşmak

Bu çalışmada, anneler çocuklarıyla konuşmadan bile iletişim kurduklarını ifade ettiler. Beden dili veya sadece göz teması gibi sözsüz iletişim aracılığıyla çocuklarının isteklerini ve düşüncelerini anladıklarını söylediler. A. Hanım bu şekilde çocuğuna tuvalet eğitimi verdiğini anlattı:

> Beden diliyle derdini anlatıyordu zaten. Tuvaletin geldiğini hissettiriyordu, bana söylüyordu. Gözümün içine baktığı zaman ben anlıyordum artık onu sıkıntı yok, sıkıntı yaşamadım. 1 yaşında kurtarmıştım bezden yani.

3.3 Eğitim Konusunda Mücadele

Bu üst tema, *eğitimci olarak anne, eğitim için gereken ekstra para, sınıfta istenmeyen çocuk* ve okuldan yanlış bilgi alt temalarını içerir.

3.3.1 Eğitimci olarak anne

Down sendromlu çocukların erken yaşta eğitime başlamaları gerektiği gerçeği nedeniyle anneler, çocuklarının eğitimine aktif olarak katılıyorlar. Bu çalışmadaki annelerin birçoğu, çocuklarına sunulan eğitimin yetersiz olduğunu fark ettikleri için öğretmen gibi davrandıklarını anlattılar. B. Hanım eğitimi yetersiz bulduğu için çocuğunu okula göndermeyip çocuğunun eğitimini kendisinin verdiğini söyledi.

3.3.2 Eğitim için gereken ekstra para

Anneler, devlet okullarının yeterli eğitim sağlamadığını açıkladılar, bu nedenle çocukları için birçok özel ders öğretmenleri ve bakıcılar veya 'gölge öğretmenler' tutmak zorunda kalmışlar. E. Hanım bu konula ilgili olarak şöyle anlattı:

> 2 aylıkken B, fizyoterapiste başladık özel, haftada 3 gün ve o bize çok kazandırdı. B. 1.5 yaşındayken yürümeye başladı fiziksel olarak çok iyi durumda ama o imkânı olmayan binlerce aile var. … Bir yaşında da bireysel eğitime başladı, o da evde özel alıyorduk sonra kuruma da başladım. … Özel dersleri vardı, fazlasıyla özel dersleri vardı onları mecburen bırakmak zorunda kaldık, o şekilde geçiyordu yani derslere gidiyorduk.

3.3.3 Sınıfta istenmeyen çocuk

Annelerin çoğunluğu, çocukları ilkokula başladığında öğretmenleri konusunda benzer sorunlar yaşadıklarını söyledi. Onlara göre, öğretmenler çocuklarını sınıfta istemiyorlardı. B. Hanım, oğlu okula başladığında öğretmenlerin şikayetleri nedeniyle son derece üzgün hissettiğini ve üç gün boyunca ağladığını paylaştı. Çocuğunun davranış sorunları olduğunu iddia eden öğretmenin aslında çocuğu sınıfta istememesi nedeniyle bu şekilde davrandığını belirtti.

3.3.4 Okuldan yanlış bilgi

D. Hanım, görüşme sırasında kızının kas zayıflığından sıkça bahsetti ve kaslarını güçlendirmek için çeşitli yöntemler denediğini anlattı. Özellikle bacak kaslarını güçlendirmek amacıyla bir özel eğitim ve rehabilitasyon merkezindeki bir öğretmen, çocuğunun trambolin kullanmasını önermiş. Ancak kızının trambolinden düşmesinin ardından bir doktora başvurduklarında, trambolinin Down sendromlu bir çocuk için zararlı olabileceğini öğrenmişler.

3.4 Çocuğun Karakteristik Özellikleri

Bu üst tema, *çocuğun pozitif karakteristik özellikleri* ve *çocuğun negatif karakteristik özellikleri* alt temalarını içerir.

3.4.1 Çocuğun pozitif karakteristik özellikleri

A. Hanım, oğlunun neler yapabildiğini anlattı. Oğlu eğitime alışkın olduğu için, öğretmenlerinin ondan memnun olduğu olumlu şeyler hakkında konuştu. Ayrıca, Down sendromunun kendi başına olumlu yönlerini vurguladı:

> Güzel, aşk zaten, sevgi yumağı sevgi yumağı, sev beni öp beni yani benimle eğlen benimle gül, Down bu demek. … Öğretmenler Y.’ye hayran çünkü hazır çocuk önlerinde, sürekli eğitim almış hazır çocuk önlerinde.

3.4.2 Çocuğun negatif karakteristik özellikleri

D. Hanım, diğer annelerin aksine, kızının yaramazlık ve inatçılığını daha fazla vurguladı:

> Ne yapıyor, mesela biliyor ki onun yaramazlık olduğunu ama yapıyor. Ne için yaptın dediğimde saklanıyor, biliyor yaramazlık olduğunu. … İlk zamanlar zaten atma huyları vardı şöyle 5 6 yaşında, masadaki şeyleri atma huyları vardı atıyordu, döküyordu. Mesela bir şey yapma dediğinde onu yapıyordu, yapma deyince ona yap demek gibi oluyordu. Şu anda da öyle yapma dediğin şeyi inadına yapıyor.

3.5 İdeal Annelik İmgesi

Bu üst tema, *güçlü anne, fedakâr anne* ve *merhametli anne* alt temalarını içerir.

3.5.1 Güçlü anne

Araştırmaya katılan annelere göre, anneler güçlü olarak kabul edilmesi ve dinlenmesi gereken kişilerdi. Bu alt tema tarafından ortaya konulduğu gibi, anneler, çocuk sahibi olma konusundaki karar vericiler olduklarını, Down sendromlu bir çocuğa bakma gücüne sahip olduklarını ve ailenin daha çok "dinlenen üyeleri" olduklarını ifade ettiler. E Hanım şöyle dedi:

> Erkek güçlü, kadın güçsüz diye hani; güçlü kim derseniz ben annelerin güçlü olduğunu söyleyebilirim. Doğum anında, hamilelik anında çok yani ciddi efor sarf ediyor kadın.

3.5.2 Fedakâr anne

B. Hanım, annelik kavramının kendisi için ne anlama geldiğini ifade eti ve annelikle ilgili düşüncelerini paylaştı:

> Anne olmak demek bol bol fedakârlık, bol bol sevgi, bol bol şefkat içeren farklı bir duygu. … Ya o da (Bayan B'nin eşi) elinden geldiğince bana destek olmaya çalışıyor ama anne kadar, bir çocuk için, özellikle özel çocuğu varsa, en çok büyük fedakarlığı annenin yapması gerektiğini düşünüyorum. Hiç kimsenin anne kadar onun ilerisini, geleceğini düşüneceğini düşünemiyorum.

3.5.3 Merhametli anne

E. Hanım anneliği merhametli olmak şeklinde anlattı:

> Annelik çünkü çok farklı, merhamet duygusunu çok yoğun yaşıyor anneler. Babalar öyle değil, merhamet duygusu fazla olduğu için endişeleniyorsunuz.

> … Anne olmak ne ifade ediyor? Anne olmak, merhamet duygusu çok fazla. 4 tane çocuğum var, hepsiyle bir oluyorsunuz, hepsi farklı.

3.6 Annelerin Baba Algısı

Bu üst tema, *duygusal baba, öfkeli baba, sınırsız baba* ve *dahil olmayan baba* alt temalarını içerir.

3.6.1 Duygusal baba

E. Hanım, çocuğunun teşhisini ve durumunu kabullenme sürecinin, eşinin duygusal yapısı nedeniyle onun için zorlayıcı olduğunu ifade etti:

> En baştan beri böyle hareket eden bir insanım boyumdan büyük sorunlar olmadı. Babası çok zor kabul etti, baba çok duygusal onun biraz zor geçti ama sonra o da kabullendi.

3.6.2 Öfkeli baba

C. Hanım, çocuğunun Down sendromu olduğunu doğurduktan sonra öğrenmiş ve doktorunun gebelik sırasında testlerinde veya ultrason görüntülerinde herhangi bir anormal şey fark etmediğini söyledi. Eşinin Down sendromunu doğumdan önce fark edemeyen doktora verdiği tepkiyi anlatıyor:

> Eşim bu süreci daha ağır geçirdi. Doktorun bunu bilememesinin nasıl bir şey olduğunu falan hani… Dava falan açmak istedi, ben de dedim ki davayla falan olmaz, dava bizi daha çok yıpratacak.

3.6.3 Sınırsız baba

Bazı anneler, eşlerinin çocukları için sınırları etkili bir şekilde belirlemede başarılı olmadıklarını belirtti. C. Hanım şöyle anlattı:

> Babayı da sosyalleşme aracı olarak görüyor E biraz çünkü babamız biraz bizim hayır demeyi bilmiyor. Çoğu konuda babayı yönetmeye çalışıyorum çünkü artık hayır deme zamanı geldi. Çünkü bu E'ye zarar vermeye başladı. Her şeyi elde ettiğini düşünmek yani bunu kime yapsanız aynı şeyi yani reaksiyonu gösterir. Bu E için geçerli değil yani şimdi bu noktada babayı biraz geri çekmeye çalışıyoruz.

3.6.4 Dahil olmayan baba

Anneler, çocuklarıyla bir gün geçirirken sanki sadece kendileri ve çocukları varmış gibi anlattılar. Babanın çalışan kişi olduğunu belirttiler ve çoğunlukla işte zaman geçirdiğini, çocuğu okula götürüp getirme, çocuğun kişisel bakım ihtiyaçlarına dikkat etme veya ödevle ilgilenme gibi sorumluluklara katılmadığını ifade ettiler. Anneler, babaların işten döndüklerinde sadece kısa bir süre çocuklarıyla oynadıklarını sıkça vurguladılar.

4. TARTIŞMA

Bu bölüm, mevcut çalışmanın sonuçlarının mevcut literatür bağlamında incelenmesini içermektedir.

4.1 Doğum Kararı

Katılımcıların neredeyse hepsi çocuklarının tanısını hamileyken öğrenseler de çocuklarını aldırmayacaklarını çünkü bu çocukların Allah tarafından verildiğine inandıklarını söyledi. Literatürdeki çoğu çalışmada da bu konuyla ilgili olarak dini inançlar önemli bir faktör olarak görünüyor. Araştırmacılar, annelerin kendilerini bulundukları durumu bir nevi gerekçelendirme veya açıklama arayışında olduğunu gözlemlediler (Barbosa, Chaud ve Gomes, 2008). Bu noktada dini inanç annelerin ‘Neden’ sorusuna bir cevap veriyor gibi duruyor. Başka bir açıdan bakıldığında, çocuğun engelli doğmasının anne ve babadan gelen genetik faktörlerle ilgili olduğu görmezden gelinerek, annelerin sorumluluğunu kendilerinden uzaklaştırdığı da söylenebilir.

Lacan, dini anlamanın semptomları etkili bir şekilde maskeleyeceğini söyler, böylece bireylerin engelleri göz ardı etmelerine ve etkisiz olduğunu kanıtlayan şeyi reddetmelerine olanak tanır (Richardson, 1992). Down sendromlu bir çocuğa sahip olmak kendi başına zorlayıcı bir durumken neredeyse hiçbir anne bu durumdan zorluk olarak bahsetmemiştir. Görülüyor ki din bu noktada annelerin yaşadığı durumu maskeleme ve başa çıkma mekanizması görevi üstleniyor. Ancak yaşanılan zorluğu konuşmama ya da bastırma durumunun bu gruplarla çalışırken konuşulması sağlıklı olabilir.

Daha önce engelli bebek kürtajı yaptıran annenin durumuna bakıldığında, dini hiçbir vurgudan ya da başa çıkma mekanizmasından bahsetmediği görülüyor. Bu açıdan değerlendirildiğinde, bu annenin kürtaj kararı vermesi akla yatkın duruyor. Önceki kürtajlardan da pişman olduğunu söyleyen anne, kürtaj kararını doktorun istemesiyle verdiğini anlatmıştı. Bu şekilde annenin kürtaj sorumluluğunu doktora yüklediği ve bir şekilde kendini rahatlattığı söylenebilir.

4.2 Çocukla İç İçe Geçmiş Sınırlar

Psikanalizde, doğumdan hemen sonra annenin ve çocuğun ilişkisi simbiyotik bir ilişki olarak açıklanır (Lacan, 1957). Ancak, bu simbiyotik benzeri ilişki zamanla değişir.

Bebek büyüdükçe ihtiyaçlarını ifade etmeye ve bağımsız olarak karşılamaya başlar (Lacan, 1957). Anne de çocuğun ihtiyaçlarını karşılamak için her zaman orada olmamaya başlar. Çocuk annenin ilgisini ve dikkatini istemeye devam edebilir. Bu noktada, simgesel baba bu ikili ilişkiye müdahale etmelidir. Böylece, anne ve çocuk birbirinden ayrılabilir ve özne olabilirler (Lacan, 1957). Annelerle yapılan görüşmeler sırasında, çocukların yaşlarının 7 ila 9 arasında olmasına rağmen, bu ikili ilişkinin devam ettiği gözlemlenmiştir.

Bu ikili ilişkinin devam etmesine katkıda bulunabilecek iki önemli faktör gözlemlenmiştir. İlk faktör, Down sendromunun doğası olabilir, bu da çocuğun ihtiyaçlarını karşılamak için daha uzun bir süre anneyle bağlantıda kalmasını gerektirebilir. Ancak her ne kadar bu çocukların birine ihtiyacı daha uzun sürse de kendi başlarına birçok şeyi yapabilecek düzeye gelebilirler. Bu durumda bu çocukların ihtiyacını gidermek gerçekten kimin ihtiyacı sorusunu sormak yerinde olacaktır. Çalışmadaki annelerin de çocuklarının annelerine olan ihtiyacını devam ettirecek hareketlerde bulunduğu dikkat çekmiştir. İkinci faktör ise anne ve çocuk arasındaki ikili ilişkiye müdahale etmede babanın yetersiz kalmasıdır. Babalar, "Baba-Adı"nın işlevi, anne ve çocuk arasındaki ilişkiye müdahale etme konusunda yetersiz kaldığında ise anne-çocuk ilişkisinde iç içe geçmiş sınırlar, bu çalışmada olduğu gibi kaçınılmaz hale gelebilir. Lacan (1957), bu ikili ilişkinin ayrılmasının hem annenin hem de çocuğun bir özne olması için hayati olduğunu vurgular.

4.3 Eğitim Konusunda Mücadele

Araştırmadaki anneler, çocuklarının sağlık sorunlarından bağımsız olarak en çok zorlandıkları dönem ve konuyu, okula başlama ve eğitim süreci olarak belirttiler. Down sendromlu çocukların neredeyse doğduktan hemen sonra eğitim almaya başlamaları gerekmektedir. Kas zayıflığı ile doğdukları için genellikle ilk eğitimleri fizyoterapidir. Bununla birlikte, bu ve diğer gerekli eğitimleri ücretsiz olarak alabilmek için bir engelli raporu almaları gerekir. Rapora sahip olmadan, bu eğitimler ücretli hizmetlere dönüşmektedir. Rapor olsa bile, eğitim saatleri genellikle haftada 2 ila 4 saat arasında değişen, çoğu durumda yetersiz olan bir süre ile sınırlıdır. Özellikle Türkiye'deki Down sendromlular için ülkedeki sağlık ve eğitim alanındaki yetersizliklerden bahseden anneler bunların telafisi için eğitimci rolüne bürünme veya eğitim için ekstra harcamalar yapma yollarına girmişlerdir. Görülüyor ki Türkiye'de bu konu ilerleme kaydedilmesi gereken bir alan.

Psikanalitik açıdan bakıldığında, ilkokul daha simgesel denebilecek bir ortam. İlkokula kadar ailelerin çocuklarını götürdüğü eğitimler bir okul ortamı gibi kuralların olmadığı yerler, bu sebeple bu döneme dair pek de bir sorun anlatmadılar. İlkokula başlamayla birlikte, okuldan çocuklarının eksiklerine dair çok şey duyan anneler zor zamanlar geçirdiklerini ifade ettiler. Annelerin çocuklarıyla olan ilişkilerinde iç içe geçmiş sınırlar da göz önüne alındığında annelerin bu eksikliği üzerlerine alıp çocuklarının eğitimine harcadıkları zaman ve para, kendi eksiklerini telafi etme çabası olarak da değerlendirilebilir.

4.4 Çocuğun Karakteristik Özellikleri

Annelerin çoğunluğu çocukları hakkında "mucize," "çabalarımızın karşılığını veren çocuk" ve "ailemizin mutluluğu" gibi olumlu referanslarla konuşurken, bir anne çocuğunun olumsuz özelliklerine, yaramazlık ve inatçılığına vurgu yaptı. Bu durum, annelerin Down sendromlu bir çocuğa sahip olma durumunu kabulü açısından değerlendirilebilir.

Ailelerin engelli bir çocuğu olacağını öğrendiklerinde şaşırma ile başlayıp kabullenme ve uyumla biten bazı süreçlerden bahsedilmişti. Çocuğunun pozitif özelliklerine vurgu yapan annelerin anlatımlarında şaşırma, inkâr, yas ya da depresyon gibi süreçler gözlemlenmese de kabullenme ve adaptasyon süreçleri dikkat çekti. Çocuğunun negatif özelliklerinden bahseden anneye bakıldığında ise henüz kabullenme ve uyum sürecine geçemediği düşünülebilir. Birkaç kez ‘çocuğu diriltmek’ şeklindeki ifadeleri düşünüldüğündeyse yas benzeri bir süreçte olduğunu söylemek mümkün.

4.5 İdeal Annelik İmgesi

Lacan'ın çalışmalarında, özdeşleşme önemli bir yer tutar (Evans, 1996). O, imajın/imgenin rolünü vurgular ve özdeşleşmeyi "bireyin bir imgeyi üstlendiğinde gerçekleşen dönüşüm" olarak tanımlar (Evans, 1996). Bir imgeyi üstlenmek, o imge içinde kendini tanımak ve onu kendi kimliğinin bir parçası haline getirmek anlamına gelir (Evans, 1996).

Görüşmelerde annelere "annelik" ve "anne olma"nın onlar için ne anlama geldiği soruldu. Bu soruya cevap verirken, anneler aslında bir annenin kendi algılarına göre nasıl olması gerektiğiyle ilgili imgelerden bahsettiler. İlginç bir şekilde, anneler, çocuklarıyla ilişkilerini anlatırken annelik ve aile dinamikleri tanımlamalarıyla uyumlu bir şekilde kendilerini tasvir ettiler. Lacan'a paralel olarak, annelerin annelikle ilgili ideal bir imajı olduğu ve bu imajla özdeşleşerek bu ideal imaja uygun bir anne kimliği oluşturdukları gözlemlenmiştir.

4.6 Annelerin Baba Algısı

Bir anne çocuğun hayatında büyük öneme sahip olduğu gibi, baba da oldukça önemlidir. Ancak bu noktada, babanın kendi öneminin yanı sıra, babanın annenin dilindeki varlığı da çocuk için büyük bir öneme sahiptir (Lacan, 1957). Bu bağlamda, annelerin babaların tepkileri hakkındaki "İyi ki anne değil, aksi takdirde başa çıkamazdı" gibi ifadeler veya annelerin babaların kendileri kadar güçlü olmadığı gibi açıklamaları dikkat çekiyor.

Annenin babanın "Hayır"ını ve otoritesini kabul etmesi ve tanıması da önemli olduğundan, baba-çocuk ilişkisinde babanın rolü yalnız başına tam olarak etkili olmayabilir (Fink, 1957; Ruhs & Bernstein, 2015). Annelerin babalar hakkındaki açıklamaları bu açıdan düşünüldüğünde, çocukların, babaları otoritesiz olarak algılayabileceği, çünkü babanın rolünü tam olarak tanımadıkları anlaşılıyor. Bu, çocukların gözünde babanın pozisyonunu olumsuz etkileyebiliyor.

5. SINIRLILIKLAR VE SONRAKİ ARAŞTIRMALAR İÇİN YÖNERGELER

Bu çalışma, Down sendromlu çocukların anneleriyle yapılmıştır. Çalışma yalnızca Down sendromlu çocukların ilkokula gitmeleri gerekliliğini içerir. Bunun nedeni, zaten ilkokula başlamış olan çocukların konuşma, yürüme ve okula başlama gibi önemli gelişim evrelerini geçmiş olmalarıdır. Ancak, yorumlayıcı fenomenolojik analizde örneklem homojenliği önemli bir kriterdir. Bu nedenle, gelecekteki çalışmalar annelerin doğum yaptıkları yaşı, çocukların yaşı ve cinsiyeti gibi kriterleri ekleyerek örneklemi daha homojen hale getirebilirler. Ayrıca, bu çalışmada Down sendromlu çocukların bazıları tek çocuktu, diğerleri ise kız kardeş veya erkek kardeşlere sahipti. Bu, gelecekteki çalışmalarda düşünülebilecek başka bir kriter olabilir. Çalışmaya katılım için doğumdan sonra çocuklarının Down sendromu olduğunu öğrenme şeklinde bir kriter olmasa da çalışmaya katılan tüm anneler bu durumda bulunuyordu. Ancak, gebelik sırasında bu durumu öğrenen ve doğum yapma kararı alan aileler de bulunuyor. Gelecekteki çalışmalarda katılımcılarla bu şekilde çalışmak, literatüre katkı sağlayabilir.

6. GENEL SONUÇ

Sonuç olarak, bu çalışma Down sendromlu çocukları olan annelerin deneyimlerini ortaya koymaktadır. Çalışmaya katılan annelerin en yaygın deneyimlerinden biri, çocuklarıyla kurdukları ikili ilişki ve bu ilişkiye babayı veya üçüncü bir kişiyi dahil edememe olarak tanımlanabilir. Down sendromlu çocukların doğal olarak daha uzun süreli bakıma ihtiyaç duyduğu bilinmekle birlikte, annelerin çeşitli davranışlarla çocuklarının ihtiyaçlarını karşılamaya devam ettiği görüldü. Ayrıca, annelerin Down sendromlu çocuklarıyla çok zaman geçirdikleri için diğer çocuklarına ve eşlerine ayırdıkları zaman da azaldı. Bu nedenlerle, klinisyenler bu grupla çalışırken çocuğa verilen aşırı dikkatin kimin ihtiyacı olduğunu ve annelerin öznelliğini vurgulayabilir.

Karşılaşılan diğer bir deneyim, Down sendromlu bir çocuğa sahip olmanın kabullenilmesi durumudur. Bu çalışmadaki anneler çocuklarının durumunu doğumdan sonra öğrenmiş. Bunu, genellikle beklenmedik bir durum olarak tanımlayan annelerin çoğu durumu kabul ettiklerini ifade etti, ancak kabul edemeyen anneler de vardı. Bu annelerle terapi çalışmalarında kabul süreci ele alınabilir.

Kabulün yanı sıra neredeyse tüm anneler, devlet tarafından geçirdikleri süreci kolaylaştırmak için herhangi bir fırsat sunulmadığını açıkladı. Bu konuyu tartışırken, gelişmiş ülkelerde sunulan fırsatları ve genellikle Türkiye'de böyle bir durumun olmadığını belirttiler. Bu aileler için yaratılacak fırsatların ve imkanların, annelerin ve ailelerin hayatlarını ve bu süreci kolaylaştıracağı öngörülmektedir.

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YAZARIN / AUTHOR

Soyadı / Surname : KANTEKİN
Adı / Name : Pınar Edacan
Bölümü / Department : Psikoloji / Psychology

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