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RAISING A CHILD WITH DOWN SYNDROME: A QUALITATIVE INVESTIGATION ON FATHERS' EXPERIENCES

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Raising a Child with Down syndrome: A Qualitative Investigation on Fathers' Experiences

Down Sendromu Olan Bir Çocuk Yetiştirmek: Babaların Deneyimi Üzerine Nitel Bir Araştırma

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ABSTRACT

Studies focusing on the experiences of individuals with special needs, such as Down syndrome (DS) and their fathers, are increasing in the literature. Issues such as the meeting-acceptance process of children with DS, the difficulties and satisfactions they experience, and the quality of their relationships with their children attract the attention of scientists. Despite this increasing interest, studies on fathers of children with DS in Turkey are quite limited. Existing studies are mostly studies that investigate the experience of two parents of individuals with DS together, generally focusing on negative emotions such as depression, stress. This study aims to examine in depth the experiences of fathering a child with DS. The study aims to explore fathers' experiences with their children, their involvement in child care, their own perceptions of fatherhood and coping methods with difficulties. For this purpose, interviews were conducted with fathers living in Turkey, whose age range is 37-52, and whose children have DS with anage range of 5-14. The data obtained from the interviews were analyzed using thematic analysis method. Four main themes were generated: a) making sense of and accepting DS, b) fulfilling fatherhood role and duties, c) adjusting to the child with DS, d) holding a positive image of the child with DS. As a result of the analysis, it was seen that fathers were surprised when a person with DS joined their family, they felt the need to stand strong and keep the family together, then they made critical changes in some parts of their lives by adapting to the needs of their children with DS. Almost all fathers shared that they have a positive attitude towards DS and have a loving relationship with their children. The research findings contribute to understanding the experiences of fathers in the context of Turkey. The findings are discussed in relation to the existing literature on involved fatherhood and the changing perceptions of fatherhood after meeting with DS. The strengths of the study and, its limitations are discussed and suggestions for future studies are presented.

Keywords: Down syndrome (DS), father involvement, traditional fatherhood, coping, Turkey.

ÖZET

Son yıllarda Down sendromu (DS) özelinde bu kişilerin DS ile tanışma- kabullenme süreci, yaşadıkları zorluklar, çocuklarıyla olan ilişkilerinin niteliği gibi konular bilim insanlarının ilgisini çekmektedir. Bu artan meraka karşı Türkiye'de DS sahibi çocukların babalarıyla yapılan araştırmalar oldukça sınırlıdır. Varolan araştırmalar çoğunlukla DS sahibi bireylerin iki ebeveyninin deneyimini birlikte araştıran, genellikle depresyon, stres gibi olumsuz duygulara odaklanan araştırmalardır. Bu çalışma DS sahibi bir çocuğa babalık yapma deneyimlerini derinlemesine incelemeyi amaçlamaktadır. Araştırma, babaların çocuklarıyla yaşadıkları deneyimleri, çocuk bakımına katılımlarını, kendi babalık algılarını ve zorluklarla baş etme yöntemlerini keşfetmeyi amaçlamaktadır. Bu amaç doğrultusunda, Türkiye'de yaşayan, yaş aralığı 37-52 olan, DS sahibi çocuklarının yaşları 5-14 aralığındaki babalarla görüşmeler gerçekleştirilmiştir. Görüşmelerden elde edilen veriler tematik analiz yöntemi kullanılarak incelenmiş ve dört ana tema oluşturulmuştur: a) DS'yi anlama ve kabullenme, b) babalık rolü ve görevlerini yerine getirme, c) DS sahibi çocuğa uyum sağlama, d) DS sahibi çocuk hakkında pozitif bakışa sahip olma. Analiz sonucu elde edilen sonuçlarda babaların ailelerine DS sahibi bir birey katıldığında bunu şaşkınlıkla karşıladıkları, güçlü durma ve aileyi birarada tutma ihtiyacı hissettikleri ve ardından DS sahibi çocuklarının ihtiyaçlarına uyum sağlayarak hayatlarının bazı kısımlarında kritik değişiklikler yaptıkları görülmüştür. Neredeyse tüm babalar DS'ye karşı pozitif bir tutum belirlediklerini ve çocuklarıyla sevgi dolu bir ilişkileri olduğunu paylaşmışlardır. Araştırmadan elde edilen sonuçların Türkiye bağlamında, DS sahibi çocukların babalarının deneyimlerini anlamada öncü olacağı düşünülmektedir. Çalışmanın bulguları, ilgili babalık ve DS ile tanıştıktan sonra değişen babalık algısı konusundaki alanyazın bağlamında tartışılmıştır. Çalışmanın güçlü yönleri ve sınırlılıkları tartışılmış ve ilerideki çalışmalara öneriler sunulmuştur.

Anahtar Kelimeler: Down sendromu (DS), baba katılımı, geleneksel babalık, baş etme, Türkiye.

CHAPTER I
INTRODUCTION
1.1. THE CONTEXT AND PURPOSE OF THE CURRENT STUDY

Due to the fact that people with developmental disabilities lead a more dependent life on their families, the importance of the duties of parents in matters such as support and care is increasing (Schippers et al., 2020). Since mothers mostly play a dominant role in special education, care, and social support of children with disabilities (Mueller & Buckley, 2014), the experiences of mothers such as anxiety and depression have been extensively examined in previous studies, and many interventions have been designed and carried out with mothers (Uğuz et al., 2004). Although some studies have looked at the common experiences of parents, studies on understanding fathers' experiences about raising a child with a developmental disability are very few in the literature (Schippers et al., 2020).

Research on understanding fathers' parenting experiences has gained momentum in recent years. In some studies, fathers have been described as inaccessible and invisible parents. Fathers talk about their difficulties in being involved in family duties and needs such as health and education (Carpenter & Herbert, 1997). According to the traditional point of view, the main task of fathers is to earn a living (Schmidt, 2018). However, studies conducted over time indicate that paternal duties have changed, that they are dealing with tasks such as babysitting and household duties, and that fathers now spend more time with their children. However, this change has not been reflected in the literature much (Schippers et al., 2020). When we look at the literature, the concepts of responsible fathering (Dohert et al., 1998) and involved fathering (Olson et al., 2001) about paternity draw attention. While the literature previously considered involved fatherhood, primary parenting, warmth and care to be a feminine condition (Wall & Arnold, 2007), recent studies have shown that involved fatherhood is more caring, responsible, accessible, and highly related (Ladge et al., 2015). Studies have found that fathers' social and emotional support, participation in activities, and

temporal and financial support affect the development of the child (Bogossian et al., 2017). It has been shown by research that father involvement affects cognitive and behavioral development in children, regardless of whether their children are disabled or not (Schippers et al., 2020).

The concept of transformation in fatherhood experiences has come to the fore in recent studies. The transformation in the perception of fatherhood (Schmidt, 2018), the acceptance of the uncertainty about the disability and new life situation and the transformation of fathers' expectations from their children with disabilities (Baumann et al., 2016) have been reported in the literature. In a similar vein, Schippers and colleagues (2020) introduce the new life perspective to indicate that fathers report transforming expectations, appreciating the little things, staying in the moment and building a positive attitude. Few qualitative studies on fatherhood state that the new perception of fatherhood has changed compared to previous years, and that fathers take a more active role in their relations with their children (Schippers et al., 2020). Carpenter and Towers (2008) refer to the fact that with the increase of fathers' participation, the success of children in education will increase, and the relationship between child-father and family will improve.

Down syndrome (DS) is a condition that causes phenotypic and cognitive differences in children. In addition, individuals with this syndrome may have heart diseases, circulatory problems, and immune system weaknesses (Antonarakis et al., 2020). When the recent studies with fathers of children with DS are examined, comparative studies are found in the literature with fathers of children without any disability (De Clercq et al., 2021) or it has been researched together with other neurodevelopmental diseases and research focusing only on DS is quite limited (Ridding & Williams, 2019). In these limited studies, subjects such as the effect of fathers' perspective on family life (Hornby, 1995), how fathers adapt to their new lives (Ridding & Williams, 2019), and fatherhood experiences (De Clercq et al., 2021) were examined.

When we look at the studies carried out in Turkey, different subjects have received attention such as education of children with development disabilities, the level of social adaptation, the stressors experienced by the mother, family functions

and the mother-father-child triangle in the family structure. However, studies on fatherhood roles when raising a child with a developmental disability are limited (Çakırer-Çalbayram & Platin, 2020). Existing research on fatherhood in Turkey look at issues such as fathers' stress level and methods of coping with stress (Eren & Doğan, 2020), raising awareness about the role of fatherhood (Çakırer-Çalbayram & Platin, 2020), and examining life satisfaction and hopelessness levels (Acar, 2009). However, the lack of studies focusing on the relationship between the father and the child with a developmental disability and examining the one-to-one experience of the father draws attention. Qualitative studies, especially examining the experiences of fathers with children with DS, were found to be almost nonexistent. According to the Turkish Down Syndrome Association (2022), although there is no clear information, it is estimated that there are 70,000 people with Down syndrome in Turkey. Considering the number of individuals with DS in Turkey, the importance of this issue becomes even more evident.

Exploring fathers' experiences is important, because fathers' involvement with caring for child with a developmental disability has been shown to be associated with improved child outcomes, better family and marital functioning (Phares et al., 2009; West & Honey, 2016). In addition, it is emphasized that children with disabilities feel as if their parents are stigmatized and socially isolated (Duman & Akçakaya, 2020; Giulio et al., 2014) and that fathers adapt positively to the situation they are in despite the difficulties during birth (Ridding & Williams, 2017). In the past years, research with parents of children with developmental disability mostly focused on negative emotions such as depression and anxiety, and stress (Cuskelly et al. 2009).

Although recent studies with parents of children with DS have moved away from the point of view of negativity or deficiency, studies looking at both the positive and negative aspects of parenting a children with DS remain scarce in the literature (Farkas et al., 2019). Considering the fact that parents of DS children are exposed to less stress and feel less negative feelings in the literature, it becomes even more important to understand the experience of the fathers of DS children in order to understand this reported difference. In addition, it is important to

understand the families of children with DS and intellectual disability not only to ensure social acceptance of individuals with special needs and family members, but also to appreciate their unique perspectives and contributions (Farkas et al., 2019). In the light of this information, learning about how they understand fatherhood, what factors facilitate their involvement and improve their relationship with their children, and how they cope with challenges can provide guidance for future interventions, such as psycho-education for fathers. Thus, this study aims to closely examine the subject of fatherhood experiences, which is a topic that has been under-researched in Turkey, in particular for the fathers of children with DS, and to raise awareness of the importance of their roles.

1.2. DEFINING FATHERHOOD

1.2.1. Traditional Conceptions of Fatherhood

Historically, cultural perceptions of masculinity and fatherhood do not progress steadily; it is fluid, diverse, multi-layered and variable (Barutçu & Hıdır, 2016; Doucet 2013; Lupton and Barclay 1997; Thoma 2011; Wall & Arnold 2007). The concept of fatherhood exists within a systemic structure affected by social and political changes (Doherty et al., 1998; LaRossa, 1997). There is an important distinction in fatherhood researches as the concepts of fatherhood and fathering. Fatherhood refers to men having children, gender roles, and status, while the concept of fathering focuses on concrete issues such as the parenting behaviors of men (Bozok, 2018a). For a long time in Central Europe, the father's duty was to bring bread to the house, while the mother's duty was to be responsible for the housework (Lewis, 2001; Schmidt, 2018). Over the years, the definitions of fatherhood have begun to change considerably. Fatherhood has been traditionally defined as being distant to children, authoritarian and closed to change in the literature (Cinel-Özyeşer & Şahin-Tezel, 2021). Over the course of the twentieth century, the way researchers define fatherhood has changed in many ways. Over time, the definitions of fathers as dominant, authoritarian, and morally guiding have transformed, and definitions such as nurturing role, gender role model and marriage

supporter have emerged after being defined as the breadwinner (Lamb, 2000). In the 21st century, the meaning of being a good father has come to the fore and the concept of fatherhood has transformed and started to be filled with the concepts of caring, nurturing, consistent, compassionate and loving (Morman & Floyd, 2006).

When the concepts of fatherhood are examined from the beginning of the 1900s to the present, we encounter some common defining characteristics. Before the Industrial Revolution, the concept of fatherhood was defined as the moral guide (Lamb, 2000). According to this conception, fathers played the role of their children's moral supervision and teaching. Fathers, who help to read the holy books and provide a model of Christian life (Lamb, 2000), are also in charge of protecting the child's good morals in Islam. Fathers are seen as the most important guide for the child, as well as being the person who provides authority and family unity (Balin, 2021).

Later, with the beginning of the Industrial Revolution, fathers began to be defined as the breadwinner. According to Lamb (2000), fathers' moral teaching duties were not over at that time, but before industrialization, parents had openly shared job responsibilities, whereas after industrialization they were forced to distinguish between working inside and outside the home. Despite the increasing interest in the concept of fatherhood after the 1970s and the fact that this concept has ceased to be the sole breadwinner of the family (Doherty et al., 1998), gender-based discrimination still continues in European countries regarding the duties of caregiver and breadwinner (Dearing, 2016; Schmidt, 2018). The fact that being unemployed affects fatherhood more than motherhood (Doherty et al., 1998; Elder et al., 1984) shows that this task is still perceived as the main task of fathers in these years.

In the 1940s, as a result of the successive problems of the period, such as the Great Depression and the Second World War, the literature evolved to focus on the inadequacy of fatherhood (Lamb, 2000). While providing for the family and moral teaching still remained important, the function of fatherhood has shifted towards gender role models, especially for their sons (Pleck, 1981). Broenstein and Cowan (1988) stated that fathers are more effective than mothers in transferring and

reinforcing traditional gender roles (Kuzucu, 2011). Researchers focusing on the fact that children grew up without a father during this period emphasized the importance of fathers in children's lives (Balin, 2021). After the Second World War, in middle-class nuclear families in Western societies, fathers who spend most of their time working outside and provide for the family are described as a figure who is distant from their children and spouses and does not actively participate in childcare (Bozok, 2018b). In the USA, in the 1950s, fathers were advised to show interest in their children, but not to exaggerate it (Kimmel, 1996).

In the 1960s, Baumrind (1971) brought very important parenting approaches to the literature after his observations in the clinical and home environment with preschool children (Yılmaz, 1999). Baumrind (1971) mentioned authoritarian, democratic and permissive parenting styles. Authoritarian parents expect their children to obey unconditionally while democratic parents expect a mature attitude from their children. Democratic parents expect their children to follow the rules when necessary, and they are also associated with warmth and patience. Permissive parents, on the other hand, have been described as giving their children too much freedom and sometimes neglectful tolerance (Yılmaz, 1999). Traditional fatherhood mentioned in the literature has been associated with authoritarian attitudes (Bozok, 2018b). Fathers in the traditional fatherhood role are defined as the ones who provide for the house, rarely play with their children, provide discipline (Feldman, Nash & Aschenbrenner, 1983; Kuzucu, 2011) are closed to change and distanced from children, and these definitions are identified with patriarchy (Özyener-Cinel & Tezel-Şahin, 2021). For fathers who adopt the traditional paternity role, it is sufficient to provide financial support and discipline, and they think that they fulfill their family responsibilities because they provide economic support. (Barnett & Barunch, 1988; Kuzucu, 2011). There has been a distance between father and child due to the perception of men as authority figures in the home and their hierarchically superior position (Belli et al., 2020; Pontes et al., 2009).

On the other hand, in the traditional family structure, it is seen that there are distant and authoritative but related relations between father and child (Bozok,

2018; Kimmel, 2013; Morgan, 2001; Seidler, 2003). Traditional fatherhood began to decline with the emergence of industrial societies, and the development and spread of capitalist relations after the industrial revolution (Bozok, 2018b). However, although the change of the concept of paternity in the culture is fast, its execution often cannot reach this speed (Barutçu & Hıdır, 2016). It is known that the traditional fatherhood role is the most common and dominant one in the perceptions of fatherhood adopted in Turkey (Özyener-Cinel & Tezel-Şahin, 2021).

Overall, in Western literature, academic interest in fatherhood started in the 1970s (Barutçu & Hıdır, 2016; Marsiglo et al., 2000). After all the changes described in the concepts of fatherhood, the perspective that fathers should be actively involved in the daily life and care of their children emerged in the mid-1970s (Lamb, 2000). Towards the 1990s, this interest became more diverse, holistic and broad (Barutçu & Hıdır, 2016; Marsiglo et al., 2000). According to Doherty and colleagues (1998), studies focusing on fathers have always had a moral aspect, and these studies were conducted by people who thought that fathers should show more interest in their children's lives (Doherty et al., 1998). Lamb (2000), on the other hand, stated that while the feminist movement encouraged to examine the transfer of the concepts of masculinity and femininity between father and child, some psychologists may avoid taking a stand on such value judgments and turn to objective and measurable research topics such as the time the father spends with his child. Some studies focused on the concept of cult of motherhood' and said that this approach positions the father as the second best backup in the parenting process (Deutsch et. al., 2001; Morman & Floyd, 2006).

1. 2.2. Father Involvement

Over the decades, with the changing political and social environment, the differing needs of society and children, research on fatherhood has changed and the moral guide, gender role model, new caregiver father, breadwinner (Lamb, 2000) and responsible fathering (Doherty et al., 1998) have changed. The return of the ideal worker duty attributed to fathers has brought tireless commitment to work,

and the perception of involved fatherhood contradicts both this and the social definition of masculinity (Ladge et al., 2015). Nevertheless, the definition of fatherhood with the studies carried out in the field changed from qualitative definitions such as dominance and masculinity to more measurable dimensions such as the time they spend with their children (Lamb, 2000). In this section, the concept of involved fathering, which is frequently researched in the 21st century, will be examined. It has been observed that this field is enriched by the focus of social scientists on the concepts of parent involvement (Lamb, 2000).

The concept of involvement is defined by important concepts such as physical presence in the family, emotional commitment, equal distribution of responsibility for child rearing and housework. (Collier, 2010; Collier & Sheldon, 2008; Deinhart, 1998; Dermott, 2008; Henwood & Procter, 2003; Ives et al., 2008; Lloyd, 2003; Sullivan, 2000). From fathers today, there are expectations such as expressing love to spouse and children comfortably, taking an active role in child care, compassionate communication, and providing financial support (Çelik, 2019). The "new fathers" of these times exist in closer emotional relationships, are more nurturing, and share the duty of care and happiness with mothers (Wall & Arnold, 2007). Similarly, Marsiglio, Hutchinson, and Cohan (2000) defined ideals and dreams about fatherhood as visions of fatherhood in their research. Definition of good father in their research emerged as someone who is emotionally available, provides a balanced friend-discipline position, is able to support his family financially, and spends enough time with his children (Morman ve Floyd, 2006).

Much of the father involvement literature does not consider father's performance from a one-dimensional side such as financial resources, and evaluated with cognitive, behavioral and emotional results (Morman & Floyd, 2006; TamisLeMonda & Cabrera, 2002). Thus, the father's role, which has been traditionally defined with strict discipline and distant approach towards his child, has evolved into a position that carries out the care of the child with his spouse (Aksoy & Tatlı, 2019; Ünal & Kök, 2015). In family system theory, involved fathering is handled in two ways, direct and indirect (Lamb, Tamis, & Lemonda, 2004). While direct ways describe positive interactions between father and child,

indirect ways include concepts such as domestic processes, emotional and physical accessibility, in which the father indirectly affects his child (Garcia et al., 2022).

Considering the content of the time spent with their children by fathers who do not perceive the role of paternity as only disciplining the child or meeting the economic needs of the family, they expressed wanting participate in the care of their child. (Kuzucu, 2011). Despite this willingness, while father-child time is defined as more play and leisure time, it is seen that mothers' caring duties are more dominant and mothers are more likely to be with their fathers (Craig, 2006; Silver, 2000; Wall & Arnold, 2007). Similarly, studies in Europe and America reported that fathers specialize in play and mothers specialize in basic care (Lamb, 1981). Looking at parental leave statistics surveys, the difference is modest, although fathers spend more time feeding and caring for babies than in the past (Wall & Arnold, 2007). In addition, it has been seen that the high demands from the work together with the long working hours and the rigidity of the working conditions reduce the participation of the father (Crouter et al., 1987; Kuzucu, 2011).

In a nutshell, involved fathering is a concept that started to form in the 1970s and continues to evolve today. Fathers have additional roles such as sharing responsibilities within the family, taking an active role in child care, and increasing the time they spend with their children, as well as showing more emotional closeness, caring and compassionate approaches with children, which also positively affects the father-child relationship. Although there are not as rapid changes in daily life as in academic literature, its effectiveness continues to increase and it affects father, child and family. In the next section, research on father involvement will be discussed.

1. 2.3. Father involvement and child-family outcomes

In the last few decades, there have been many positive and negative perspectives on fatherhood, and many scientific studies have been conducted with the increasing importance given to the role of fatherhood in the literature (Morman & Floyd, 2006). In the study of Rolle et al. (2019) in which they compiled the

relevant fatherhood literature, it was revealed that the effect of father involvement on children's cognitive skills was positive. There are other studies in the literature reporting that father involvement affects healthy child development. In the study conducted by Liu et al. (2021) with parents of preschool children, it was found that positive father attitudes and encouragement benefit children to adopt positive behaviors. Similar results were obtained in the study of Garcia et al. (2022), which looked at the effect of father involvement on child development in environments with insufficient resources in Kenya. A positive relationship was found among positive child outcomes, co-decisionsin the home environment and situations where fathers gave more interpersonal support to mothers (Garcia et al., 2022).

According to Kil, Martini and Andrade (2020), it is very critical for healthy child development to keep in touch with both parents. Mother and father cannot provide each other's roles, but can complement and support each other (Belli, Akçay-Didişen & Bal-Yılmaz, 2020). Father involvement can positively affect not only the father-child relationship, but also the mother-child relationship. There are social support theories that emphasize the importance of measuring domestic lives, and research shows that the father's informative, emotional or instrumental support to the mother can facilitate direct mother-child interaction (Garcia et al., 2022; Heaney & Israel, 2008). In another study conducted with the families of adolescent children, it was reported that the participation of the father would help family flexibility and this could directly lead to better psychosocial health of the children, and indirectly affect the psychosocial health of the mothers positively (Malette et al., 2021).

Father involvement is considered important, because in the study conducted by Rakotomanana et al. (2021) with fathers in Madagascar indicated that although the men and their spouses who participate in childcare are criticized by the society, it is heard that fathers want to be more involved in childcare. In addition to the studies showing that father's participation positively affects child development and family life, negative results can also occur in families where father involvement is lacking. In a study conducted by Çelik (2019) on families in which the mother acts as a mediator between the father and the child, it was seen that this situation

negatively affected the father-child relationship, and it was seen that this situation could cause a feeling of deprivation.

It is seen that the involvement of fathers in the life of their children does not only affect family life or children, but can also affect life outside the home. In the study conducted by FitzGerald et al. (2019) together with the fathers of secondary school children, they observed that more nurturing and egalitarian father attitudes affect educators positively and indirectly contribute to their children's education.

Overall, existing studies show that fatherhood, defined by authority, emotional distance and provider role, has changed to include more relational characteristics with children. The notion of involved fatherhood has captured the changing needs of the father-child relationship over time, the response of fathers to these needs, the roles they transform in the family structure, and their contribution to the family structure. Research suggested the positive associations of involved fatherhood with a number of emotional, behavioral, social and developmental outcomes of children as well as more adaptive family and couple functioning. These studies highlight the importance of changing roles of fathers in shaping children's well-being in general. However, raising a child with a developmental disability, particularly DS, can pose different challenges to parents and fathers, and may change the nature of interactions among fathers, their children and families. In the next section, research on parenting a child with DS will be summarized.

1.3. PARENTING CHILDREN WITH DOWN SYNDROME

1.3.1. Down Syndrome (DS)

Down syndrome is the most common chromosomal aberration in humans, affecting one out of every 400 to 1500 newborns born in various countries, depending on mother age and prenatal diagnostic protocols (Anthorakis et al., 2004). There is a common hereditary basis of intellectual disability over the globe, and a huge number of individuals with DS also suffer from heart abnormalities, hematological problems, and early-onset Alzheimer's disease (Jiang et al., 2013).

Trisomy which occurs in whole or some regions of chromosome 21 followed by an enhance in expression owing to trisomic gene dosage leads to this condition (Gardiner, 2010). Inborn heart anomalies, weak neuromuscular structure, delays in cognitive development, gastrointestinal anomalies, unordinary physical and facial features, immune system issues are associated with this condition. Even though one of the reasons which increases the risk of this syndrome is age of the mother, the rate of children with DS in younger mothers is higher due to high fertility rates under age of 35 (Hattori et al., 2000).

The human species normally has 46 chromosomes arranged in 23 pairs. According to Shaffer & Lupski (2000), chromosomes are the carrier of human genetic information. Numerous human genetic illnesses are caused by chromosomal defects that result in a net change in value of genetic material. Shaffer & Lupski (2000) claims that approximately 0.6 % of live newborns are affected by numerical and structural chromosomal abnormalities, which often result in dysmorphism, deformities, and/or developmental impairments (Shaffer & Lupski, 2000). The most common of these chromosomal abnormalities is DS (Kazemi et al., 2016).

DS has no known medical cure. The beginning of developmental interventions and medical care for children with DS should begin in infancy. Speech, physical, and occupational therapy may help children with DS. It is possible that they may get special education and help in school. In recent decades, the life expectancy of patients with DS has significantly improved (Presson et al., 2013). The quality of life of people with DS has improved greatly because of the advances in heart surgery, thyroid hormones, leukemia medicines, immunizations, antibiotics and anticonvulsive pharmaceuticals. In fact, average lifespan, which was barely 30 years in the 1960s, is currently above 60 years of age due to these medical improvements (Kazemi et al., 2016).

According to the Down Syndrome International Organization (2020), it is seen in 1 out of every 800 live births, regardless of race, gender, socioeconomic level - although there are differences worldwide. There are three different types of DS. Trisomy (nondisjunction), a cell division defect that results in an embryo with

three copies of chromosome 21, is the most common cause of DS. It is generally agreed that trisomy 21 is the most common (approximately 95 %) cause of Down syndrome (Hassold et al., 2000; Oliver et al., 2008). According to Antonarakis et al. (2004), chromosomal translocations have been implicated in a much lesser proportion of DS patients (roughly 3-4 %). In order to differentiate between familial and non-familial forms of DS, translocations responsible for the illness are occasionally called into question. Chromosome 21 is transferred to another chromosome in these circumstances, most often to chromosome 14 or 15. It is possible to inherit two common chromosomes and a chromosome translocated with an additional fragment of chromosome 21 and DS will result. There may be an increased risk of Down syndrome in future pregnancies for couples who have had a child with DS from translocation trisomy 21 (Florez-Ramirez et al., 2015). This is due to the fact that one of the parents might be a balanced translocation carrier. The likelihood of a child inheriting the altered chromosome 21 is gender-dependent. Antonarakis (2004) claims that there is a 3 % possibility for the scenario where the father is the carrier, but there is a 12 % possibility where the mother is.

Mosaicism is an uncommon variant of DS, accounting for fewer than 2% of cases. However, unlike a simple trisomy21, the third copy of chromosome 21 is present in certain cells, but not all (Florez-Ramirez et al., 2015). After the fertilization, irregular cell division causes this kind of syndrome. DS can be diagnosed with measurements such as nasal bone measurement and nuchal translucency. If the risk of DS is found to be high as a result of the double or triple test performed before pregnancy, families are directed to amniocentesis. It is widely used in the 15th and 21st weeks of pregnancy in Turkey (Madazlı, 1999). Today, such screening tests are routinely recommended by doctors (Kara Eştürk, 2019).

In the postnatal period, some physical features that distinguish DS babies from other babies come to the fore. In almost all individuals with DS, genetic differences such as flattened nose, slanted eyes, low muscle tone, developmental differences in the fingers, thick neck, and a single line on the palm are noteworthy (Down, 1866). Various physical features such as full cheeks, protruding and drooping tongue, microcephaly, and anomaly in the palate structure are also

observed (Baum et al., 2008; Kara Eştürk, 2019). On the basis of these symptoms, the diagnosis of DS can be made in babies by doctors and as a result of genetic tests.

1.3.2. Fathers of children with DS

Studies on the roles of fathers have generally been conducted with fathers of naturally developing children (Çakırer-Çalbayram & Platin, 2020). Most of the studies investigating the effects of children with disabilities on families focused on mothers and siblings, while studies with fathers remained at a very low level (Bogossian et al., 2019; Hornby, 1995). Until the 1990s, studies with children with DS and their families were also very limited. Having a child with a disability brings challenges such as stigma, increased economic expenditures, and additional care responsibilities, but few studies explain how these situations influence family roles and relationships differently (Van Riper et al., 1992). In recent years, there has been a growing awareness of the contribution of fathers to the development of their children, but the majority of studies have examined maternal factors and perspectives. Gender differences in parents and levels of involvement can be helpful for understanding family adaptation and coping mechanisms in relation to children with DS in depth (Al-Yagon & Margalit, 2011). In particular, qualitative studies used to gain an in-depth understanding of fathers' experiences in this area are lacking (Hornby, 1995; Ridding & Williams, 2019).

1.3.2.1. DS, Parental Stress and Coping

Many studies have suggested that having a child with DS has effects on the family. Cuskelly et al. (2009) indicated that weak and strong aspects such as social interaction, verbal communication, information processing, and motor skills affect the relationship between the caregiver and child, and DSmay cause increased difficulties as parents and decreased satisfaction in conditions such as work. It has been seen in the family adjustment studies carried out until the end of the 20th century that the negative aspects of raising a child with a disability have been

focused on (Glidden et al., 2014; Helff & Glidden, 1998). Having a disability such as DS in a family member is seen as a source of deep stress on the family and subsystems (Bubolz & Whiren, 1984; Byrne & Cunningham, 1985; Kazak, 1986; Murphy, 1982; Seligman & Darling, 1989, Van Riper et al., 1992).

Most studies show that parents of children with DS have lower levels of well-being than parents of children of the same age with naturally developing children (Cuskelly et. al., 2009; Hedov et al., 2002; Scott et al., 1997). In studies conducted with parents of children with DS, it has been observed that the behavior problem of the child in the mother and the possibility of low social acceptability of the child in the father create stress (Cuskelly et al., 2009). Parental stress can affect not only the quality of life but also the adjustment of children. Stress experiences can manifest as depression, relationship conflict or social isolation, and appear as a major concern among families of individuals with disabilities (Al-Yagon & Margalit, 2011; Keller & Honig, 2004; Margalit et al., 1991).

Studies with families with DS show negative experiences and stressors including factors such as medical experiences, DS diagnosis process, social acceptance and lack of connection (Farkas et al., 2019). Besides these daily stressors, other stressors may be about future planning for the child and family (DePape & Lindsay, 2015). In a related vein, parents of children with DS report that they experience frustrations caused by the lack of social acceptance and support from their environment and the difficulty in accessing services (De Clercq et al., 2021; Farkas et al., 2018; Povee et al., 2012). Recognizing DS in prenatal tests and being able to choose to terminate the pregnancy can be considered another disadvantage of DS (Glidden et al., 2014).

Few studies have explored coping strategies for parents of children with DS. It can be said that there are two types of coping; with the first one focusing on changing the individual's behavior and/or environmental conditions, and the second one emphasizing emotional regulation (Al-Yagon & Margalit, 2011; Folkman & Lazarus, 1988). DS has been shown to affect not only the individual, but also the well-being of other family members (Van Riper et al., 1992).

Having educational and socio-economic resources seem to be important

factors when coping with stress of supporting a child with DS. Knowing DS more than other types of disability may provide familiarity and convenience to parents (Al-Yagon & Margalit, 2011). Since DS may be more common in high-aged parents, it may increase the probability of having a DS baby in people with a high level of well-being, and higher cognitive functions of DS babies may also have a positive effect on parents and family members (Al-Yagon & Margalit, 2011). However, it is unclear whether this difference is due to the high income of the parents or the maturity that comes with the age of the mother (Skotko et al., 2011).

1.3.2.2. DS as a Positive Experience

In addition to the aforementioned negative experiences, some studies mention the "DS advantage". Parents of children with DS are reported to experience more positive and less negative affects than families of children with other disabilities (Abbeduto et al. 2004; Cuskelly et al., 2009). Fidler, Hodapp, and Dykens (2000) found that parents of children with DS experienced lower levels of stress compared to parents of children with SmithMagenis or Williams syndrome. In addition, according to Ricci and Hodapp (2003), fathers of children with DS experienced less stress about their children in areas such as acceptance and adaptability than fathers of other children with intellectual disabilities (Al-Yagon, Margarit, 2011). Children with DS show lower rates of behavioral and emotional problems than other individuals with cognitive delays (Al-Yagon & Margalit, 2011; Rosner et al., 2004). The fact that Down (1866) defined the characteristics of people with the syndrome bearing his name as humorous and having comical mimics may have generated interest in the DS advantage.

However, there is a different point of view against the advantage of DS in the literature. It has been thought that the caring image of DS children may prevent professionals and parents from taking the necessary precautions and interventions to correct the difficulties covered by positive behaviors, and if positive aspects such as the caring image of their children do not appear, parents may be disappointed and even blame themselves (Glidden et al., 2014).

In addition to the positive characteristics and advantages of children, some studies have also focused on the positive emotions experienced by parents. Parents of children with disabilities stated that they became more empathetic, understanding, compassionate, and more open to unconditional love after their child was born (Van Riper et al., 1992). Parents of DS children reported a higher level of satisfaction with the child than parents of naturally developing children of similar age (Al-Yagon & Margalit, 2011; Hodapp et al., 2001). In the study conducted by Skotko et al. (2011) with DS families, almost all of the parents said that they love their children and are proud of them, and described themselves as more tolerant, kind and empathetic. In addition to this, it is also mentioned in the literature to have a vital purpose. Having a purpose in life, which exists as a sub-dimension of psychological well-being, has not been examined in studies, but since such parents are mostly advocating for the rights of their children and other individuals with disabilities, they may have a greater vital purpose than the parents of children with natural development (Ryff, 1989; Van Riper et al., 1992).

1.3.2.3. Research on Fathers with Children with DS

Considering the studies conducted with DS (Cuskelly et al., 2009), these studies looked at parental adjustment. These studies highlight stress caused by factors such as feeling overwhelmed by responsibility, isolation, demanding behavior and temperament of the child, situations such as activity level, and approaches that focus on the mental health-psychological functioning of the parent such as anxiety, depression and acceptance. A few studies have examined marital satisfaction. While mentioning that having a child with DS affects marital satisfaction positively and the number of divorces is lower in the literature (Urbano & Hodapp, 2007), 10 % of them mentioned that their children force their marriage (Skotko et al., 2011).

When we look at the studies conducted with the parents of children with DS, it is seen that the studies examining the mothers or both parents are in the majority. In a study conducted by Van Riper and colleagues (1992), parents with children

with DS and parents of children with natural development were evaluated on individual, family functions and maternal functions, and no significant difference was found between them. In a qualitative study conducted by Skotko and colleagues (2011), they examined the feelings of parents towards their children. With the increasing interest in the concept of involved fatherhood in recent years, research with fathers of children with DS has increased, but it is not yet adequate. These studies can be seen below.

In a qualitative study conducted by Hornby (1995), the experiences of fathers with children with DS aged 7-14 years were examined. Among the results of the study, the joy of raising children with DS and trauma after diagnosis were the most heard experiences, while some families mentioned that their children had little impact on the family. The biggest concern expressed by fathers was what their children would do after they left. In a qualitative study conducted by de Falco and colleagues in 2008, the quality of playing games of fathers playing with their children with DS was examined. The researchers, who found that children exhibit more exploratory and symbolic play when there is father-child interaction during play, observed a significant increase in children's cognitive level.

In the literature, it is seen that children with DS parents have less stress and less negative experiences when compared to the families of other disabled individuals. However, this does not mean that they do not have problems. Some children with DS are accompanied by high levels of behavioral disorders, different illnesses, and daily life difficulties, although they are likely to experience more sympathy and fewer behavioral or physical problems. Among these, there are reasons such as lack of support, stigma, difficulty in accessing information, and not getting enough support from professionals. It has been observed that families cope by holding onto situations such as the sympathetic appearance of their children and family loyalty. In the next session, perception of fatherhood and fathering practices with children with DS will be examined in the context of Turkey.

1.4. RESEARCH ON FATHERHOOD AND DS IN THE IN THE CONTEXT OF TURKEY

Considering ethnic origins, geography, urban/rural distinction in Turkey, it is difficult to generalize about gender and family, but it can be said that men are superior in the traditional family structure (Boratav, Fişek & Eslen-Ziya, 2014). Considering the results of the Research on Fatherhood in Turkey conducted by AÇEV (Tol & Taşkan, 2018), fathers evaluated themselves in terms of money, violence, and not showing their feelings, referring to patriarchal relations.

It is known that the traditional fatherhood role is widely adopted in Turkey (Özyeşer-Cinel & Tezel Şahin, 2021), and in a study conducted by AÇEV (Tol &Taşkan, 2018), when fathers were asked for their opinions on fatherhood, it was seen that most of them assumed the traditional fatherhood role. Although they reported happiness about their children, they talked about financial anxiety and increased feelings of responsibility and self-sacrifice after the child (Tol & Taşkan, 2018). In addition, the concept of being a man in Turkey means being the head of the house and the person who makes a living (Boratav, Fişek & Eslen-Ziya, 2014). These values define patriarchy, that is, the head of the family is the person who cannot be questioned (Özyeşer-Cinel & Tezel-Şahin, 2021).

On the other hand, in collectivist societies such as Turkey with a culture of relatedness, there are changes that are reflected in family relations with the increase in welfare level, education level and urbanization (AÇEV, 2017). In today's Turkish society, it is a matter of father helping his wife at home and being involved in childcare. The traditional authoritarian father is replaced by a cooperative and educative father model (Kocatepe & Bilgi, 2018; Onur, 2012). In Turkey, fatherhood studies adopt a more psychological approach compared to the international literature, but the focus is more on the changing values of the child for families instead of parental experiences (Barutçu & Hıdır, 2016; Beşpınar, 2015).

Kakaliçoğlu (2019) examined the experiences of fathers in the context of changing social roles in in Istanbul. The most important findings of the study were that fathers valued teaching something to their children, watching them grow up,

showing love in the father-child relationship, and they focus on the emotions experienced by their children. Özyeşer-Cinel and Tezel-Şahin (2021) looked at the relationships of fathers with their own fathers and their children. They reported that while fathers defined their own fathers as a person who had financial difficulties and who brought bread to the house, they defined their own fatherhood experiences as a hero who added life experience to their children. In addition, it has been found in this study that fathers who can spend more time with their children now wish to spend time with their fathers when they were children.

Considering the Turkish context, the interest in research on fathers of children with disabilities is quite limited. In the studies conducted with the families of children with intellectual disability, the level of anxiety (İçöz & Baran, 2002; Koçak-Uyaroğlu & Bodur, 2009), the various difficulties experienced by the families (Özsoy et. al., 2004; Kaner, 2004) were examined and as a result of these studies, the anxiety level of the family members was reported to be high and families reported lack of social support. In the study conducted by Cavkaytar and colleagues (2012), the needs of parents who have children with intellectual disabilities for support services were examined. It has been revealed that they need support on issues such as child health, future life, and education methods. In another study by Çakırer-Çalbayram and Platin (2020), an effort was made to raise awareness of the fathers of children with intellectual disability, and it was seen that fathers assumed the role of participatory father at the level of thought and traditional father at the level of behavior. Their study showed that after the study, fathers' interaction with their children increased and they started to take more responsibility. These findings were also supported by the observations of the mothers.

Studies with parents or only fathers of children with DS are almost nonexistent. Yıldırım and Sarı (2001) focused on mothers and the problems experienced by mothers in their study. They examined families with children with DS and looked at the effects of DS on them (Kara-Eştürk, 2019). They found that mothers have difficulties in family relations, social life and financially, and they have difficulty in allocating time for themselves. The results also showed that they are stuck between housework and child care and they have anxiety about the future

of their child with DS. Similarly, Kaygusuz (1993) conducted his research on mothers. He compared the depression and anxiety levels of the mothers of child with autism and child with DS with the depression and anxiety levels of the mothers of normally developing children. The study showed that the depression and anxiety levels of the mothers of children with autism and children with DS were significantly higher. Sipahi (2002) investigated the probability of mothers who have children with DS experiencing depression and reported that the incidence of depression increases when mothers have problems at home, their spouses are unemployed, have a low income, or feel lonely and have no close friends.

In addition to studies with mothers, there are also some studies with both parents. Kuloğlu (2001) conducted a study with parents of DS children and looked at the impact of informative health services on families. It has been reported that the hopelessness levels of the mothers decreased and their spouse relations were positively affected after the didactic information program was implemented. At the end of the program, it was also observed that the need for emotional support and the need for information decreased. In Kara Eştürk's study conducted in 2019, considering this deficiency in the Turkish literature, various problems experienced by the parents of children with DS were investigated. As a result of the research, it has been seen that parents need support, information, access to social services, and they expressthe need to explain the situation of their children to the environment and financial needs.

1.5. THE PRESENT STUDY

When we look at the studies on fatherhood and the studies with the fathers of DS children, it is seen that there is a lack of studies examining father-child interaction and examining fathers' feelings in depth. Personal sources, stress sources, fathers' perspectives and coping resources of parents with DS children need to be investigated further in future studies (Al-Yagon & Margalit, 2011). As suggested in the literature, this research aims to examine fathers' personal resources, coping mechanisms, their own perspectives, and the quality of father-child

relationship. Evaluating the studies conducted for them, fathers of children with disabilities reported positive effects such as increased satisfaction, reduced stress and grief after the social support they received (Hornby, 1995). It is thought that after the research, resources can be developed to support fathers and their relationship with their children with DS. Thus, the research questions were formed as follows:

a. How do fathers of children with DS describe their experiences of fatherhood?

b. How do they define their roles as fathers and establish their paternal relationship?

c. How do fathers of children with DS become involed with their children's care? What factors facilitate or hinder their involvement?

d. How do fathers of children with DS cope with challenges related to parenting?

CHAPTER II

METHOD

2.1. DATA COLLECTION

Following Istanbul Bilgi University Ethics Committee's approval, the researcher used convenience sampling method to reach the participants. While reaching the potential participants, an announcement was prepared and shared in various mail groups, social media accounts and the special education center where the researcher worked. Participation in the research was voluntary. Inclusion criteria in the study were a) being a married father, b) having a child under the age of 18 with Down syndrome, c) having a child actively continuing their education in a special education and rehabilitation center. No condition was determined as an exclusion criterion.

Initially, there was no response from any potential participants to the announcements. Then, one-to-one communication was established with potential participants through the researcher's own professional network and the research was explained to potential participants as well as professionals working with children with DS in all its aspects. Some potential participants were told about the research face-to-face in the special education and rehabilitation center where they brought their children, while others were referred by professionals in the researcher's network, contacted by phone and invited to participate in the research. Some of the participants (2 participants) who agreed to participate in the research were interviewed face-to-face and some of them (9 participants) via the Zoom platform. Written consent was obtained by giving an informed consent form (see Appendix B) during face-to-face interviews. In the online interviews, the participants' informed consent was received via e-mail. Demographic information of the participants was obtained with the help of a form (see Appendix A). Demographic information was obtained verbally during the interviews from the fathers who had difficulties in filling out the form online. It was explained to the

participants at the beginning of the interview that they could leave the interview if they did not feel comfortable or at any time.

After the completed procedures, a semi-structured individual interview was held with the participants. For the interviews, a guide was prepared as a data collection tool and followed in the interviews (see Appendix C). In the guide, there were questions to understand fatherhood experiences, fathers' roles in the relationship with their children, what tasks they took in child care, what difficulties they faced, and their coping methods. As suggested by Braun and Clarke (2013), the interview guide consisted of opening questions to make the participants feel safe, then open-ended questions to help them share their experiences on the subject in depth, and closing questions to bring the subject together. One pilot interview was conducted to evaluate whether the guide worked well to collect rich data and to understand the strengths and weaknesses of the questions before actual data collection started. This interview was not included in the analysis due to the fact that the participant's narrative was not clear enough and that the probe questions asked in the interview were not sufficient to generate rich data. No changes were made in the interview guide after the pilot. The final guide involved 17 main questions and 22 probe questions about the experience of being a father, relationships with children, the process of receiving a diagnosis of DS, and expectations and hopes for the future. Completing the interviews took 33 to 144 minutes. While voice recordings were made over the phone in face-to-face interviews, voice recordings were made over the Zoom platform in online meetings. The interviews were transcribed and kept in an encrypted form by the researcher along with the informed consent forms and demographic forms.

2.2. PARTICIPANTS

As Braun and Clarke (2013) suggested, the sample size was planned to consist of 10-12 participants in the study. Twelve fathers were interviewed and 11 fathers were included in the analysis. The ages of these fathers ranged from 37 to 52. Although their education levels varied from primary school to university, they

were mostly high school graduates. The age range of the spouses of the participants varied between 37-47. The education level of the spouses varied between primary school and high school and they were mostly high school graduates. All but one of the participants lived in Istanbul. All families lived with their nuclear families, their spouses did not work, and they did not get any help from anyone about child care. They stated that they were middle-income families. Seven of the participants worked in blue-collar jobs and 4 of them were white-collar. The age range of the children of the participants with DS varied between 5 and 14, while the age range of the other children varied between 2 and 23. In terms of gender, 6 were girls and 5 of them were boys. Eight of the participants had 2 children, and 3 of them had 3 children. All of the children with Down syndrome continued their education in a special education and rehabilitation center, and none of the participants stating receiving psychological support until now.

Table 2.1

Demographic Information of the Participants

P. no	Age	Education Status	City of Residence	Occupation	Spouse's age	Spouse's educational status	Age-gender of the child with DS	Age-gender of other children
P1	40	High School	Istanbul	Electronic Security Specialist	45	High School	6- Girl	12- Boy
P2	37	High School	Istanbul	Textile Business	42	High School	4- Boy	2- Boy
P3	52	Bachelor	İstanbul	Financial Advisor	44	High School	6- Boy	10- Boy
P4	48	High School	İstanbul	Mechanical Technician	46	High School	14- Boy	23- Boy
P5	45	Primary School	İstanbul	Textile Business	47	High School	13- Girl	17- Boy
P6	48	Primary School	İstanbul	Chauffeur	39	High School	5- Boy	14- Girl
P7	39	High School	İstanbul	Typography Business	40	Secondary School	14- Girl	6- Boy
P8	45	High School	İstanbul	Fireman	42	Primary School	14- Girl	22- Boy 4- Boy
P9	39	High School	İstanbul	Mechanical Technician	37	High School	7- Boy	2- Boy
P10	44	High School	Kars	Worker	42	Primary School	7- Girl	16- Boy 13- Boy

P11	50	Primary School	İstanbul	Salesman	41	High School	10- Girl	21- Girl 18- Girl

2.3. DATA ANALYSIS

Thematic Analysis (TA) was used to understand the unique experiences of the participants who fathered a child with DS and their coping mechanisms. Thematic analysis (TA) is a systematic approach used to identify, analyze and report themes in datasets in many studies involving personal experience since the early 2000s (Braun & Clarke, 2013). Thematic analysis was considered to be suitable for the present study, since it is a type of analysis that helps to understand and explain the subjective experiences of the participants in-depth, to define the explanations, and to work on different subjects (Braun & Clarke, 2013). Following Braun and Clarke's (2006) recommendations, the analysis was carried out in 6 steps. In the first step, before starting the analysis, all audio-recordings of the interviews were transcribed. The transcriptions of the interviews and the field notes were read and re-read at the beginning of coding with paying attention to reflections that were taken by the researcher after each interview. This step served to increase the researcher's familiarity with the data. In the second step, the collected data was systematically coded to summarize the information. While coding the interviews, in order to convey the experiences clearly and accurately, the researcher adhered to the participants' experiences, using short codes. After initial coding of the first interview, a special education specialist was asked to check whether some codes matched with the experiences. Some examples of initial codes developed in this step were "fatalism", "educational effort", and "playing games with the child". Then, in the third step, potential themes that can be combined under the framework of the determined codes were created. When defining these potential themes, frequencies of initial codes were examined. The codes were ordered from high to low frequency. Then, as common experiences such as difficulties, coping mechanisms, and acceptance were found, the codes began to be grouped. Some examples of potential themes defined in this step were "adapting to child", "monitoring child progress", and "making sense of DS". In the fourth step, by reviewing the previously determined potential themes, some of them were improved, and some themes were added to others. In this step, different ways of

organizing themes and sub-themes were explored on the basis of code frequencies and repeated meanings in the data set. In addition, the relationship between different codes and meanings were re-examined to guide the theme development process. After the themes were finalized in the fifth step, the clear meanings and names of these themes were defined. Finally, in the sixth step, the final report of the analysis was created. MAXQDA 2020 software program was utilized to code each interview and form the themes.

According to Braun and Clarke (2013), researchers can ask participants to check the data, check it with co-workers, or get the opinion of a different person familiar with the subject in order to evaluate the trustworthiness of the analysis. Accordingly, during the coding and theme development steps in the present analysis, interpretations were discussed and reinterpreted with the advisor as well as a special education specialist. These discussions enabled researcher triangulation. The researcher, in the interviews she had with her advisor and the specialist, started to see the places that she had difficulty with seeing in the data and managed to stay away from subjective evaluations as much as possible. In addition, member checking was conducted after the themes are revealed to ensure that the results reflect participant experiences and views. For member checking, a single page summary of the results was prepared, and shared with the participants via e-mail, by phone or in person, depending on their choice and availability. Their feedback about the results were sought. They provided positive feedback about the final themes and did not make any suggestions for revising the analysis.

2.4. THE RESEARCHER'S PERSPECTIVE

The fact that the researcher has a bachelor's degree in psychology, has been working with children in need of special education for 4 years and is continuing her clinical psychology master's degree has been the main factor in determining the subject of this research. The fact that she was in contact with mothers during the time she worked in special education centers led her to wonder about the position

of fathers. In addition to her special education experience, the researcher's current psychodynamic-based psychotherapy studies also fed this curiosity.

Despite the increasing interest in research on fatherhood, especially in the international literature, there are still few studies examining fathers' experiences, especially in Turkey. In the studies conducted with parents of children with disabilities, it was observed that negative emotional states such as depression and anxiety were generally examined and these studies were mostly conducted with mothers. In order to create both clinical and educational curiosity about fathers' experience and a different path in the literature, the researcher wanted to examine fathers' experiences and relationships with their children. Initially, the plan was to study fathers of children with different developmental disabilities and not to limit the inclusion criteria in the study. However, considering the fact that each type of disability could create a different experience for fathers, the experiences of fathers of children with DS were examined. The decision to focus on DS was informed by the researcher's previous work experience and familiarity with working with children with DS. Because the researcher has been working mostly with children with DS for many years, her experience increased her curiosity about children and their families as they experienced and coped with DS.

It is still considered to be a taboo to examine the concept of fatherhood in Turkey to some extent. The reactions received when the research was first announced and the interviews were conducted confirmed this idea. At first, most families thought that both parents would be interviewed, and when they were told that the researcher would only meet with the father, this was found to be strange by both parents. It was generally difficult to reach the fathers directly, because almost all communications about the child's education were already established with the mother. Thus, the research was initially explained to the mothers, and if they agreed, the fathers were contacted. Some mothers did not find it appropriate for their husbands to be interviewed, whereas some said that they would ask their spouses and did not return. Some stated that their spouses did not accept and they thought that they had no experience to tell since their spouses were did not take part in taking care of the child and/or supporting his/her education.

Most of the fathers who participated in the interviews stated that they were worried about what they would talk about before coming to the interview, but at the end of the interview they stated that it did not come out as they expected and that the conversation was good. Coupled with this observation, the fact that some fathers conveyed their experiences completely positively and sometimes expressed a feeling of implicit anger in the face of questions that asked them about their child's DS made the researcher think that the fathers were quite afraid of being judged. The fact that they knew the researcher as a psychologist-teacher may also have caused them to see themselves as being evaluated. Although they were told that they were not evaluated and that the only goal was to understand their experiences of fatherhood, this situation mostly lasted until the end of the interview. In the face-to-face interviews, one-on-one conversations were provided with the fathers, but in the online interviews, most fathers attended the interview with their children or spouses. The fact that the fathers answered interview questions in the presence of family members may have increased their concerns over being evaluated and fed this tension. In particular, the fact that children with DS constantly entered and left the room during some of the interviews showed a cross-section of the daily experiences of the fathers.

It was noticed by the researcher that her tendency to listen from a psychodynamic perspective was quite active while listening to the participants and then during the transcription and analysis process. In order to prevent making assumptions about the fathers' experiences and generating codes on the basis of her own feelings and psychoanalytic understanding of the fathers during the analysis, the researcher tried to adopt a researcher's mindset. On the other hand, it has also been observed that retaining parts of her psychotherapist identity was fruitful in some ways. It was observed that fathers shared their experiences more comfortably and their sharing became richer, with the adoption of her therapist identity to some extent. This was evident when the researcher listened to the fathers' experiences with curiosity during the interviews and attended to their emotions. At the end of the interviews, feedbacks were received from the fathers were very positive. They

stated that they were relieved, that talking felt like therapy, and that they had never talked about these issues before.

Considering all these experiences, the researcher realized how important it is to include fathers in their interactions with their children, and how often they feel excluded. This research helped the researcher to realize that she had some prejudices against fathers in addition to her curiosity about the fathers' experiences before the interviews. Most of time researcher realized that she saw the father as distant from the child and from the life of the child and interpreted this as a choice. Although most fathers see the mother as the primary caregiver at home and the father as the person who meets the needs outside, depending on their gender roles, they also had to stay away from the child's life as a result of this. Sometimes this is a choice, but sometimes it is experienced as a necessity. It has been observed that fathers are caught between their own personal emotional needs and the responsibility and financial needs that increase especially with living with a child with a developmental disability at home. This study enabled the researcher to understand them more deeply and to see how much gender roles take from men as well as women.

CHAPTER 3

RESULTS

With the help of the thematic analysis mentioned above, the interviews were examined and four main themes and their sub-themes were found. The names of these themes are "making sense of and accepting DS", "fulfilling fatherhood role and duties", "adjusting to the child with DS", and "holding a positive image of the child with DS". These four themes and their sub-themes can be seen in Table 3.1.

Table 3.1.

Themes and Subthemes of the Research

Themes	**Subthemes**			
Making sense of and accepting DS	Not knowing what to do	Turning to religion	Accepting the reality of DS	
Fulfilling fatherhood role and duties	Providing for the Family	Perception of paternity: being strong	Spending Time with the Child	Maintaining Discipline
Adjusting to the child with DS	Prioritizing the Needs of the Child with DS	Changing Expectations from the Child with DS and Life	Staying in the moment	
Holding a positive image of the child with DS	Focusing on Potential for Improvement	Feeling Proud of the Child with DS	Emotional Bond with the Child with DS	Dealing with stigma

3.1. MAKING SENSE OF AND ACCEPTING DS

The combination of the excitement of a new child in families, the increased stress with the introduction of Down Syndrome (DS), the state of not knowing what to do, and feelings such as shock and helplessness were seen as the most important common experience. Although some families knew before birth that their child had DS, most learned it at birth. After the stages of shock, sadness, and difficulty in

accepting, they mostly found explanations in religion and began to explore what to do with support from other DS families. These experiences will be examined in detail with the sub-themes "not knowing what to do", "turning to religion", and "accepting the reality of DS" below.

3.1.1. Not Knowing What to Do

Although most of the families were told by the health personnel about the possibility of their child having DS, they were afraid of miscarriage and refused most of the prenatal tests, saying that even if their child was born with DS, they would not mind it. During the pregnancy process, this possibility was ignored by most families and they acted as if it did not exist. The participants who preferred not to think about the possible diagnosisstated that it is better and more important for them to have a comfortable pregnancy:

> *'My wife was 5.5 months old pregnant when they asked us for that test. When we made an appointment, they gave us an appointment for 2 months later. After that time, my wife did not want to go through with it. "I don't want to do it" she said. Even if we learned that there was such a thing after that time, the process would be the same. . The fact that we did not learn motivated us a little more. It seemed better to us to have it without learning, because if we did, maybe our psychology would deteriorate and during the birth process, maybe we would have problems, but it came as a surprise to us. It seems to me that we had a more comfortable time, because we learned about it when she was born. We would have been worse if we had learned and waited. Because if I remember correctly, when we went to a hospital, there was a family that was still pregnant and found out about DS. That woman waiting there, that woman's way of thinking, I was upset there.. She knew what kind of child, what kind of baby she was going to have. We didn't know, it was good for us…. Well, I'm glad we didn't know, I'm glad we did it without learning.'*(P11)

'In a way, it was good that we did not learn, because we do not know how we would have survived the pregnancy process, what kind of psychology we would have experienced, so it was a little better to learn at birth.' (P9)

A majority of the participants stated that they, as a couple, were uncomfortable with the abortion option and they felt that they were pressured into that option. Some of the participants stated that they refused the tests for this reason:

'After the double test, we only went to routine examinations. We did not do any tests. Because in every test we go, pregnancies over the age of 35 are troublesome, I don't know, go to the periontology department, they look at risky pregnancies or something. Okay, let's go, but we always felt that they treated us as if we had committed a crime. Wherever my wife goes, we heard "your child can be born like this, born like that", they always intimidated us like this. We said, this 9 months we can't live like this. After the double test, we did nothing.' (P1)

'It was said to us that our child had a 90 % chance of having DS, but my wife knows the medical term better, they said "there is a test and it is a very long process, we will send that test to Ankara, we will do that test for you, only if you accept to have the child removed". We were subjected to such psychological pressure.' (P8)

While half of the fathers experienced the period immediately after birth negatively in terms of the approach of the health personnel, half of them stated that they received positive support. Some families were not given sufficient information by the health personnel, and some were criticized for not having an abortion. One of the fathers described this situation as follows:

'Like I said, they are a bit harsh. You have to prepare a person who has a disabled child for the first time, psychologically, and answer their questions accordingly. You will have a lot of difficulty, why didn't you have your tests done'. I don't know what. There, they really demoralized us,. We couldn't adapt. Maybe we didn't come across a good doctor, they say 'all five fingers are not the same'. We started a bit negative from the beginning.' (P1)

Another father shared his experience with healthcare professionals as follows:

‘”Didn't you just take an intelligence test”? Like we didn't know that. She was a bit of a rude person, a female teacher, a professor, so she spoke a little rudely. “They give birth like this, then we keep trying”, she said something like that.’ (P10)

On the other hand, some of the fathers who had positive experiences with healthcare professionals and received support talked about the feeling of gratitude to their doctors. One of the fathers recounted his own positive experience:

‘They were very helpful. They said that “we have it too, but child are very smart”. They said “you can close the gap with education”. They said “you will follow them, no problem”. The doctors there guided us, God bless them.’ (P2)

Despite these different experiences before the birth of their child, almost all of the fathers who knew or did not know about DS prenatally mentioned the shock that came after birth. The participants’ acccounts showed that shock and not knowing what to do were more common in fathers who were not acquainted with DS before. One father described his own shock as follows:

‘First you experience a shock, because you are faced with a disease you don't know, I even heard its name for the first time. People don't care, if it doesn't happen to them. Even now, if you ask, a lot of people don't know what DS is, but now it has become quite common on television and social media. It is not the same as before, but there are still many people who do not know. Our doctor said this for the first time, you are in shock at first because you are expecting something normal, you are expecting a normal baby. After that, when our doctor started totalk about it, we started to relax a little bit. ’ (P5)

The shock experienced by the fathers involved reactions like not believing the reality of the diagnosis at first. Being told that there was no problem by the prenatal health personnel led to the thought that the diagnosis could be a mistake. The shock experience of another father is:

‘They told me first. Of course it was troublesome. Why is it troublesome? For one thing, this is a very bad thing. The doctor says that “you get this

done", we go to the ultrasound every two weeks, he looks at it and says "there is nothing to worry about", he says "everything is normal". E is born, he says on the morning of birth that E is not a normal kid. Well, of course you're in shock. Everything went normal, you trusted it..' (P3)

Especially right after birth, hearing the sentence "Your child may have DS" made the fathers feel like they did not know what to do. While some of them had never heard of Down syndrome in their lives before, some of them did not want to think about the possibility of DS and did not know how to act after the diagnosis. One of the participants said that the duty of telling his wife about the possibility of Down syndrome was given to him by the medical staff. He said he delayed delivering the news, because he did not know what to do.

'The doctors didn't make such a statement, they just asked, we said we didn't know. Well, when the baby was brought to the mother's room from upstairs, they wanted me to tell my wife. I said, I'll tell her. Then they said, did you tell her? We will bring the baby? I said ok, I'll tell her. In the meantime, my wife began to ask what. So we started to explain.' (P11)

Another emotion mostly experienced by fathers after giving birth was sadness. Although the feeling of sadness seemed to be intertwined with the feeling of helplessness, most of the fathers stated that they experienced this feeling for a short time and then looked at what they could do. Below are two participants describing their their feelings of sadness:

'Obviously it was difficult. We were both happy and sad. It was a very sad happiness. I remember that I took my daughter to my father's grave. I know I cried there. I am unable to speak even now. I brought him his granddaughter, but I said "here's your granddaughter, daddy, but that's what they call her. We don't know what to do". I know that I cried like that at the graveside. But after that, I didn't have any more sadness. I guess I poured all my thoughts and feelings to my father there. So, we were fine after that.' (P1)

'So now you feel the first uncertainty, helplessness, fear. Uncertainty is a very strange thing. I know what DS is and I know there is nothing that can

be done. That's how it will be. As far as I can get him with training, there are things that you can't fix.' (P4)

3.1.2. Turning to Religion

When the DS diagnosis was learned or the possibility of DS was told to the families, the fathers reported that they first turned to their religious beliefs. They stated that they refused abortion on a religious basis, and considered their child and DS as being sent to them by God. Some fathers relied on their religious beliefs and saw DS as a gift from God and as a test from God. Other participants considered complaining about this situation that happened to them as disrespect to God. On the other hand, besides religious feelings, there were also fathers who were primarily concerned about the health of their wives. After making sure of their spouse's health, they explained that they accepted what happened to them by saying that it was from God. Below are the three fathers' ways of conveying similar experiences:

'We said, are we ready for something like this? If it came from God, there is nothing we can do, we accept and respect it. If this is our destiny, we cannot be like murderers. A doctor told me "there are people who found out two weeks before the last three weeks and said that we can't take care of this child and ended the pregnancy. What do you think?" he said. I said "There is nothing to think about. If we're meant to live through it, we will. We said "God will help us somehow".' (P1)

In addition to not wanting to question God's decision, religious beliefs also helped fathers to accept what happened to them, and to make sense of the emotions they experience such as shock and sadness.

'Before the birth, my wife had check-ups, she had doubts. There was a suspicion that he might be disabled. We said to our doctor "God gave it to us. It's up to us to look after it". So, we never worried. It may or may not be. We said that everything was accepted and our daughter had DS.' (P5)

'They said there is a possibility that it may or may not happen. We risked everything and said it doesn't matter to us. We said that it is a life given by Allah Almighty.' (P6)

Religious basis was one of the main ways of making sense of DS and coping with the difficult emotions such as shock, sadness and helplessness that fathers feel after the diagnosis. The participants shared that the answer to the question of 'why me?', which was asked from time to time, was sought in religion, and that religious support gave almost all fathers the strength to continue. Two fathers described their experience as follows:

'Once you accept that it came from Allah, you will not have any questions in your mind. You're asking me, but I don't know how to answer. I've never thought of why me, nor did my wife.' (P7)

'God blessed it like that, so it happened. If you have faith in God, you know what we are doing, that is, it was granted. You will go there, you will take these trainings together, it is written in my destiny. I say thank you as much as I can, thank god for my son.' (P2)

3.1.3. Accepting the reality of DS

After the emotional turmoil and shock they experienced, the fathers who found their support on the basis of religion explained that they started to do research and learn what they could do about their children. Many fathers did various research such as internet searches, doctor's advice, reaching foundations, and made educational efforts to understand DS. They considered this process as acceptance, and in the acceptance process, they compared their children's situation with worse examples. They expressed that they were grateful, balanced their previous feelings such as sadness and pessimism by taking concrete steps, and they received support from other families who are in the same situation as they were.

Although there are various factors that helped and facilitated the acceptance process, the participants expressed that the most facilitating factor for fathers was knowing that their child did not have a different disease and seeing that their child

was physically healthy. Some of the fathers described this experience in the following ways:

> *'Thankfully we didn't have a heart condition. That's where the biggest problems start. When a child is born unhealthy in terms of physical health, they cause a lot of trouble. Actually, they are a little tiring. Since we did not have much trouble there, we always tried to enjoy it like this. We tried to raise him in a pleasant way.'* (P1)

> *'He took my son and listened to every part of him. He said to us there "you are one of the luckiest group of DS". He said "your child does not have any problems". They call it ultrasound, he looked with it. He said to come for the next control in two years. I was very relieved when the doctor said it was nothing. After that doctor comforted us, we continued that way, perhaps because we were more relaxed.'* (P6)

Some participants' accounts showed that acceptance was a not a straightforward process. In this process, some had to learn to ovecome feelings of anxiety and pessimism. Learning about DS over the internt seemed to be not helpful in this effort. A father described how what he saw on the internet negatively affected him while he was doing research in an effort to understand DS:

> *'As time passes, you always think about the bad, and open the internet today, even if you look for the simplest fire, you always see the worst. Unfortunately, we realized it too late. You should definitely not look at the internet or anything. That process also destroyed us, especially me.. My wife always stayed away from those issues, she didn't look at anything. She said she would take care of my son. She was saying, "Everything is normal, his physical health is good". That's right. When she said that, I was saying yes or something. After that, I was recovering a little, but when I was alone, I started to think again.'* (P4)

Two fathers mentioned that they experienced delays in the acceptance process because their children's development was similar to children who did not have DS. Similarly, the families who refused tests despite the possibility of prenatal DS tried to ignore this possibility throughout the entire pregnancy. In the process

of accepting the situation that happened to them after birth, the development process of their children being similar to children with natural development madeit difficult for families. While they already had difficulties in accepting the difficult emotions they experience and the situation they are in, the seemingly normal development process caused the fathers and their families to oscillate between denial and acceptance.

> *'Yes, he was a child with DS, but his development was always the same with a normal child. This was one of the stages that made it difficult for us to accept. What a normal one month old baby does, my son was doing the same. We try one month, two months, three months, four months, we looked at what he did and everything he did was normal, it took some time to accept because the process i-was going normally, Later, of course, the facts emerged, but we accepted them. We had to accept it, there's nothing we can do anyway.'* (P9)
>
> *'He never stayed in the incubator. You know, in the things I look at, read, and mostly hear, they say "When you are born with DS, there is always a problem in your body. They usually stay in the incubator when they are first born. They stay there for 6-7 days, 1 month, 10 days whatever". After that, they allow parents to see their child. But that day, when my son was born, he went to upstairs with his mother. They prepared him, we saw him. Then you think that he was not like what they say'* (P6)

On the other hand, the participants stated that meeting and talking with other families in the process of understanding DS facilitated the acceptance process of fathers. Seeing someone else go through the same path as them provided them with a supportive factor against their feelings of pessimism and helplessness.

> *'I was so overwhelmed that we went to a morning prayer chat, the conversation ended, a citizen I did not know invited us to breakfast.... The person who invited us went out to the hall. He came with a child in his arms. None of his limbs was working. A disabled child at the age of13. Well, he brought him, took his in his arms, he said "this is the insurance of my paradise, thank God, Mevla gave him to me, I will feed him now". ... I cried*

there. I told him "God sent you to me. I was in big trouble, Mevla said look what my servant has, he is praising, so collect yourself accordingly"….. We talked there, I said that I have a similar situation. We said that Mevla brought us together.He gave me great advice, he told me "I put my son through surgeries that I can't count for 13 years, but I still didn't give up hope". Saying that helped me a lot.' (P8)

They stated that it was good to see that the same difficulties they experienced were experienced by someone else and that the troubles were alleviated. The fact that the son of the principal of the foundation they went to also had DS helped them feel understood.

'Especially my friends. My friends and let me tell you, there are more experienced brothers in Dost Yaşam and we still see each other there. Of course, since we joined them later, their children grew up, they shared their troubles with us, what kind of troubles they had. When we went through the same things, we needed to communicate. Especially the friends we met in Dost Yaşam who have such children, or my own friends who were fathers before me and had the same problems,, my family, my wife. They also supported me when I had difficulties.' (P9)

'The son of the director of the foundation also had DS. Then you realize that he is one of you, so someone to help you out will do something like this. Our troubles would be over once we walked through the door. Even though we had a normal conversation, it would be very good for us, we would relax when we were leaving.' (P7)

After the acceptance process, families who thought about what they could do for their children started to take concrete steps and the notion of "doing their best" began to come to the fore:

'Well, I accepted DS in three or five days, frankly. Because as I said he was born already. You cannot return him. What can you do? Hit your head against the walls if you want, it does not matter. Therefore, here is what we need to do in order to accept him and move his life to a better point.' (P3)

'I am doing my best. I'm doing my best for Mehmet. I consider myself as a good father, also the people around me regard me very good.' (P2)

Some families immediately took action during the acceptance phase of DS after the complex emotions experienced wane and started to look for ways to go. While some of them searched for the best doctors, others tried to illuminate their path through contacting a foundation.

'Well, we didn't think anything bad about our child, because we accepted him. I can't think of how, can we do it, can we manage it. After all, the child is our child. After all, it's our child. We have to do all kinds of training and maintenance. So we didn't think that we can't do it. We tried to do everything for his education. We never thought if we couldn't take care of our child. We researched. The doctor said to us, for example, he must have a room, he must have a mirror, he must see himself. For example, the house we lived in was 1+1. After that, we moved to 3+1. We made a room for my son's education, so he can see himself. Whatever the doctors said, we mostly tried to follow their recommendations.' (P6)

'Then it happened that way, we accepted. After that, we started to do research on what we need to do, where we can go, where we can get such training, what we can do. We found the only thing on people with DS, Tek Method, what was it before, Dost Yaşam on the internet. We came to Dost Yaşam, we started that process. As a result of our research, our processes there began, early education, physical therapy at work, and then individual training. We went through a process like that, but we went through a process of acceptance, like in every family.' (P9)

After an individual with DS joined the family, feelings such as shock, pessimism and sadness arose at first. However, the fathers stated that they did not get lost in these feelings too much and started to look at what they could do for their children as soon as possible. The thing that supported them the most in accepting the situation they were in was their religious beliefs. They accepted their questioning 'why it happened to us' more easily by saying that it came from God.

After accepting the truth about DS, they quickly started to take action about their children's education.

3.2. FULFILLING FATHERHOOD ROLE AND DUTIES

When the perspectives of fathers on fatherhood roles were examined, the definition of 'duty' came to the fore. In their accounts, the fathers described various duties towards the family and their children such as providing discipline at home, providing for the house, playing games with their children, spending time outside together, taking part in the care of their children from time to time, and having "helper" roles in housework. The participants' perspectives on fatherhood, their family duties, and their experiences with their children are examined in detail in the following four sub-themes: 'providing for the family', 'perception of paternity: being strong', 'spending time with the child', and 'maintaining discipline'.

3.2.1. Providing for the Family

Among the duties of fathers, the foremost duty was described as providing for the family. Although most families stated that they receive childcare allowance, all fathers interviewed were the only ones working at home, so they were the main source of income of the household. While mothers undertook most of the duties at home, fathers undertook the duties outside. In addition to seeing themselves as devoted to this task, the participants seemed to experience shyness when talking about themselves and stated that the views of their family members are more important. In their accounts, it was evident that meeting the needs of the family and prioritizing the family view affected each other, and the fathers' need to do something for their families was at the forefront.

> *'I call myself a good father. I am a father who tears himself apart and takes care of his house, works for his family. It is necessary to ask the household and outsiders what kind of a father I am.'* (P11)

'So you have to ask my family who saw me from the outside. Now I say myself, what kind of a father am I? When I look at it, I say I don't know. I am a father the way they see me.' (P1)

'I mean people doesn't want to praise themselves much. I think of myself as a good father, if you ask my wife and eldest son it would be different, but I feel like a good father, especially after having my daughter.' (P8)

One consequence of the important task of providing for the family for fathers was that the busy work schedule affected the relationship with their children or family life. Six participants stated that their hard work necessarily affected the amount of time they could spend with their children. They stated that life and working conditions inevitably kept fathers away from their children's lives.

'Well, my teacher, in this type of disabled children, fathers are always in the background, because they have to support the house. Mothers are in the first place. My wife is always at school, I am always at work. We are in the background.' (P5)

'Fathers cannot spend time with their children, because they are working, mothers are spending more time with them. For example, his grandmother knows my son more than I do. She knows some things more, but she's his grandmother after all. Men's lives are spent working. There is no such requirement for women, but men do.' (P6)

Some fathers stated that the time they spend at home naturally decreases due to the intense working conditions and the length of the commute.

'Well, this is how our life process continues. The more things happen in 2 hours after 8 pm, the closer we are. After that, we can spend 2 hours as the process of going to bed, going to school and getting up early tomorrow begins.' (P11)

'We go by car, when we arrive, there is nothing to do because we are tired, but if we can play a little with the children, it is not the case always. It goes like that, plus we go to training on Saturdays anyway.' (P7)

On the other hand, some fathers thought that they can balance their busy working hours with holidays. They expressed their willingness to compensate for

the times they had to spend at work. One father added that he is pleased to be able to spend the weekend with his child and that he thinks that his child is not adversely affected by this situation:

> *''Since my Saturday and Sunday is a holiday, I can focus on my son a little more. But we have a long working period on weekdays, a working period of 9-10 hours, a working environment that changes day by day. Sometimes you can be very tired and sometimes not. There is fluctuation during the week. That's why I think it's not too negative for my son, to be honest.'* (P9)

A father, on the other hand, stated that his family complained about the intensity of work, despite working from home during the pandemic period and being with his family more:

> *'It's 10 o'clock and the phone rings, it's 11 o'clock and the phone rings again. So there are times when the phone rings until 2 am,3 am. Even when I'm eating, I have a phone in my ear. Household is getting bored with this too. They say "enough is enough, we are tired of your phone".'* (P1)

According to the participants' accounts, this intense work pattern experienced by most fathers also affected the distribution of tasks at home. While most fathers defined themselves with the role of 'helper' in domestic duties, they conveyed that they aresupporting their wives as much as possible.

> *'Of course, I try to help my wife as much as I can, apart from my own work. We try to share life, whether it's at home or taking care of children.'* (P5)
>
> *'I help clean the house when appropriate. I'm going out for grocery shopping. Even when I'm at work, even when I'm working at home. I'm trying to help, I'm trying to be supportive.'* (P1)
>
> *'Thankfully, I'm not struggling with anything. My wife is looking after our sons, I see them for 1-2 hours. I'm doing my best, trying to help her. Thankfully we didn't experience anything bad.'* (P2)

One of the participants mentioned that he had the chance to see and experience the living conditions of his wife closely while he stayed at home at the beginning of the pandemic period. He talked about how challenging not only

childcare but also housework can be, and he said that as a result of these experiences, he started to take on more duties in housework.

> *'I help with housework as much as possible. For example, because I had high blood pressure in the early stages of this covid… I didn't go to work for about 2.5 months, I was at home for about 3 months. That's when I realized that being a housewife is a very difficult job. When you're home for 3 months, it's a never ending cycle; You get up in the morning for breakfast, then you clean up, you clean, you vacuum, cleaning, lunch. Lunch ends, you clean again, then evening comes, you cook dinner. I mean, by the way, I don't talk about the processes of taking care of our son. Bathing, lesson, other things. It doesn't end 24 hours. I was saying 'I don't get this tired when I'm at work'. That's when I realized what it really is. I knew, but it's not really easy when you live it one-on-one. That's why I try to help as much as I can… Well, I don't know, I also cook, I do cleaning, I wipe and vacuum. We do things together as much as possible. Now I try to lighten the load, at least in that way, when I'm at home.'* (P4)

In their accounts, some fathers stated that they undertake some duties in housework and child care when there is no other option. One of the fathers who talked about not taking part in childcare under normal conditions mentioned that after the second child was born, his wife had to take the responsibility of younger children and he had the responsibility of their older child.

> *'After the second child, it became a bit of an obligation. In other words, you have to take care of someone while their mother takes care of someone. Because of my son's fondness for me, and more precisely, because I have skills that I can use with older children, I can't do much with a younger child, I change his diaper at most. Naturally, I had to take care of my eldest son because his mother was taking care of the youngest. I did it out of necessity, but I did it.'* (P9)

Another father stated that he would not give this care under normal conditions, but that he had no other options due to the illness of his family members.

'I'm doing it all. I mean, usually when my wife is present, of course she is doing it, but when she is not or she is in the house but she has a job, I don't know. Helping with the toilet, change of top and bottom clothes. I don't do a lot of changing diapers, but if there is an opportunity, I do if my wife is not around. For example, my wife was absent for 3-4 days recently, I took care of our child. His aunt took care of him when I was gone. So, I don't have a problem with it. Cooking a single dish is a bit of a hassle, other than that, I can cook all of them.' (P3)

The natural reason for the helper role of fathers was that they believed the mothers took on the role of primary caregivers and the mothers were better at providing care. The fathers who consider mother's love and care more important than anything else thought that no one else can give that care to their children.

'My wife is at home, taking care of Alya's condition and doing her self-care, because she needs it. She can't work now, and it is more important to grow up with mother's love and mother's care. No one else will look at your child the way you do. Other than that, they are at home. We go to rehabilitation institutions, we come and go. I also work at work.' (P1)

'I can dress my son, but of course I can't be like his mother because she understands him more and is more enjoyable. The clothes she chooses suit him very well, because her mother chooses beautiful items.' (P9)

On the other hand, some fathers saw the mother's primary caregiver role as a natural consequence of their working conditions. They already mentioned that the time that fathers spend at home is limited and that they cannot take part in the care even if they wanted to. When the mother asked for help, they mentioned that they had a duty of care.

'We are already in the background in the game now, the truth of the matter. Because after all, the father goes to work in the morning and comes in the evening. As you say how much time he can spend with her for 2 hours and 3 hours. When the mother stays at home, she is actually in a more active role. We're already players on the sidelines, the fact of the matter is.' (P7)

'I was doing it, changing diapers. Her mother said to change the diaper, I was changing it. She says take him to pee, for example, I take him to pee. There is nothing that I take as a responsibility because when I come, I either dive into something or get tired. Unfortunately, I can't say that I should do this or that. We want it to happen, but it doesn't. There is nothing to do.' (P6)

Some fathers stated that they could not participate in responsibilities related to their children, such as hospital visits, because they were working.

'As I told you at the beginning, I go to work at 8 o'clock, I come home at 6 o'clock. At that time, my daughter always has her mother with her. It was a hospital visit, I don't know, children with DS have some problems; here is giving blood, here comes the time to go to genetic diagnosis. Since the mother was running all of these, I didn't have much difficulties. It was always the mother who experienced the difficulties. If you do not have a car, going to the hospital is even more difficult with such children. Because why a child wants to sit, you can not sit. Since it's crowded, she doesn't want to get on, you have to but you can't. There are some stubborn aspects of these children, I think these are the aspects of trouble. There is no other downside. I didn't experience those troublesome aspects, frankly, the mother did. So I can't say anything about it.' (P11)

For the fathers, the time spent with their children on weekdays consisted of the time until bedtime after work. Some fathers stated that they met their children's caretaking needs in this limited time, while others stated that they only played games. A couple of participants stated that they helped their children with eating and and they took care of their children by feeding them:

'Well, in terms of nutrition in my daughter's care, she sits at the table with me. When we eat, she eats little by little. I say "girl wait, I will feed you". I'm helping her. That's how it is about food, she'll definitely be with me, we'll eat together.' (P5)

Regarding other caretaking tasks, three of the fathers with daughters stated that they were dismissed from their caretaking duties as their children grew up.

Drawing attention to the gender difference between father and daughter, they stated that as their daughters grow up, they naturally give up on care. A father's experience is as follows:

> *'Well, when my daughter was little, I always used to take a bath when she had problems in her bathroom, but after she got older, I am out of duty in her care because she is a daughter. Her sister is taking care of her, her mother is taking care of her. I have nothing else to do.'* (P11)

Some fathers, on the other hand, stated that although the mother was the primary caregiver regarding caretaking duties, they tried to be involved in these tasks as much as possible.

> *'Well, I will do anything. I also have the bathroom done. I change her diaper a lot. So I also take care of her by myself. I comb her hair. I'm not very good at it, I never knew how to tie hair, fasten it, now I turn it around on my finger and collect it. I also actively participate in her self-care.'* (P1)

Another reflection of fathers' duty to provide for the house was that their future concerns were generally financial concerns. Almost all fathers indicated that they feel more responsibility for their children in this respect in the future, as they undertook this duty within the family. In addition to trying to create financial resources such as better homes and cars, they also thought about vacations and activities they can do together. They thought that this financial investment would be good for their relationships and the living conditions of their children.

> *'Of course, we want to increase the possibilities even more of a more comfortable life, a more beautiful life, we have a house and a car, here we want to buy a nicer house, a better car. We always want our lives to be one step, two steps above. There are such plans, let's see, hopefully that is our wish, that is our intention, the rest is destiny.'* (P5)

> *'How can I say that everyone wants it, although as I said, I wish my situation to be good. You know, when the income level of the person is a little better, the work is a little less, the time spent with family members at home is a little more. Personally, I would like to be able to make their dreams come true, to travel with them more, to travel to different cities.'* (P10)

One father mentioned that he wanted to give his child more as an economic resource, because he could not see this in his own family, and that he was striving for this.

> *'I'm trying to make plans for her. How well can I keep their economic situation? They are my plans, we make some sacrifices, so they can be in peace. Our family didn't do that much, we got married and they saidbye bye. But, as I said, we can't say "we got you married, so go on" to the child that we couldn't even send to the grocery store. You know, you have a house, you have something. We're already worried about whether we can leave something to her... What kind of investment can I make, what can I do financially.' (P1)*

3.2.2 Perception of Paternity: Being Strong

The participants stated that as fathers, they were mostly expected to be the strong member of the family. While defining themselves, their duties as supporter of the spouse and protector of the family came to the fore and these attributions were related to both fatherhood and masculinity perceptions. The participants stated that when they met with DS, they made expectations from themselves according to these perceptions. They described themselves as more powerful, while describing their spouses as more sensitive. At times, they emphasized that they felt like they have to stand strong.

> *'When my wife first got the news, of course, you know women, she immediately got emotional and shed tears. Well, I mean as much as I can, I watched her cry, I tried to pretend it was a normal thing the first time I heard it.'* (P8)

After meeting with DS, the participants indicated that the part that adapted to the situation faster and accepted it faster was mostly themselves as the father. While describing their spouses as more sensitive individuals, the fathers defined themselves as rational, as the person who should be strong and as the person who watches over the family.

'After the test result came out, we learned that he had DS, and the process of acceptance began. This of course took longer for my wife, I adapted more quickly.' (P9)

'I don't know if it could take a week or ten days. But I don't think it takes that long. Maybe it took 2 days, maybe 3 days. I don't expect it to take long. It took my wife 40 days, but mine was not that long.' (P6)

'Of course she was even more upset. Because I've always been a rational person, I thought "so there's nothing to do now. From now on, we will fight whatever needs to be done". I adapted a little bit more quickly, she adapted a little later. He stayed in hospital for a month, they have breathing problems, lung problems. He stayed in the incubator for a month.' (P3)

A majority of the participants stated that they do not talk much about their own feelings, because of this strong standing role given to men and especially fathers. They indicated that they had difficulty in sharing their feelings during the interview, and six fathers stated that they had never talked about the topics discussed during the interview before.

'I talk to my wife a lot, but sometimes you cannot share some things with your spouse or children. I don't want to show whether I am weak. There is a father figure, after all. Fathers, as you said, are also victims. Dad is a human after all, he has feelings. He has to share something. Of course you share with this family but you cannot share your every disappointment, every sadness. You live them inside yourself, but it also tires you out and wears you out a lot. This happened to me a lot at first. We started to share some things afterwards. That's why I thank you very much for your good work... If I could help, I would be happy. As I said for the second time, I haven't spoken to anyone like this for 14 years. I told you, it felt good to say it and hear it myself.' (P4)

'Something like this; After a while, our conversaition does not decrease a little bit, but we cannot spare time for each other because of the increase in housework. There are questions that I cannot explain, that I cannot speak, for example, that we do not think of during the day. It seems

to me that it has gotten better. I disclosed myself a little, as if I was relieved. Maybe I haven't talked to even my wife.' (P1)

One of the participants, on the other hand, talked about not being able to stand strong, while describing his feelings of helplessness and sadness when they met with DS.

'At that time, they faxed it to my workplace, it said 47s+1. I can't explain my desperation when I saw it, what I felt. We learned that way, but my wife took it very firmly. She was so good, she stood up. Because I'm a man, I have to stand strong, she should have gotten support from me, but I got support from her.' (P4)

3.2.3. Spending Time with the Child

Considering how fathers spent time with their children, the prominent activities reported were walking outside, going to the park together, traveling by car, shopping together, and going to playgrounds. As mentioned above, the time spent together at home was at a minimum level for most fathers, as they had a busy work schedule, felt tired when they came from work, and some fathers describe themselves and their children as impatient. In this limited time, most fathers stated that they could not support their children educationally even if they wanted to, that educational activities were the duty of the mother, and that they spent more time playing games with their children.

In the theme of 'Providing for the family', it was mentioned that fathers prioritize the wishes of family members, and similarly, children's wishes were generally kept in the foreground when it comes to what to do in the time spent together. The fathers reported that they usually go out on the weekends, and the children usually decided what to do:

'The playground we go to the most is ordinary parks, that is, apart from my daughter's school, we usually go to the playground at home, whenever we can, we go to the park or to visit family. "Let's visit the aunt, let's visit the mother". She loves his grandmother. On the weekends, sometimes she says

"dad... grandma", that's it, she says "take me to grandma", or she says "dad, we're going to play", we go to the game room. We go out for a walk, she says 'let's get some fresh air'. Whenever she sees a park, she says 'daddy the park... we will go to the park, we will ski, we will swing and so on".' (P5)

''He was throwing stones into the sea. He will throw a stone into the sea, that way, he will go to the park,, we have two types of parks that we go to, one of the parks has a trampoline and the other has sand. Which park should we go to? It's completely up to his psychology. After that "let's go to the sea to throw stones, I'll drink juice, you drink tea, then let's go to the sea and throw stones"' (P9)

According to the participants' accounts, the most important of all father-child activities was going to the park together. All fathers who participated in the study were asked to go to the park by their children every week. Below are the sections in which a few fathers shared these experiences.

''We are just going to the park with my daughter. Our activity is riding the swing, riding the seesaw, walking around with my daughter. When her mother and sister go out, if we are at home, we play on her tablet,this is our biggest event.' (P11)

'If the weather is good, we definitely go out on the weekend. We take him to the park and take a tour. If he's okay on Saturday, though, he's coming to the rehab center. He arrives at 9 in the morning, leaves at 12, and comes home at 1 am. That's how it goes already. I mean, I usually try to do it if there is an opportunity, I try to spend time with him. At least 15-20 minutes and half an hour, depending on the situation, maybe more if I am at home.' (P3)

'So we try to turn off the TV in the evenings, that is, after 9 o'clock, we turn off the television, we spend time with them until 11, we chat. I take them out on the weekends. So I try to help them as much as I can.' (P2)

One of the fathers described how his child's illness affected the activities they did together as follows:

'We used to go and sit together, father and daughter, and eat hamburgers at the hamburger shop, until this celiac diagnosis was made. You know, we used to do some activities like this, but now, after this celiac, we can't do any social activities outside anyway. Because you are going somewhere, they are eating and drinking something, after all' (P7)

The fathers in the present study stated that they sometimes played games together with their children, sometimes they did housework, and sometimes they were just in the same environment and did different activities from each other during the time spent at home. The time spent at home, on the other hand, covered the time from when fathers come from work to bedtime. They reported that they spent almost all of their limited time with their children.

'It doesn't happen much during the week because he goes to school anyway, I go to work. However, when I come home in the evening, if they are here, they go to bed at 9:30. I'm coming at 7 and half past 8. There is little time left. If it happens in the meantime, this is the balloon game, ball game or we are dealing with it together. So weplay.' (P3)

'I am at home at half past 7 during the week. We are all together from 7:30 to 11-12. We're all together on the weekends. If we're going somewhere, we're going together. As long as I don't have a very private job, R. and I are always together.' (P5)

'I am at home during the day for about 6 days. I go to work on a Tuesday. We are all together at home with the child, with my daughter.' (P1)

The participants shared that their children get excited and tell them something when they come home as a compensation for the time spent while they are at work. They explained that they talked about the summary of the day together.

'He tries to explain in his own way the things he did with his mother during the day. Here's what I drew, like I did, or what he watched. He was interested in such things, for example music, I don't know, he finds a trailer for a TV series and shows it. We have this type of thing like 'Oh what's up X here', we spend some time like this. Apart from that, as I said, we are together, we are together in the living room after dinner. That's why I

wouldn't say there is something we do in the evenings, something like this, let's do something like that. But we are together. Everyone is not on one side according to their own mind, we are always together.. So the four of us are always together in the living room.' (P4)

Two fathers with daughters stated that they took part in the housework together and helped the mother together. Especially with the increase in the time spent together in the pandemic, some participants indicated that as father-daughter pairs they did various household chores together and they were quite satisfied with it.

'For example, we spent a lot of time at home at the beginning of the pandemic, so we cooked dessert together and it was nice.' (P10)

'If the house is being swept, she also vacuums, she especially likes to clean the table and helps her mother, together. Very tidy, orderly. She arranges things one by one, for example, if the cover of the sofa is broken, she fixes it. She's a bit of a picky girl. We both love children's games and help my wife together, especially in the pandemic.' (P8)

It was evident from the participants' accounts that the most important role that comes to the forefront in this type of time fathers spend at home with their children was the role of playmate. Some fathers stated that although they wanted to study with their children, they were unsuccessful in this regard because the children coded them as playmates. It became the mother's duty to follow the lesson:

'I said "'What if he encoded me as someone to play games with?"He's just playing games with me. For example, he does not sit down and study with me, as he does with his mother, he certainly does not. I try a lot,, but it does not work iSo that was the case 5 years ago. In no way, "let's sit together, come on, let's study", or "here is a puzzle, let's study it" or something, he definitely does not do it. He pretends to, but does silly things. It immediately brings tears to his eyes, so we leave it that way. We play ball or something. That's how he coded me. So I'm just a playmate with him.' (P4)

'I don't know about social activities such as education and handcraft games, making legos, playing ball in the house, for example, I do playful things that

children can enjoy as much as I can. At the same time, with my wife, I mean the educational thing,, the lesson, my wife supports it more by lowering it to the children's level. Frankly, I can't be a teacher, it's my job to be a child and play with children. I love it very much, I enjoy doing it.' (P8)

A father, on the other hand, mentioned that while he wanted to take a more active role in the care of his child, his child's stubbornness did not allow this, and he shared his experience as follows:

'Because of my son, he only sees me as a play partner, a friend. I want to teach him something, show him what he can do and so on. No, definitely, he didn't code me like that. It is always the mother who will be teach something. When he learns something, he always wants to show it to me, he makes a video call to his mother, tries to explain it to himself, etc. He'll have his video taken or something, if he's done something. I want it so that I can personally contribute to his education a little more, but unfortunately he does not allow it.' (P4)

The games they played together included various games such as ball throwing, chasing, jigsaw puzzles, hide-and-seek, but were generally seen to be games with physical activity. Those fathers who were seen to enjoy the time they spend together in general played mostly physical activities with their children.

'Yes, there are some games. There are games that her mother can't make sense of, but we can do it to each other even with our facial expressions. We spend time with some games like that. Even our gestures become a game. I'm doing something, her mother is looking at her, she can't understand what we are playing. We're having a good time about it.' (P1)

'We also get into a fight with his brother or something. We lay each other on the floor, I lift them on me, I put them on my back. We also take them outside to the park and play with them on the swing slide. That's what we usually do.' (P3)

The fathers who stated that they got bored quickly from the time they spent together said that they stopped playing to cope with this situation or that they got angry with their children.

'We're playing with their cars. He says he will paint once in a while, he paints. Sometimes we play ball. He throws it at me, I throw it at him. 5-10 minutes, whenever he gets bored or whenever I get bored, then we stop.' (P6)

'For example, when I come home from work, they both jump on me, what are you doing? Of course, they want to fight all the time, and frankly, I can't keep up with their performance since I came home from work. They want to roll with me and hit them left and right like a cotton ball. They want to spend time like that. They get on top of me, they come down from the top, so they want to wrestle with me like a wrestler, but my fitness is not enough for them. After a while I get bored of course, I have to react negatively.' (P9)

3.2.4. Maintaining Discipline

In the narratives of fathers, the concept of having discipline came to the fore while describing their own paternal roles. Although they described themselves as playmates with their children, fathers were mostly seen as a source of discipline in their accounts. The fathers in the present study generally set certain rules for their children in order to ensure this discipline, and they provided discipline by explaining from time to time and by getting angry or shouting from time to time. At the same time, the fathers who said that they have this discipline tried to be understanding towards their children. A few fathers stated that they were particularly against physical violence. As a result of being a father as the authority in the house, the fathers generally defined their wives as softer and unobtrusive.

'A person at home needs authority. Although we are very close to each other at home, I have the most authority in the house. No matter what her mother does, she won't listen. It's enough for me to just frown. I do not have a single hit in my life, I have not made one cry, I have not beaten him like that. I'm angry, you know, spanking him on the butt is not a beating, although today's kids think that's what it is. My son is like that too. He doesn't know what a beating is in his life.' (P1)

'No matter how much you shout at the child, for example, my little boy will never listen to his mother's words. They constantly shout at each other, his mother yells at him. They don't listen to your words easily because you spend time with her all the time, but they listen to my words.' (P2)

In a father's narrative, he mentioned that he tries to establish closeness and discipline with his children:

'Thank God, I am on good terms with my family, I am on good terms with my children. We act as friends with my children when appropriate, of course, we do not give up discipline. We're having a little trouble with my daughter.' (P10)

In the statements of two participants, it was evident that their children were closer to their mothers due to the distance and discipline between them. This was seen as a natural outcome of the father's position as a discipline provider at home. They stated that the children prefer closeness with the mother rather than talking to the father.

'My daughter is more involved with her friends and her mother. She doesn't talk much to me. "How are you dad, are you okay dad?". She spends more time with her mother. Just like with my son. Since my son always spends time with his mother, his mother knows about him more.' (P6)

'My eldest son also talks a lot about everything with his mother, for example. His dialogue with his mother is very good, but no matter how much with me, I said, 90 % is about my mistakes, there is some distance. He doesn't talk to me much, he doesn't want to, he's introverted.' (P4)

In addition to all this authoritarian approach, four participants indicated that they approach their children as a father who tried to teach them about the external reality and the facts of life. Sometimes as the father's imposition of his own truth, sometimes as an effort to persuade and sometimes as dictation. In particular, the fathers observed their children's behavior and mistakes and then tried to teach them the right behavior.

'She is trying to go out with a thin T-shirt in the winter weather, to go out to the garden. I say put it on my daughter, she gets so angry. You know, she

wants to do something according to her own mind, but when she does something wrong, we try to fix it.' (P7)

'We say, "Look, this is wrong. I say sit down, sit down, I say look, what you're doing is wrong, don't do it", of course she reacts differently at first, she doesn't care about you. She doesn't do anything and doesn't care. After that, you repeat, she stops and thinks like this. Then you repeat it again, she stops and says ok. It has to be said constantly because it is perceived a little late. It is necessary to warn her like this a few times, and then as she warns her slowly, she forgets and does not do it.' (P5)

In addition to wanting to correct behavioral mistakes, the fathers wanted to show and give their life values to all their children with and without DS. They explained that they chose applied and verbal methods for this purpose.

'I am not such an uninterested father, I am sure of it. I am not a very harsh father, nor am I a slapping, beating, cursing father. In other words, I am a person who looks at things from their perspective as much as possible and tries to make them accept my own truths.' (P1)

One participant stated that he took his children to work, because he wanted to teach his children about the difficulty of life conditions and wanted to show them practically.

'I also tell about life, that is, the difficulties, I say how money is not easily earned, I say that life is difficult, and I say that it will get harder and harder. I tell them not to waste, I tell them to be frugal, I tell them to be clean, I tell them to be honest. So I'm telling you everything that will be good. Sometimes, my work comes out, I get support from them, we go together, they say that they can see how hard this job is. I mean, I take them to work too.' (P10)

Each father had various references to himself and his own fatherhood. Common experiences among them were being strong, meeting the financial needs of the family, and providing discipline. Since the spouses of all interviewed fathers were not working, the only financial source of most families was the money brought to the house by the father, and therefore all domestic duties were left to the mothers.

While some fathers saw themselves as helpers, others mentioned that they hardly take part in housework. They tried to spare time for their children when they were out of work, and they spent more time with their children outside together. Activities such as going to the park, traveling by car were common experiences for all father-child pairs.

3.3. ADJUSTING TO THE CHILD WITH DS

One of the most important themes that came to the fore in the statements of the participants was that the families adjusted their lives and plans according to the needs and wishes of their children with DS. Most fathers conveyed that they do not expect the same reactions and behaviors from their children with and without DS and that they learn to be patient and more tolerant with their children with DS. Even those fathers who described themselves as impatient developed different coping mechanisms to cope with the stubborn behavior of their children with DS than they do with other children. These topics are explored in detail below in three sub-themes: 'priotizing the needs of the child with DS', 'changing expectations from the child with DS and life', and 'staying in the moment'.

3.3.1. Priotizing the Needs of the Child with DS

According to the fathers' common narratives, after the birth of their children, they wanted to spend more time with the family, put the needs of the family in the foreground and reduce socialization in the outside of the family. In addition to this general tendecy, it was evident that a similar change in life priorities was experienced more frequently after the child with DS is born. Most of the fathers defined themselves as attached to their families and they preferred their families over their social lives.

> *'What do I do outside of work, I usually take care of my children at home. I usually set aside 70-80 % of my time for my wife and children. I dedicate it to my own family, my mother, my sister and so on. I mean, it's just like that,*

let's just go and hang out, I used to do it, of course, these things changed after my daughter was born. I started to adapt myself more to the house. Because in order to truly be a family, one must be whole. I don't just leave itfor my wife, you will take care of the children, with the house, I'll walk around on my own, this does not exist. I mean, maybe it did a long time ago, when there

were no children, but now it doesn't.' (P5)

'We usually go out with friends at the fire department a lot. Here is the sea, cultural trips outside the province. I left it completely too. Let me tell you frankly, my friends complain about me at the fire department. "You weren't like this before, what happened to you, you're henpecked, that's what your lady is saying". I always say I have never been ashamed of my daughter's disability. My daughter also likes to get on fire trucks at the fire station, I take her to the fire department whenever I have the opportunity. I say to my friends "I have a wingless angel, God gave her to me and she requires special attention".' (P8)

Four participants, on the other hand, mentioned that they try to spare time for themselves as much as possible. Evaluating the time left for the needs of the children, some of the fathers mentioned that they have hobbies, while others mentioned that they try to create time for themselves during business trips. According to the participants' accounts, the time they spared for themselves began after the needs of the children are met and was shaped according to the children.

'So when I say do I have hobbies, we have our own sports, we have walks. Well, I play darts, I play bowling, whenever I have time. Of course, this happens more on trips. It does not happen in home life because when you come home in the morning and evening, it is not possible to go out.' (P11)

'We work on weekdays for my son's school one day at the weekend, and then we can spare time for ourselves as long as the conditions allow.' (P9)

In the narration of one participant, it was observed that when he felt the need to spare time for himself, he gave his child a technological tool, but felt guilty about it.

'These videos she watches sometimes, when we need to spend time by ourselves, the tablet we give her - something that shouldn't be, but - is now a must for children.' (P1)

In order to prioritize their children's needs and to increase their presence at home, some fathers quit their additional work and overtime, while some fathers spent all their days off with their children, and financial plans are arranged according to the child's education.

'I have been a firefighter in daily life for about 25 years. I am dealing with the firefighting profession,. I am at home for 24 hours, on rest for 48 hours. I usually deal with my family at work. I don't go out much, as much as I can. After my daughter was born, I was doing side jobs in order to devote almost all of our time to her, let me tell you, in 48 hours, after that I quit those jobs. Well, I'm spending my 48-hour rest completely focused on my daughter.' (P8)

'After these vaccinations, we actually started going to the company. They formed 2 groups in order to reduce the risk of transmission. People chose their groups according to their workload. Mine is Tuesday-Thursday. My daughter has started a ringworm ailment. We go to Cerrahpaşa every Thursday and Tuesday about it. It just happened to be my day. But there is no other day, there is an application on Tuesday and Thursday at the hair clinic. I don't go on Thursdays, I only go one day.' (P1)

A majority of the fathers in the present study stated that raising a child with DS requires more responsibility, that children with DS need more attention and they wanted to devote all their energies to their children and family life. As mentioned in the themes above, while the primary caregiver was seen as the mother and most of the child care was carried out by the mother, the fathers started to take more active roles in the care of their children with DS to feel more responsibility in this regard.

'If you had a normal child, maybe you would be a little more comfortable, but after the birth of your child with DS, you have to be a bit more responsible because you have a disabled child; she needs you. Every child

needs parents, but after a certain age, you are comfortable with them because they can lead their own lives. I leave work and go home right away, even if I have a job, I stop by the house first, I look at what my daughter is doing because my mind is always on her. I don't think so much about my naturally developing child. If you ask why, he is a normal child, goes to school, can lead his own life, but Habibe is different. Even if she turns 20, we are obliged to take care of her because she needs us all the time. What happens when you have this awareness, the closer you get to your child, the more you cling to your family.' (P5)

'I can't stand her crying. Now, of course, the older ones are a little jealous, but because they have grown up a little, and partly because we concentrate on her. We don't leave them alone either, but I still think she needs a little more attention. That's why we're a little more interested in her.' (P10)

As mentioned in the previous theme, while most fathers saw themselves as the authoritative figure of the family, regarding the education of children with DS, they sometimes abandoned this authoritarian attitude and mentioned offering alternative solutions to their children's intense stubborn behavior. They explained that they show the patience they do not show towards their children without DS, and they are more understanding towards their children with DS from time to time.

'For example, we want to go to a guest house. When my daughter does not want to go, we do not have a chance to leave the house. You want to go somewhere with her, you go, you can't come back. She returns when she wants. She wants to go when she wants. You know, are there any restrictions? Let me give an example, we will go to our neighbor as a guest. Let's go , I will not go, I will stay with my father. We stay at home, but the ladies go and come. Are there any restrictions? So they are decided by her.' (P11)

'Shouting and stuff, then my son started to be affected by the increase in our tone after he grew up. It didn't happen all the time in this house, maybe a few times a month, but it did happen. I saw that he is withdrawing to a

corner, his eyes are full of tears … Then, I started to pay more attention.' (P4)

Although the fathers were the ones who determined the rules and were the authority in the house, most fathers tried to develop new behavior patterns by putting their children's needs in the foreground in order to cope with the stubborn behavior of their children with DS. The participants' accounts showed that there are different coping mechanisms developed by the fathers against the stubborn behavior frequently observed in children with DS. Some fathers stated that they went for a solution by postponing the existing plans, while some others by increasing their explanations.

'If there is anything related to time, myself, work or anything else, I explain the situation. He insists for a couple of times, I say the same things on his insistence, then he forgets the situation by playing with his brother in other ways, but because I said we will go the next day, he reminds me again the next day.' (P9)

'Of course it has changed. So in the end we have to go, we will go; This time we are trying to cheat. Here, let's go, we'll buy ayran, we'll have a coke. I don't know, we are going to do something, we will go there, we will go to the park and we do something in the way of deception. Does it happen, it happens 100 % of the time.' (P11)

Some fathers, on the other hand, stated that they were tired because of the intense stubborn behavior of their children, and that they tried to find a solution by scolding and getting angry from time to time.

'What kind of a method… Of course we insist a bit. Look, if you don't do this… we also use a somewhat threatening way from time to time, but his stubbornness doesn't last that long anyway. So it's easy to convince him, it's not long lasting. Suppose I am angry right now, for example, half an hour later we hug each other again. You know, we don't stay until morning or tomorrow. In half an hour "Dad, shall we play a game again?" So we play.' (P10)

'His mother was struggling with him a lot all day. Eventually, there is no other way than yelling. He needs to be washed. His mother had to do it, shouting after all. Unfortunately, though, by using force, not by beating by tying his hands, but by saying his "This has to be". He was crying, he didn't want to, but the mother was also raising her voice. She was doing it reluctantly, but our son was overreacting.' (P4)

Altough the tasks related to the education of children were mostly with the mothers, one participant talked about the difficulty of the education process and shared that they tried to overcome the stubborn behaviors of their children with the game method. Although the participant mentioned how much he cares about the education of his child with DS, he prioritized his child's rights such as playing games and living his childhood and felt sorry for his child.

'Like a soldier, it was always education, always education, always education. Physical education, spiritual education. The next thing is education. It's always like a soldier. We have always tried to make him love it with games. Even now, we are still showing the things that will bore him with the game. She doesn't have a little childhood there. It is a little tiring, physically tiring.' (P1)

3.3.2. Changing Expectations from the Child with DS and Life

The fathers accounts showed that the perspectives of family members who have a family member with DS changed considerably. Although some participants stated that there was no difference in their lives, it was evident that the feelings of patience, tolerance and understanding towards their children were more developed in most of the participants, and the approaches to children with DS were different from those with natural development. In addition to these, attention to the quality of education and concern about the insufficient quality of education increased in

most of the participants, and it was observed that there were fathers who tried to take a more active role in the education of their children with DS.

The fathers differed in behavioral expectations from their children with DS and their naturally developing children. They stated that they were more understanding towards their children with DS when they set expectations, and this state of understanding was described as having an impact on the development of tolerance. The fathers who thought that they would be insufficient in interpreting what their children with DS do emphasized more the importance of being understanding towards their children.

> *'Don't get me wrong, but the word "it" (in Turkish) means "push" to Alya(child with DS). My son(child without DS) knows it's an insult, but Alya doesn't realize it. I cannot expect the same from them. Alya very innocently knows that it means pushing an item. Now I tolerate Alya a little more because of her situation, but since we are trying to raise my son as a decent child, "No, you can't be like that. You are not a street child, you didn't grow up on the street." we say.'* (P1)

> *'Let me tell you that what Arda (child without DS) can do at the age of 2, Bora (child with DS) cannot do it at this age. There is a very fast process between them. That's why Arda is a bit more dominant because he can say anything, knows what to do, and is twice as stubborn as Bora. But that's why we have a slightly lower level of patience with him, based on Bora, as we think he should understand.'* (P9)

> *'My son (child with DS) opens his arms and says welcome when I come home. Sometimes he doesn't let me in, he tells me to go. In such situations, I wait and ring the bell again. Sometimes he said no and hung up on me. It's okay because my son did it, but for example, if my daughter (child without DS) did it, I would be angry at her for why she did it.'* (P6)

The differences in expectations brought tolerance and understanding. A majority of the fathers described themselves as understanding and patient. After the birth of their child with DS, the participants mentioned that some positive emotions developed in their lives. For example, they said that they felt the feelings of love,

tolerance and patience more. These feelings began to develop in some fathers not only towards their children but also towards the changing life conditions.

> *'Now let me say this; We went through the process with Bora, we said that it was the process of acceptance, then we said that we had a son like him. We accepted ourselves and even saw it as a reward. That's why, emotionally, we both had difficulties in accepting and raising Bora in the process. Then we started to like it. Because we learned patience, a lot of problems arose, the patience process between the birth of Bora and his development… We had to be patient to accept Bora, analysis, results, etc.'* (P9)

> *'My thoughts about Zehra, about fatherhood have really changed. So tolerance, love and sentimentality; that is, it has increased significantly. Being the second child, the first child, of course, the feelings of motherhood and fatherhood, you are a little more inexperienced. They say the second child is journeyman, but my daughter has direct mastery… she taught us mastery, that is, about parenting, patience, beauty and tolerance. It was very different. We had difficulties, so we planted the sapling in the ground, it was a barren land, so it needed water and attention. We gave that attention, I think it was a very beautiful tree and fruit for my daughter. As I said, it taught us to be patient and to have a positive outlook on life, no matter what. Not only in terms of children, I don't know, a traffic accident, a small misfortune has happened to you. You missed the bus, you couldn't buy an item, family problems, then I think we learned to look at them positively, that is, to think with tolerance, beauty and healthy thinking through Zehra.'* (P8)

Among the participants in the present study, there were fathers who take into account the learning speed of their children with DS during the behavioral training of their children, and their tolerance increased along with it.

> *'If she were a normal child, I would say "don't do this" to my daughter, she may not, but since she is with DS, it is necessary to insist The more you repeat, the more she forgets. We are fine now, she has different movements because of her age. Here's a different move 6 months ago, now she's doing*

different moves. There are videos that she likes the most, she tries to do whatever they do.' (P5)

While the expectations between children were changing, some fathers also stated that they were afraid of being unfair to their other children. In the natural course of their lives, there were changes in their approach to their children. Although most fathers tried to care about equality between their children under normal conditions, they began to fear that their children with DS have different needs, and they started to fear injustice to other children. They said that they expected understanding from their naturally developing children.

'You know better, they are like flowers. When you don't give them water, they can wither in an instant. This part seems to be a little more important, because we always lean on it so that they do not experience those shortcomings, but I try to keep up with it as much as possible. I expect some understanding from my son (child without DS) because they are not the same, they are not equal. A little more interest shifts to Alya on that subject.' (P1)

'After having Çınar(child with DS), I realized that my eldest son actually grew up on his own. We haven't done much for him. I also take care of normal children, for example, they are around me right now. For example, my sister has a son 42 days older than Çınar. For example, sometimes they talk about things, they didn't eat or drink or something, these problems seem so small to me. We deal with very different things. I realized it later. We didn't give anything to my eldest son, we didn't really teach anything, he learned everything by himself. It went on in its natural course, you know, we tried for 6 months to hold a glass of water for Çınar. We said him "To drink like this, you can't drink while holding your head like a chicken, raise your head." I mean, it's a lot to tell, can I explain it? The simplest things. Maybe it's too late, but I noticed it.' (P4)

The same participant mentioned that while he lowered his expectations from his child with DS, he was upset about it from time to time.

'Really, we have nothing because Çınar is like that. But I mean, if you ask, is there a part of you that hurts but does not sink on one side? Because when I go out sometimes, I see my sister's son. 14 years old, the same age as Çınar. He's 1.80 tall, he's taller than me. He plays basketball, for example. They tell, for example, that he went to training. X can't eat his own food yet, he can't wear his socks. He can't do the toilet, his mother does everything for his self-care. Inevitably, there is bitterness. I'm looking at him, I'm looking at Çınar. It would be a lie if I said I don't get upset when I see his peers when that happens. But of course that takes a very short time, that moment. At that moment I feel sad, then I know that I should not compare. It comes and goes.' (P4)

Another participant had difficulty talking about this situation and interrupted his sentence.

'My friends had children who were born 3 days apart from my daughter. My daughter is still like that, for example, she is 14 years old, but you know, like a child, she is my friend's daughter, for example, the young girl is doing something on her own. You know, there's a lot of stuff going on there. You feel like[stops talking] …' (P7)

Some participants stated that they do not compare their children with DS with their children with natural development and looked at the situation in general when they had a difficult experience with their children. A couple of the participants mentioned that they were understanding towards their children, because they just being children,and explained that this is how they dealt with challenging situations.

'Because I am a reasonable person now, and because I love children very much, I actually didn't eat much, didn't listen to my words, I don't really have much trouble because I know that these may be related to childhood. All of them have a reasonable logic in my head, I put it somewhere. So I don't have much trouble in that sense, so I can understand. My other son isn't that old either, he's 10 years old. I can understand, I can solve.' (P3)

‘We say that he is a child, he has to do it. Since he is a child, there is nothing to do, we deal with him until he gets it done. Now you can't get anything by shouting at the child.' (P2)

Among the changing expectations, knowing that children with DS would not leave the house in the future and acting accordingly were one of the most frequently mentioned experiences. It was evident that fathers generally spoke of this situation happily. Especially fathers with daughters said that if their child did not have DS, they would be sad when they got married and they said that they welcomed this situation because they did not want to be separated from their daughter.

‘Sometimes she says “I will get married”, we say “there is no such thing, you are our baby, you will take care of us when we get old”.’ (P7)

‘I was always saying that if I have a daughter, I would not give her to anyone. It was such a sad moment when we learn about DS, of course it hurts, but you need to console yourself too.' (P5)

'In terms of our relations, I don't think it will go into the hands of our family, I don't have a lot of worries because she will always stay at our house. I don't know if you are married but when you get married they will feel your absence. For example, I don't feel it, I say “oh you will stay with me, no one will take you”. She is happy there, looking forward to the future. If God gives us health and well-being,we will live and grow old together. I don't have any concerns about that.' (P1)

In addition to the change in the expectations of fathers from their children and life, one of the areas where they experienced the greatest change in expectations was the field of education. Most fathers who did not report feeling much anxiety in the education of their children with natural development had doubts about whether their children with DS receive adequate education and about the absence of educators.

‘A lot of teachers were changing. The biggest problem for a student is that now a teacher hardly recognizes a student in the first month. The first month is already spent with acquaintance, whether the student's psychological

state or behavior, you can only solve it. We were having trouble,because the teachers changed so often, but we were forced to leave because of desperation. At that time, it was the only one here, there were no other institutions.' (P8)

'Three teachers changed in less than a year. Also, this was a public school. I said "keep him withone teacher, so he can stay with whoever he is assigned to". This is the year when the new term starts. Because we started, we enlisted him to someone and the teacher changed again. Frequent teacher changes are actually not good for these kids. We need someone who knows him, knows his movements and will make a training program accordingly. Unfortunately, it was the same in the special education center, it was a problem…….So the teacher is very important, but unfortunately I don't know how they do it in such institutions. I can say that I have not come across a good teacher properly.' (P3)

There were also participants who shared that they had negative experiences with educators in their personal experiences. They thought that their children were not given enough attention in the kindergarten where they took their children, and this upset and angered the families.

'My daughter's best years are gone in a class they opened just because it would look like a private class. They gave a private class to a retired teacher, a teacher who doesn't understand business. We had to take our daughter to such a teacher. We caught her a few times when she turned on the television and left our daughter alone with the cartoon. This pissed us off. In other words, you can't take care of the child, you can be a retired teacher, so there was no conscience. Teach something, take care of something, paint, I mean, we had some arguments. Then I complained to the district national education' (P8)

'We sent him to kindergarten, it was small like this….. They didn't let the mother in, they said they very interested with children. Three days passed, the boy did not want to go. When my wife went, she says that our son wet himself . Oh my god, we couldn't understand why. And then we learn that

when we watched the recordings. The children were somewhere, my son was somewhere else alone. For my son's education I'm trying to gain something miles and miles with my nails, theacher suddenly detonate a bomb and put dynamite on it.' (P4)

They stated that the teacher's ignorance psychologically damaged their spouses as well as their children, and indirectly the father, and inreased the difficulties faced in the child's transition to school.

'The process of getting used to primary school was hard on us a little, the class changed. The teacher's getting used to Bora, and the fact that they had not worked with such children before, during the first semester of the school psychologically, especially my wife, was very worn out. Naturally, it pissed me off too. He talks about the situation at school, about his situation, and so on. Naturally, you wear out too.' (P9)

3.3.3. Staying in the Moment

As mentioned in the previous theme the fathers started to feel different anxieties with the change in life expectations after having a child with DS. Chief among these concerns was the question of who would take care of their children after they died. While some fathers saw the other sibling as responsible in this matter, some fathers were worried about giving this responsibility to the child and did not see it as the duty of the other sibling.

One of the participants planned to entrust his child with Down syndrome to his naturally developing child and managed his future anxiety in this way. He shared the responsibility of giving care in the future by accepting his child as a second father, not a brother.

'The person I will entrust her to is my son. I always tell him "she's your daughter too. After me, of course, like every other person, it is not clear who will die before whom, but after me, she is yours to take care of. Your responsibility, your child. You will see her as your child, not as a sibling. It could be my greatest legacy to you"….I tell him, the reason why I get mad

at him when he does something is "because you are a role model, son. Whatever you are, whatever comes out of your mouth, she will repeat it soon. You are her role model. After all, she takes you more as an example". I always put some responsibility on him, our assurance is our son. Even if we are not, I always pray like this. May God give you a beautiful wife so that she won't even say no to my daughter. I say she is your child after us.' (P1)

However, in a father's account, the other child seemed to naturally feel this responsibility, without explicit and direct instruction.

'He (child without DS) was thinking of becoming a soldier for a while, he was thinking of going to the army. Then I heard from her mother that he gave up. He thought "I become a soldier, if I leave, my place of duty is eastern part of the country. What's going to happen to Çınar(child with DS), you're going to get old tomorrow". He said he gave up that ideas after Çınar. We didn't impose anything on him though. Loading a mission, saying things like "look son, you're going to take care of Çınar" or something. Because we noticed that, it shouldn't be like that. Because look at a child at that age, this is your brother, you will always look after him and you will destroy that child's world. However, we are in the same house. We live together, he sees the troubles and difficulties we experience; therefore he is affected. Inevitably, everyone is different, of course, but he is very possessive of Çınar. He thinks too much. Of course, he also had an effect on his introversion.' (P4)

The coping mechanism developed to convey these intense emotions was the solution of staying in the moment and making short-term plans. Some fathers coped with this situation by generalizing the situation of not making future plans and normalizing it by saying that they did not make plans for themselves.

'Not many people can plan for the future, I know. I do not have such a thing, as there is no guarantee that we will wake up tomorrow. I don't plan much. I try to live in the moment.' (P1)

‘There is nothing that I think differently. Conditions of life, what life will require, what it will make you do. I don't have a thought because I can't even think of anything for myself, I can't think about anyone, that is, about the future. No, my son will do it, not I will do it. Whatever life conditions lead to, whatever it allows.' (P6)
‘I am not makking any plans about the future because it is not clear what will happen. Because if I say that I will leave this legacy to them, let them read it like this, there is no such thing. It is unclear what will happen tomorrow. Maybe just education.' (P2)

On the other hand, a father whose child had a heart disease stated that they were afraid of losing their children for a very long time, so they managed to cope with this fear by not making a future plan.

‘Maybe because of the thing, for example, it wouldn’t be like this if the pacemaker wasn’t such a problem, but…..We sleep in bed at night, for example, if there is a sound from her, I jump out of there, even when I am sleeping from the bed. So there's that psychology. That's why she is with us, with God's permission, as we do not let her out of our sight. That's why my wife and I don't dream, the truth is.' (P7)

Another father stated that he did not consciously choose to plan for the future, because he always thought of negative situations.

> *‘Well, now that you ask, I thought. I'd be lying if I said I dreamed a lot about the future with X. You know how I said we chose not to think about some things going forward about X. Because when we think, we usually think of negative things. Because it bothers us so much, I don't imagine anything about X that is very forward-looking, I don't think.' (P4)*

Overall, the fathers' own perceptions of paternity, as mentioned in the previous themes, changed after the joining of their children with Down syndrome in the family. Some fathers added more understanding to their authoritarian attitudes, while others reported that they experienced feelings of tolerance and love more intensely. With the changing needs of children, the fathers started to take more responsibility in some issues such as education, nutrition.They came up with solutions such as staying in the moment, because sometimes the burden of these responsibilities was heavy.

3.4. HOLDING A POSITIVE IMAGE OF THE CHILD WITH DS

In the present study, all fathers of children with DS faced various problems such as behavioral problems of the child and having different diseases. In addition to these personal reasons, the fathers who had different life problems such as having to change their lifestyles, determining the financial investments accordingly with the increasing needs of their children, developed different coping mechanisms to adapt to this situation that will last a lifetime. At the beginning of these coping mechanisms, the bond of love they established with their children came first. Protecting the bond of love with their children and focusing on the potential development of their children were among the areas that fathers valued in life. These topics are explored in detail in four sub-themes: 'focusing on potential for improvement', 'feeling proud of the child with DS', 'emotional bond with the child with DS' and 'dealing with stigma'.

3.4.1. Focusing on Potential for Improvement

The participants' accounts showed that the fathers attach great importance to their children's ability to communicate with the environment. They stated that they wanted their children to be self-sufficient and they thought that keeping in verbal communication with the environment could also feed this competence. In addition, they attached great importance to the father-child relationship of their children. They thought that if their children receive adequate education, they would improve in verbal communication and this development could be reflected in their relationship with the environment.

> *'I wish Habibe could talk to me more properly. You know, father and daughter will be more beautiful. You know, everyone wants to have a father sit down and have such a conversation with his daughter. If her language was smooth, we could talk more like this, more comfortably like this. I hope she will be, so we are working for her. This is one of our goals... To prepare a better future, to carry her to a better place, so that Habibe can lead her*

life better, express herself in society, not be in trouble, not be in a difficult situation; this is my aim. As I said, it will be even better if we decipher the language.' (P5)

'In order for our relationship with Doğu to develop, he needs to react to our conversations. He has to respond somehow, so that our relationship can continue in a good way, both for him and for us.' (P3)

According to the participants' accounts, the families who tried to keep their children's sensitivity in the foreground while improving their children's verbal communication had difficulties. A father stated that his communication with the environment was minimal, because they cared about his child's sensitivities and he was worried about this situation.

'It would be a great happiness for me if Çınar could do his self-care, talk, get along, and at least talk enough to tell his troubles when he meets someone other than us. It's a little difficult for me, for her brother and for her mother, because it's a little difficult for her to get along with people in a place where Çınar's mother, me or her brother are not present, because now we understand her when we are together 24 hours a day. Maybe we did it wrong, maybe it's not a good thing, but we always feel that he needs us. This is our common concern when the three of us talk, I wish he could talk enough to tell his troubles and express himself, even if he could express himself when something like this happens and meet his needs without needing us. It would be unrealistic if I said I thought one step beyond that. I think that even this is enough for me.' (P4)

The fathers who attached importance to verbal communication and their child's independence tried to support their children's education more socially and to support them with educators.

'She is already in education. You know, they are progressing more socially in education, rather than lessons.' (P7)

'I do not have a financial problem frankly, because I work. I find tutors, professors, whoever is good at this job, I try to take him to these

professionals so that somehow this kid's life can be a little better. No matter how much money I spend.' (P3)

Towards the same goal of improving their child's skills, two participants attached great importance to including their children in social activities, especially outside. One father stated that they followed the activities of the municipality and tried to participate in as many activities as possible, and they watched their child's behavior there and thought about what they need to improve.

'Metropolitan municipality. You register with their social services, they send you somewhere, you stay there for a week. They give you prefabricated houses, they belong to you, there are 1+1 houses. It has a casino, entertainment venues, cafes, it is very beautiful. Lots of disabled children meet there. Such great events. We try not to miss these events. We just mingle and follow, let's see what Habibe is doing in society. Look at how she treats people, what are her mistakes, what is correct, if she does something wrong, we say "Habibe, don't do this"' (P5)

Another father said that he attaches great importance to the socialization of his child and that he is waiting for his child to grow up to participate in activities.

'When I say planning, I don't have anything planned, but in the future, when she gets a little older, attending events, entering a crowd are things that we have in mind.' (P11)

The fathers reported that they did their best, so that their children could live their potential, and sometimes even looked at what they could do better. According to their accounts, this was sometimes by forcing financial means, sometimes by starting early education and sometimes by making personal efforts.

Some fathers expressed that they try to do their best and examined their own behaviors for the development of their children. They stated that they followed their children's education and tried to improve their children by keeping in touch with the educators.

'I make observations. I make a comparison myself. Are we getting better, are we getting worse. We're trying to compare her and support her

accordingly. Alya is fine now. She can count up to 20, even counting up to 10 in English.' (P1)

'We did our best. So, in conclusion, I sometimes think, who would do it to let their psychologist and their primary school teacher meet. Let him meet with his teacher at primary school with his individual teacher there. Thankfully, their teachers in rehabilitation were also very helpful. We really did the best we could because we know that Bora is at a certain level, we don't want him to leave fusion class, we don't want it to be subclassed privately.' (P9)

One of the participants stated that he and his wife started their son's education earlier than other families, fearing that their son would not receive adequate education.

'When Kemal was 4 months old, Cerrahpaşa said come to us. They said they will report to you. You're going to start training. Since my wife was a little worried, she said that we should go as soon as possible. Let's take private lessons with our own means. We went to an institution. They said that some hospitals in the institution give these trainings earlier. That's when we went to Zeynep Kamil. We had Kemal's checks done there, they immediately reported to us. We started training after that, Kemal was 2-2.5 months old when we started training. So we started training early from there.' (P6)

Some father expressed that as their children grew up, they did not lose hope that their children could get better.

'Even if not perfectly, she can speak three-by-fours, she can tell her troubles, she can communicate with people. I was saying that when Habibe turns 18, I hope it would be like this, if it was different, even better. Let's hope that's our goal. She can speak more fluently. That's my biggest goal right now. Hopefully, let's see.' (P5)

The fathers in the present study expressed that they feel motivated to try as much as possible because they did not want to regret later.

'When you lose hope, you will not want to do anything, but when you do not, that child will suffer more. We said that no matter how sad we are… My

thing about X has always been this, material and spiritual: I have always pushed my financial means to the end for him, I still suffer from his thing, I am struggling. In order not to say "I wish I had done this to X" tomorrow or the next day, we had all kinds of language training, sensory integration therapies, all physiotherapy; All the trainings are complete, whatever we can do. When we hear about a training, what if it would be beneficial for X? I mean "dad, if you had taken me to these trainings, it wouldn't have happened like this". We said "let's do what we can, do what we have to do".Oh I wish, I'm not saying this for X now, X still can't speak properly. But I'm not saying that I didn't send X to language training or something.' (P4)

Some fathers stated that they received support from educators while trying to do their best. In addition to the bad experiences with education mentioned in the previous theme, it was seen that fathers also had positive experiences. They explained that the care of the educators increased the motivation of their families and ensured the development of the child's potential.

'Let me put it this way, we go to the language therapist during the education process of X, and our psychologist started a dialogue process with us by saying "Constantly ask questions for X's speech, always try to get answers from him". When he started the dialogue process in that way, the persuasion ability of other things also improved. What if we don't go that day, I'm asking questions again because the psychologist said, ask questions to get X to talk. Now, while we are in dialogue, we both improved our dialogue and improved our speech. As I said, some things started early, because he started education early.' (P9)

'When you say nice things, we get motivated and become twice as strong. A little bit of your support has affected us positively. Of course, you do not have the luxury of calling evil good. You have to say the bad, but you always said good things to us. We are also very motivated. For example, we were very demoralized during the teacher changes….. You were the people we considered to be our favorite, and you were the same. A little bit of your

support has kept us afloat. What we took from you, what we applied from you at home… Being good as we see them and see the good made us good.' (P1)

A few participants wished their children to realize their potential and work in a job and they strived to realize this wish.

'To be honest, it crosses my mind sometimes, but now I want her to work in a suitable environment. The state has great support for this, or what my wife and I wanted the most, we saw it on television, I don't know if you saw it on the news, but the child of mosque imam, who is 14-15 years old, has DS. He was a muezzin and could read the Quran. Zehra can now read 4-letter syllables. In other words, we can understand a foreign citizen cannot, but my wife and I both want and desire for her to recite the Qur'an. I want her to work in a suitable environment. I want this for herself, not for a financial contribution to the house.' (P8)

'There was something like opening a cafe in mind, but you can hardly set it up in this era. My wife says we'll set up a cafe, Kemal will run it, it'll stay there and so on. In our dream, we set up a cafe for him, he works as a waiter or sits at the cash register.But maybe we can do it, we don't know.' (P6)

One of the participants mentioned that while helping their child realize their potential, they chose a goal that would help them in this process, and this goal was to have their child be an exemplary person with DS. The father stated that if they achieve this goal, they thought that they can support other families with DS.

'Someone once saw us in the market and said, "Tell me what you are doing, this boy is in very good condition". He asked us for advice. I can tell you that I am happy. I felt happiness. Frankly, I chose a target for families who couldn't accept it and had difficulties after having Bora. We chose such a target for ourselves, to be honest, for situations that would facilitate the acceptance process of what we went through. When they reacted like that, we said that we should walk a little more firmly towards the target we chose. Of course, after setting the target, the difficulties begin, the school process,

hardships etc. I was very happy when the family said so. I said we are on the right track.' (P9)

3.4.2. Feeling Proud of the Child with DS

In addition to helping their children realize their potential, another feeling that motivated fathers was to be proud of their children's development and not hide them from society. The fathers who expressed their pride in DS often praised their children's progress.

'When something happens, I always say that I have two children, one of whom has DS. I share it with everyone. I don't have any reservations about this either, I have a disabled child, and I don't upset. I do something with pride. I have shared it with many people and I have told it to every person I meet. Even in the company, when we have a meeting from home, for example, she makes noise, shouts and calls. For example, we have a friend from the sales department. We are talking about something serious with him, she came and started to talk gibberish. We left the meeting, I said to my friend, come and have a talk with her. She chatted with her, how are you? I mean, a lot of people know. Almost everyone I talk to knows about my daughter's situation.' (P1)

'Let me tell you this. I went to the foundation before, there is noone like Sinem. I'm not saying that because she is my own daughter. When you look at her as a type, you can never compare her to someone with Down syndrome. I see some children, you can understand from the outside. You say stop, those children don't stop. But my daughter is not like that.' (P7)

The participants accounts showed that as the fathers adjusted their expectations according to their children's development as mentioned in the previous themes, they started to think more positively about their children's development. Even if children behaved behind their ages, these situations made fathers happy when they remembered little things and learned new words.

‘For example, I sometimes take another road by car, she said "my father, we will go from here.". When we pass in front of her mother's hairdresser, she says "Look, my mother’s hairdresser.". When we pass by the gym, we went to my friend's gym a few times, she recognized this place. Mashallah great intelligence. One does not forget what she sees, she certainly does not forget. Even if time passes, she does not forget that person, nor does she forget the places she saw.' (P5)

'Well, as I said, I like every time Kemal uses new words, new things he learns, hearing and playing music, hearing a song and trying to sing it, coming and playing a game all the time. He relaxes me in that respect. It's like a brain cube. When he does something, he doesn't forget it easily. He says it all of a sudden. You sit down, all of a sudden he says something, he makes me fly.' (P6)

‘According to what my wife said, it was going well. For example, Mehmet likes the song very much, I said sing the song last night. She says he does the same things, the same movements. I see Kemal in a very good place. He goes up and down from the fifth floor alone.' (P2)

Sometimes the participants expected the children to cause problems to the family due to DS, and when the children did not cause these problems, the fathers experessed their happiness. The involvement of their children in daily chores also pleased the fathers.

“Thank God, she loves traveling very much, she is very patient, she never gives us any trouble. For example, while driving in the car, I have never seen it cause us trouble on a long trip. She sits patiently, if she is going to watch cartoons, she watches cartoons, if she is going to sing, she sings. We're cruising as much as we can. If the house is being swept lately, she also likes to clean the table, especially to help her mother, together. Very tidy, orderly. She arranges such things one by one, for example, if the cover of the sofa bed is broken, she fixes it. She is a bit of a meticulous girl.' (P8)

In order to sustain the positive image of their child with DS, the fathers at times compared the situation of their children with a worse situation and felt

thankful. According to their accounts, this was both a method of coping with the feeling of uncertainty they experienced and they tried to see the positive aspects of the situation they are in and held on to them.

> *'She can walk by herself, she can meet her own needs, she lets us know when she is hungry, when she wants to do something she expresses it. She teels us when she wants to play games. You know, thank god, we saw other disabled people in the camps, we were going to the camps, I mean, when I look at my daughter, I am always grateful.'* (P5)

> *'We never let go, we always hold on. Both my daughter's health condition gave us strength. There are some children who really come with their glasses full, they do not take it. You are also a teacher, you know, no matter how hard you try, you cannot raise some children above a certain level. But her glass was really empty.'* (P1)

Supporting the development of their children with DS and seeing their children progress wass a great support for fathers and evoked a sense of pride. Some fathers mentioned that they felt privileged in their environment.

> *'Now I can't make a comparison, but being the father of Bora or someone like Bora is really like a reward… Being the father of a child with DS has been a reward, because it has taken up a really, really strangely large area in our lives. We went to places we did not know, we saw. We had a social circle, we had a huge social circle, thanks to X, so I feel privileged, in a positive sense.'* (P9)

Although some families were acquainted with disability before their children, most of the participants stated that their views towards disabled individuals changed after their children were born. They stated that they approached people with disabilities more empathetically. They stated that when they see a disabled person outside, they are more interested and if those people need help, they try to help.

> *'When we saw a disabled person outside, we used to look more indifferent, now we started to look more carefully, you are more interested. For example, when you see a visually impaired person, you immediately try*

to help, or when you see a disabled person, you see that there is a negative situation and you try to intervene immediately. It allowed us to get closer to the disabled. Our perspective has changed a lot towards disabled people, because we also have a disabled person. Since we live with that individual, we can understand them better now. Before, we were just looking, so to speak, we were looking at it with an ignorant eye, we were passing by, but now you can act in a more understanding way, more rationally, you can do something, you can intervene.' (P5)

'Having our child with DS revealed our shortcomings a little. I don't why, but it made me love them more. They are not missing anyhting, we are missing something. There is no malice in people with DS no sense of lying, no grudge or hatred, those feelings made me love them more. I've never been upset. Now believe me, don't get me wrong, I'm not saying this because I'm in the interview. I wish I had another child with DS. I wish it was the same. I realized my humanity.' (P1)

In their accounts, the participants sometimes criticized the discipline methods of other families and fathers who abandon their families, as a result of their increased sensitivity to other disabled individuals in the environment. They explained that these comparisons and observations helped them define their own perception of paternity and the values they attribute to themselves. Regardless of the fatherhood values mentioned in the previous theme, they stood by their families, coped with difficulties, and prioritized the needs of the family even if they had difficulties. Despite the difficulties that arose when a person with Down syndrome joins the family, not leaving the family, being proud of their children, doing their best were among the values that fathers had.

'Why me. Whoever says that I never asked this question, I will kiss him on the forehead, so if there is such a person, really. So you ask that question. Some people can't get out of there, they go to many other places. There are those who leave their spouses, and there are those who never accept the child. You've encountered it too, maybe you know. There are some who accept after a certain period of time like me' (P4)

'My wife told me that a woman gave birth and said I don't want the child. She said "I don't want it because he has DS". She left her child and nothing like that happens.' (P2)

3.4.3. Emotional Bond with the Child with DS

Almost all participants talked about their emotional bond with their children with DS to a great extent. In their accounts, it was evident that the way the fathers of children with DS related to their children was affected by the sympathetic appearance of their children, their ability to express their love easily, and the fact that they do not hold grudges. Most fathers described their children as daddy's children The fathers, who proudly talked about their children's love for the environment, said that people around are sometimes surprised by these displays of love.

'He shows his love, for example, when someone passes by, he says hello, when he does not say hello to him, he looks behind that person. Why didn't he say that? For example, we are walking at the cottage or outside, Kemal says hello when passing by. When they don't say anything to him, the child gets angry.' (P6)

'Zehra, for example, was going to hug a firefighter she had never met. They liked her so much that when I saw many of them, I saw such secret tears of joy in my firefighter friends. They were surprised how this person does not know me and hugs me so cordially. They say that in DS, she has a strong sixth sense. She knows what she likes and dislikes' (P8)

The fact that children with DS can easily show their love seemed to have a positive effect on the father-child relationship. The participants mentioned that this bond of love motivated them. Some fathers talked about their children teaching hisself about love. In particular, they stated that they liked the fact that their children called them on the phone when the fathers were not at home, as it showed that their children were curious about them. It was very important for the fathers to be thought of by their children and to share something with their children.

'What pleases me, for example, when she opens the door, she immediately hugs me in my lap. For example, she goes to school in the morning, if she sees it at noon, she hugs at noon, for example, she sees it in the evening, she comes home and hugs in the evening. For example, I like it. She brings water, for example, she drinks some of the water herself and brings the rest to me. She says 'dad I drink it too'. For example, she brings half of it to me. For example, he brings my slippers. In general, most of them always do not have any behavior that I do not like anyway, sometimes they are stubborn, of course, but other than that, we are compatible with each other.' (P10)

'She picks up the phone and asks: "Daddy, where are you?". It feels good to me to she said that. When I go on trips, I don't come at work one day, I don't come on Monday, I don't come on Tuesday. She calls when I'm no longer on Tuesday. "Dad, where are you?" she said and I like it. Because why, there is someone waiting for you at home, thinking about you, and there is someone wondering. There were people who were wondering at home, but now someone is very curious at home, that is, when he doesn't come. That's why I like it.' (P11)

The fathers thought that their children have pure love and also expressed that they were quite pleased that their children do not hold grudges. In this way, they said that they did not remain offended, their relationship progressed well, and they defined this relationship as true love. They stated that this intense love between them motivated them against difficult living conditions.

'For example, let's say that no matter what I do to Alya, even if I get angry or hit her butt, it makes her very angry. Then I open my arm, she comes and gives me a hug. It is so tight that I am ashamed of what I did when I hug her. The absence of those bad feelings in them gives me very good feelings there. . These are what keep me holding on. The unadulterated love in them makes me more dependent on them. I love it very much, frankly, I love children with DS. For example, we have a neighbor and he has a daughter. When I see her too, I don't see her apart from my daughter. I like her just as well, she is very sweet. Although they are not the same, I like the same, even if

she acts a little colder because I am not his father. When I look at people with DS, they make me feel positive.' (P1)

'True love. Everything is fine even if it is with our interests, with your spouse, and after a point, such things come into play, even if it is with your parents. But Çınar has no such side. So he motivated me a lot. To be able to communicate with him. For example, hearing him say dad. When he says daddy, it motivates me so much. That's why I said to a child who loves me so much that I should do whatever I can, whatever I can, and I should respond in the same way. Sometimes when I get angry and raise my voice, we reconcile immediately, we can't stay apart. Çınar taught me to apologize, he taught me love, he taught me to be aware, to be aware of what we have. These have always been a mainstay for me after a point. Without really knowing all this, people like that normally say rolling, rolling rock, that's how we lived, I realized that after Çınar. I realized that I am experiencing these emotions more intensely. He has always been such a positive motivation for me, really.' (P4)

It was evident that this intense sharing of love attributed to children with DS was experienced intensely, especially between father and child, and fathers expressed their satisfaction with it. On the basis of this love and strong emotional bond, the fathers in the present study sometimes saw themselves as privileged in their relations with their children.

'Let me tell you, Habibe is very fond of me. She spends 90 % of her time with me when I'm at home outside of work. If I have a job, I say "Habibe, I will go to a place". She sends me by asking a lot of questions. "When will you come, where are you going, what are you doing?" Since she is a daughter, she is a little more fond of her father and I am overly fond of her.' (P5)

'I am coming home from work, there cannot be such a nice, sweet welcome. Sometimes she doesn't greet me when she is on a tablet, some days I can't see her face at all. Sometimes, as I said, as soon as she sees me, she throws

everything in her hand and says, "Dad, where are you?" She starts immediately. I tell her that I go to work. She is not satisfied, she says "where are you), I miss you". The separation seems to take a long time now, even with one day of work a week.' (P1)

Some participants mentioned that this privileged father-child relationship emerged, as the children grew up and separated from the mother. When their children were younger, they were more attached to their mothers, but as the children grew up, the communication with the father increased and the father-child pair developed a closer relationship.

'It used to be less, why was it less, she used to be younger, the mother was more interested. Now, as they grow up, they become a little more fatherly as they understand some things and their intelligence develops. I would say that they become fathers' children. Well, when I come home, I can say that the mother is comfortable when I come home. Because this time she leaves the mother, she takes me. But we can't do without the mother. When the mother is away from us for ten minutes, she starts to ask where is the mother.' (P11)

'Now when she was little, she was mostly interested in her mommy for the most part. For example, my wife came here before me. I came later, my daugther said that she missed me. So she concentrated on the father a little bit here. She's still mama's girl, but she's a little more concentrated on me.' (P10)

3.4.4. Dealing with Stigma

The positive image that the fathers tried to create towards the environment in their narratives was sometimes shaken by the discrimination they faced in the society, the criticisms from the family and the environment, the sad situations created by the ignorance of the health personnel and the society. As a result of the negative reactions from the environment, difficulties experienced in the process of

acceptance, and feelings such as sadness and anger, the fathers sometimes felt angry at the environment.

Some fathers mentioned that they were very upset about the lack of support and ignorance of their own families. The fathers who complained about the ignorance of the society also expressed that they experienced negative emotions when their extended families did not understand them. They stated that it was sad to see the discriminatory behavior they felt in the society in their own families. Among the examples of the stigma they experience are the pressures coming from the environment regarding abortion in the prenatal period, and the sentences "don't take this child to education anymore".

> *'It is very painful, I heard this from my father and mother" How long will you take him to education, what will happen, what is the point?" I heard that. I said "what does it mean, whatare you saying, what should I do, should I let it go?". I said "what should I do, what do you want?" I said "I don't want anything from you, don't be a hindrance to me, don't upset me, don't bother me". Unfortunately, it is very bad, this perception exists in a large part of society. Here are two of them, my parents.'* (P4)

The fathers who mentioned receiving support from their extended families overcame the acceptance process more easily and did not have to think about other problems.

> *'As I said, we already made our decision, they had to respect it, they couldn't do anything else, what will they do? After all, life… We will live our life. In other words, we will live that life, we will take the responsibilities. We will experience the difficulties. Well, that's more than a hundred… but I can say that they were not a hindrance. So they were supportive. Let it be my wife's side or our side.'* (P7)

> *'Now, we do not open up too much, but we share, as I said, my wife has a brother and he has a wife, and we spent a lot of time with them. In other words, they have always been our supporters, whether materially or spiritually," whatever you need to do, we are by your side. don't do anything, don't worry". For example, blood tests were quite a thing in the*

early days. My brother's wife was also working at Capa at the time, and she was quite helpful. In the process after that, as I said, it was our advantage to have a lot of supporters. If we were alone, it was a problem for us, I don't know how we would have survived this process, I mean, because our morale was high, we got through the process well. It's already being taken care of right now.' (P10)

This familial support mentioned sometimes did not come from the whole family, but only from the spouse's side. When this happened, the fathers not only felt gratitude, but also felt sad because their own families did not support them.

'Thank God my wife's side, they are the opposite. How can I say how much my parents are like this, let me say ignorant, it is not easy to say this, but this is the truth. If they behaved indifferent, irrelevant, ignorant, my wife's parents were very interested. For example, my father-in-law was taking my wife and son to and from the rehabilitation center because I was working. He took them to hospitals, I don't know where, for years. They tried to do whatever they could, whatever they could. It's still like that.' (P4)

Two fathers felt the need to physically react with the feeling of anger they experienced in reaction to the negative experiences caused by the ignorance of the health personnel, which was also mentioned in the previous themes.

'The doctor came in the morning. Child doctor. So, as if we have committed a crime, don't you know that such pregnancies are problematic at this age, I don't know what. What if you put my child in my arms, you can guide me and say something nice to me. The man started to talk like this, officially. After that, of course, I got a little angry there. I walked over to the doctor there. I said, what are you saying. I said to doctor, tell me what's wrong with our child. Let me know her problem, let me look at something according to that, what will happen, what will it end. What should I do at this hour, I couldn't say send this boy back. ' (P1)

In their accounts, the participants stated that they considered their children's behaviors and reactions as normal from time to time and conveyed that they do not see their children as disabled. This need for normalization also served as a way of

preventing discrimination from the environment. There are families who think that if their children communicate verbally well enough, they can ignore the image of "this child is different" and that their children can be accepted by the environment. It is also seen that this child's normal image is used as a defense against the environment. As a defense against the criticism heard from the environment and the people who constantly say that their children are missing fathers, the participants often said that they had positive effects on their children's lives.

> *'What I want to tell you is that no one should say that this person disabled, they should not do anything with him. Every person is a disabled person. The normal person you look at has a disability, we are not all the same. One of us is smart, one of us is normal smart, one of us is different, not everyone is the same.'* (P2)

> *'Something like this; revealed our shortcomings a little. I don't know their structure, it made me love them more. They are not missing, we are missing they are one more really….. The obstacle for me is only in the mind. She is opposite. In other words, if you see the other person as disabled, the disability is not yours. Alya didn't seem like a minus to us because I always had that mentality. In fact, +1 is a plus for our lives.'* (P1)

It was also observed that some fathers felt the need to use the word normal frequently.

> *'…everything is normal, a normal healthy kid. All we need now is to talk about what we have. If we solve the language anyway, Habibe will be a normal individual…We act with this psychology and let me tell you, we do not see Habibe as a disabled person within ourselves. X is a normal member of our household. She can share everything with us. Even though she is 13 years old, she does what she can do.'* (P5)

One of the participants felt angry with the researcher's questions. He found the questions meaningless from time to time and mentioned that he never thought about these issues because his child was a normal person.

> *'Because we lead a normal life, I never have such thoughts, I don't think so. That's why I think when you ask questions, so I can't think of anything. Since*

we live a normal life and see it as normal, I don't have the answers to the questions you asked ' (P7)

As mentioned in the previous themes, the fathers and their families faced many different difficulties after meeting DS. These difficulties could be related to the development of their children, the difficulty of the educational process, and sometimes discriminatory discourses from the environment. One of the most important solutions that the fathers use to cope with such situations wass to focus on the development of their children and to bring them to the best place they can come. Many fathers adjusted their expectations to the situation of their children and took pride in their development. One of the main sources that supported these positive feelings was the bond of love between them and their children. One of the things that pleased the fathers the most was that the children with DS showed their love easily, the transparency and closeness in the father-child relationship.

CHAPTER IV

DISCUSSION

The main purpose of this study is to understand the fatherhood experiences of fathers with children with DS in Turkey, to see their difficulties and coping mechanisms, and to examine the relationship between fathers and their children. The experiences of their children since their diagnosis, the relationship between father and child, the quality and duration of the time they spent together, and environmental factors were investigated. After the thematic analysis of semi-structured interviews with 11 fathers of children with DS, four main themes were identified: making sense of and accepting DS, fullfilling fatherhood role and duties, adjusting to the child with DS, and holding a positive image of the child with DS. According to the analysis of the narratives of the fathers participating in the study, making sense of and accepting DS for fathers pointed to three critical sub-themes: Not knowing what to do, turning to religion, and accepting the reality of DS. The second theme, fullfilling fatherhood role and duties, was characterized by four sub-themes named providing for the family, spending time with child, maintaining discipline, and perception of paternity: being strong. The theme of adjusting to the child with DS which describes the experiences of fathers with their DS children consisted of three sub-themes: prioritizing the needs of the child with DS, changing expectations from the child with DS and life, and staying in the moment. The fourth theme, holding a positive image of the child with DS, which helps us understand fathers' experiences in depth, consisted of four sub-themes: focusing on potential for improvement, feeling proud of the child with DS, emotional bond with the child with DS, and dealing with stigma.

In the next section, the four themes mentioned above will be discussed with the help of literature. After discussing the themes, practical implications will be presented on the experiences of fathers of DS children based on the literature. Then, the limitations and strengths of the current study will be mentioned and suggestions will be made for future studies.

4.1. DISCUSSION OF THE THEMES

4.1.1. Making sense of and accepting DS

Making sense of and accepting DS was the first theme produced from the participants' answers. In this theme, the fathers shared their experiences, the processes of acceptance following experiences such as the feeling of not knowing what to do, shock, seeking support, and turning to religion when they met with DS.

Almost all fathers shared that they were shocked at first when they learned about DS and said that it could not happen to them. However, they mentioned that they thought their spouses were more sensitive and forced themselves to be strong. In a study conducted by Ridding and Williams (2017) with fathers of children with DS, it was observed that fathers' experiences had difficulties in coping with feelings of helplessness and uncertainty, and they entered a grieving process with the loss of a wished-for child who was likely to be perfect. This study supports the data in the literature showing that fathers with children with DS cope with this situation by hiding the stresses such as shock and sadness they experience after diagnosis (Barak-Levy & Atzaba-Poria, 2013; Cummings, 1976; Houser & Seligman, 1991; Ridding & Williams, 2017). Similarly, in the present study, the participants stated that they felt compelled to pull themselves together in order to support their spouses after facing various feelings such as postpartum shock, sadness, and despair.

One reason why the fathers in the present study felt the need to accept the diagnosis can be related to the masculinity roles they adapted. Men surrounded by patriarchal masculinity codes strive to be strong with the responsibility of being the head of the family and role models, and they try to become a figure who surrounds the family with their authority (AÇEV, 2018). It is thought that all these roles are trying to stand strong to protect the family after the difficult feelings such as shock and sadness experienced by the fathers.

While the fathers were unsure of what to do at first, the incomplete information from the health personnel and their critical attitude increased the challenges the fathers experienced in the initial period after the birth of their children with DS. Except for a few of the interviewed fathers, none of them stated

that they had ever met DS before and that they heard it for the first time in the hospital. The incomplete information from the health personnel left the families in a very difficult situation, since only negative information come to mind for those who met with DS before the child was born. A similar problem was mentioned in the study conducted by Farkasand and collagues (2019) in which they examined the negative and positive emotions experienced by children with DS families. When the experiences of fathers of hildren with DS are examined, the presence of heart disease or a different disease in their children, and maltreatment by health personnel are reported to be among the most important problems faced by fathers.

It was observed that many of the participants were grateful for coping with negative situations such as the one above, by comparing their children with another child who was in a worse situation. This finding is also supported by the literature. Families with children with DS are found to experience less negative emotions than other families with children with disability (Abbeduto et al., 2004; Cuskelly et al., 2009), while parents of children with DS experience lower stress than parents of children with SmithMagenis or Williams syndrome (Fidler, Hodapp, & Dykens, 2000).

Another coping mechanism that the participants used as a way of coping with the situation they were in was turning to religion and finding answers through religion. Ten of the 11 participants said that they thought God sent DS to their families, while the other participant described what happened to them as "it had to happen, it was our destiny". It is thought that this coping mechanism is highly dependent on the sample in which the research was conducted. More than half of the participants were Muslim people who define themselves as religious people. When we look at the studies conducted in Europe and America on subjects such as acceptance and coping, it is seen that the issue of religion is not on the agenda. Goff and colleagues (2016) reported in their study with children with DS families that 10 % of families turn to religion to cope with the situation. In the study conducted by Eştürk (2019) in the context of Turkey to understand the difficulties experienced by individuals with DS in their family, it was found that the participants needed the support of religious officials in accepting DS and explaining it to the environment.

While religious support may be helpful in making sense of it, it may also cause them to blame themselves by saying that I am being punished for a mistake (Treloar, 2012). Positive religious coping has been defined as seeking spiritual support from God in the face of negative situations, collaborative approach, and seeking support from clergy or community members (Karakaş, Koç, 2014; Pargament, 2005), and it has been found to have a positive effect (Harrison et al., 2009). For this reason, it is seen that the religious support sought by fathers affects them positively. Looking at the interviewees, it was observed that almost all fathers saw DS as a gift, not a punishment. It supports the finding that the function of religiosity is more positive in families of individuals with disabilities (RogersDulan & Blacher 1995).

On the other hand, raising children with DS has been associated with resilience and adaptive function in the literature (Van Riper, 1999). It is thought that among the interviewed fathers, those who can more easily accept their reality (about DS) have an adaptive capacity. When the participants' narratives were analyzed, it was seen that they coped with the situation more easily by getting support from other children with DS families. They mentioned that listening to their previous experiences was good for them. In the literature, it has been observed that families with children with DS report frustration when they experience a lack of support from the community or difficulty in accessing services (Farkas et al., 2018; Povee et al., 2012). When we look at the literature, it is seen that fathers prefer to participate in support groups despite limited support (Gault, 2009; Ridding & Williams, 2019). Interviewed fathers did not participate in any support groups, but received support from other families of children with DS. The results of Çakırer-Çalbayram and Platin's (202o) awareness study with fathers also support this result. As a result of the study, it was seen that fathers took more responsibility and were more accessible for their child.

In summary, in the first theme, it is seen that after the shock effects such as sadness, helplessness, not knowing what to do, and sometimes negative experiences when children with DS join the family, fathers seek support without getting stuck in these feelings, accept the reality about DS and look at what to do. It is thought that this situation may be related to the effect of the dominant patriarchal order in

Turkey on the perception of masculinity. In this process, one of the biggest supports to the participants was religion. This result is thought to be related to the fact that almost all of the interviewees define themselves as religious individuals.

4.1.2. Fullfilling fatherhood role and duties

The second theme provides how the fathers define their own duties in the family and and how they fulfil fatherhood role and duties. One of the sub-themes, providing for the family, defines the father as the person who provides for the family. Many of the participants described themselves as breadwinners. According to the literature, although the definition of fatherhood has taken different definitions such as moral guide, gender role model, caregiver (Morman & Floyd, 2006) since the last century, the breadwinner task still continues today (Schmidt, 2018). While the fathers see themselves as the sole source of income in the house, the primary caregiver automatically becomes the mother. While fathers see themselves in the role of helper in housework and child care, most of them stated that they see themselves in the position of providing domestic discipline. Some fathers reported that they do housework when their spouses are sick or not at home. On the other hand, although there are fathers who state that they take charge in child care when they have to or when their spouses request, they said that they take on the task of feeding their children, especially in the basic care of their children due to their changing needs. The division of labor within the family is not the result of the biological differences, but the result of cultural and economic ties (Coltrane, 1995; Kuzucu, 2011). The fact that most of the participants in the present study come from the traditional Turkish family culture and only fathers worked full-time in the household is one of the important factors affecting the distribution of roles in the house.

When we look at the literature, some of the common uses of the concept of fatherhood are tasks involving social interaction such as providing care, education, and discipline (Lamb, 2002). Most of the participants mentioned that their children, especially children with DS, could not study together with them. Although they

followed the quality of education their children received, they could only play games. When we look at how fathers spend time with their children, it is seen that they usually spend time together outside and play various games when they are inside the house. This result is compatible with the knowledge that the paternal role mentioned in the literature is mostly realized through play (Caneva & Venuti, 1998; de Falco et. al., 2008 Hewlett, 1992; Lamb, 1997). It is seen that fathers are caught between traditional roles and involved fatherhood roles. Çakırer-Çalbayram and Platin (2021) mentioned a similar situation in fathers in their study. They found that the fathers who participated in the interview assumed the role of involved father in the dimension of thought and traditional father in the dimension of behavior. As mentioned in the previous theme, the feeling of "I need to be fine immediately" after having negative feelings is thought to be related to the men's duties as the head of the family, role model and authority and the person who gathers the family in the context of Turkey (Bozok, 2018a).

In summary, the second theme was about how fathers defined their fatherhood roles, their duties in the home and child care, and how they spent time with their children. It has been observed that the concepts in which fathers define themselves mostly conform to the traditional father definition, such as moral educator and discipline provider. On the other hand, it is seen that some of them started to increase their involvement with their children, especially through play. Many participants spend less time at home due to their busy work schedules and most of the housework is done by mothers. Despite this, some fathers stated that they sometimes participate in childcare and housework voluntarily and sometimes they are forced to participate. The results here showed that the interviewed participants combined traditional fathering roles and involvedt fathering, and it was observed that they underwent a transformation, albeit slowly, in the dimension of thought-behavior.

4.1.3. Adjusting to the child with DS

In adjusting to the child with DS, the third of the four main themes, it is seen how the concepts that fathers define their own paternity with are shaped according to the needs of the child with DS. Some participants reported that after their child with DS was born, they restricted their social life and spent more time at home. In the study of Olsson and Hwang (2001) with Swedish families with children with disability, restriction of social life and time constraints were seen as the most obvious sources of stress for parents (Van Riper, 1999). On the other hand, when we look at the results of the research, it is seen that the participants who spend most of their time with their children talk about it with satisfaction. The fathers who could not spend enough time with their families due to their busy working conditions expressed their regret. It is seen that fathers experience pressure between the requirements of the father's duty to bring money to the house, as required by the patriarchal order, and the requirements such as allocating time for the child, which defines the concept of involved fatherhood, and taking part in their children's care.

In the previous themes, it was mentioned that fathers were in a position to provide discipline. However, when the subject was children with DS, it was seen that the participants flexed their authority. When asked during the interview what kind of difficulties they had with children with DS, half of the participants stated that their children's stubborn behavior made them very difficult and even though they would not allow this under normal conditions, they accepted this situation because of their children's condition. In the study conducted by Farkas and colleagues (2019), it was seen that parents evaluated the behavior problems experienced by children with DS negatively. The participants in this study did not complain about this situation despite having difficulties. It is seen that fathers develop new problem-solving skills as a coping strategy with the situation they are in, and lead to behavior patterns such as re-creating and framing life-related behaviors (McCubbin & Thompson, 1991). Similarly, it has been reported in the literature that families who can use positive coping adapt better to the stress factors they experience while raising children (Bentley, 2011; Twoy, Connolly, & Novak,

2007). Although social isolation and time constraints are mentioned as sources of depression and stress for parents in the literature (Al-Yagon & Margalit 2011; Van Riper, 1992), it was seen that the interviewed fathers did not have any complaints about this situation.

It is thought that this finding can be explained by the description of the experiences in the next theme. The situation referred to as the DS advantage in the literature (Hodapp, 2001) has been associated with the sympathetic appearance and loving nature of children with DS, as described by the fathers in the present study. Similarly, it has been reported that families of children with DS experience less stress than families of individuals with other disabilities (Fidler, Hodapp, & Dykens, 2000).

The above-mentioned state of acceptance shows that the expectations of the participants from their children and from life change. The fact that they accept the behaviors and attitudes that they cannot accept in children with normal development and doubt about the quality of education received by children with DS while not worrying about the education of other children are proof that their expectations have changed. Consistently, while raising children with DS, individual and family expectations are reported to change (Van Riper, 2007), and parents of children with DS report that they learned lessons from their children about patience, acceptance and flexibility (Skotko, Levin, & Goldstein, 2011). It is seen that it is not always easy for fathers who introduce themselves as the authoritative person of the house to create flexibility in their own parenting behaviors and behaviors, but it is an acceptable option considering their children's DS status. It is thought that with this acceptance and flexibility, they cope with the difficulties in daily life more easily.

Another important sub-dimension of adjustment to the child with DS theme is staying in the moment. When the participants were asked about their future plans for themselves and their children, most of them mentioned that they hesitated to make plans for the future after children with DS were born. According to the literature, fathers of children with disability have mentioned the lifetime uncertainty in their lives (De Clercq et al., 2021) and the positive effects of staying in the moment (Schippers et al., 2020). It is thought that the behavior of staying in the

moment is another preferred way to deal with troubles. In the narratives of fathers, it has been observed that their children face many different difficulties in their daily life and developmental levels, and they prefer to stay in the moment and cope with these problems step by step. In addition, the negative issues that come to mind when they think about the future may also be related to the desire to delay or deny thinking about these issues.

In summary, looking at the third theme, it was seen that after children with DS joined the family, fathers determined their priorities according to their children, changed their expectations from life and their children, and enjoyed the moment by not making future plans. It has been observed that the participants have more flexible expectations in cases such as expectations from children and stricter expectations in requirements such as education.

4.1.4. Holding a positive image of the child with DS

The last and fourth theme was named as holding a positive image of the child with DS. In this theme, it was seen that fathers focused on the development of their child with DS and tried to reach the best level they could reach. The bond of love they experience with their children, the sympathetic appearance of their children, and being proud of their children have a positive effect on this positive image. At the same time, it has been observed that these positive experiences help to cope with their stigma experiences. Most participants stated that after meeting DS, they helped their children realize their potential and did their best. The perspectives of the participants, who especially defend the importance of verbal communication, take their place in the literature as follows. Parents with children with cerebral palsy and DS have mentioned that their children have difficulties when their verbal communication is limited (De Clercq et al., 2021), and it has been reported that problems such as speech delays are a source of stress for fathers. When the participants' expressions were examined in the present study, it was seen that they did not describe the situation they experienced as stress, but they were upset when their children had speech delay.

On the other hand, it was observed that almost all participants were very proud of their children's progress. Looking at the literature, it has been reported that parents of children with DS report more satisfaction with their children than parents of children with other disabilities (Hodapp et al., 2001). It is seen that this situation about the development of their children is also reflected in the participants' feeling of empathy and responsibility towards other disabled people. It is mentioned in the literature that families with children with disabilities have to advocate for the rights of other disabled people (Ryff, 1989) and they have defined themselves as more compassionate, understanding, empathetic, and open to unconditional love after the birth of their children (Hornby, 1995).

The subject of unconditional love has been heard as a frequent experience of the participants with children with DS. Most fathers expressed their satisfaction with how their children can show their love easily, being sympathetic and the bond of love between them. In the literature, this situation is often referred to as the DS advantage and it is thought that its beginning may have started with the definitions made by Down (1866) about the syndrome that bears his name. It is mentioned that individuals with DS have sympathetic mimics and they exhibit more socially attractive behaviors compared to individuals with other disabilities in studies (Kasari & Hodapp, 1996).

On the other hand, it is mentioned in the literature that the caring and sympathetic image of children with DS can prevent children from seeing existing difficulties and taking precautions and interventions when necessary (Glidden et al., 2014). It was seen that this situation emerged as a difficulty in education in the narratives of some interviewed fathers. There have been fathers who were happy because their children were very sympathetic, but because of this sympathy, the educators and sometimes they themselves felt compassion for their children, and therefore they had difficulties in behavior education. Another explanation for the DS advantage is that the refusal of children with DS families who have lower-than-average functionality and behavioral problems to participate in research may have caused these reports of advantage (Cuskelly, Hayes, & Grace, 2007).

In addition to this intense sympathy and understanding, it is seen that children with DS families are stigmatized by the society. In the literature, stigma which is the subject of many studies conducted with individuals with disabilities has been defined as difficulties to face (Farkas et al. 2019), and in some studies, it has been mentioned that parents respond to obstacles such as stigma with resistance (De Clerq et al., 2021). It was seen that the comments made due to criticism from the environment and sometimes ignorance in the narratives of the participants pushed them to social introversion behavior. While families with children with disabilities are discriminated against because of children's differences (Van Riper, 1992), they can also come across as courtesy stigma (Goffman, 1963). In the literature, it is mentioned that families will become stronger in the face of such reactions and may become rights defenders (De Clerq et al., 2021). The interviewed fathers stated that some people from the environment do not understand diverse types of disabilities. While some fathers preferred not to share, others mentioned that they are now more empathetic to other disabled individuals, supporting the literature.

In sum, it was observed that the participants mostly had positive feelings about children with DS such as pride and love, and they saw this as an advantage, as stated in the literature. On the other hand, trying to cope with the stigma in the environment has sometimes forced them. Considering the difficulties of fathers in sharing their feelings, it is thought that increasing awareness studies with stigma will have a positive effect on fathers of children with DS and other family members. The practical implications of these results will be discussed in the next section.

4.2. PRACTICAL IMPLICATIONS OF THE PRESENT STUDY

In this study, there are some important findings about the fatherhood experiences of fathers of children with DS. With the help of these findings, some practical implications and solutions will be proposed. To begin with, the participants contributed to an understanding of the experience of fathers, and especially fathers of children with DS, in the Turkish context. Their participation

in the interview is significant because, as mentioned in the literature, some family members may not be psychologically available to talk about these issues or may show lower emotional expression (Hornby, 1995). It is thought that the limitation of some of the participants in their sharing may be because they have difficulty in contacting their emotions. In addition, according to some researchers, the reason for the difficulty in finding fathers to participate in research may be that fathers describe themselves as unworthy or difficult to reach individuals to participate in research (Carpenter & Towers, 2008; May & Fletcher, 2013; Ricci & Hodapp, 2003). This situation was reflected in the study participants as they were surprised when they were invited to the research and half of the invited people did not accept participation in the research. It is thought that further examination with fathers may normalize this type of research in the eyes of men. It is thought that organizing seminar series in which research results are shared, and especially sharing this information source with educators will raise awareness of educators. It is thought that thanks to this awareness, fathers will be more easily involved in the educational process and will be encouraged, and this will challenge the perception of worthlessness and distance in fathers.

Secondly, it is thought that future work that will focus on father-child or family-child attachment will have a positive impact on family life. Since fathers are seen as breadwinners, the intensity of research conducted with them examined the effects of having children with disability on work, insurance and paternity leave. Many studies have looked at the effect of the father's presence at home on the mother. According to Bogossian and colleagues (2019), more mothers have been given the right to speak and the voices of fathers have been lowered in parenting studies conducted in the last 30 years. Intervention studies with fathers of children with DS will help fathers to be more involved in their children's lives, to feel more important and to contact their emotions more easily, and as a result, to develop coping mechanisms. As mentioned above, it is thought that attachment studies will involve fathers more in the process and as a result of this inclusion, they will feel more encouragement to improve their relationship with their children.

Since this study looks at the father-child relationship in children with DS, it could not focus on the mood, experiences and father-child interaction of other children in the house. It is thought that the situations experienced at home will be understood from a broader perspective if studies and researches involving other children are carried out in the future. With the help of this broad perspective, domestic difficulties and coping mechanisms can be developed, and skill development interventions for parents can be created.

As heard from both the fathers participating in the interview and mentioned in the literature, parents of children with DS reported that they were disappointed when they lacked social acceptance and support from the people around them or had difficulty accessing services (De Clerq, 2021; Farkas et al., 2018; Povee et al., 2012). In addition to individual support for children with DS fathers, opening father support groups where they can socialize, feel themselves and share experiences will help them cope with the difficulties experienced. In order to prevent social acceptance and lack of support, social awareness studies can also be carried out, and people who do not have DS in their family can be helped to see their prejudices.

Another important sharing is that half of the participants had a negative experience with at least one health personnel. In a study conducted by Farkas and colleagues (2019), it was seen that parents of children with DS had similar negative experiences. Healthcare workers are defined as insensitive and uneducated during medical treatment (Farkas et al., 2019). In order to prevent the state of not knowing what to do, especially for families who have never encountered DS in their life and joined their family for the first time with children with DS, there is a need for the health personnel on duty to inform about DS and to be trained to be ready to support families when necessary. Gibson (2016) stated that the identification of existing problems may be delayed when children with DS families avoid obtaining information, deny it, and cannot access sufficient information, together with the shock they experienced after the diagnosis. It is thought that this situation can be alleviated if the experts (educators or health personnel) who are in contact with children with DS and their families have sufficient knowledge and approach the families more empathetically.

4.3. STRENGTHS AND LIMITATIONS OF THE PRESENT STUDY AND SUGGESTIONS FOR FUTURE WORK

It is thought that this qualitative study on the fatherhood experiences of fathers of children with DS will make an important contribution to the literature. Especially in the context of Turkey, besides the scarcity of studies on fatherhood and children with diabilities, the number of studies examining only the experiences of fathers with children with DS is negligible. Research in this area either focused on mothers only or was planned to understand the experience of both parents (Çakırer-Çalbayram & Platin, 2021). Most of these planned studies have focused on negative situations such as distress, depression and anxiety experienced by families in daily life. The experiences of fathers with children with disability and the level of their relationship with their children have not been the subject of research. For this reason, it is thought that focusing on the positive experiences of fathers and listening to the points they are satisfied with will be a valuable contribution to the literature. It has been useful to listen to the experiences of fathers of children with DS that they have never talked about until the interview, benefiting from the in-depth analysis of the qualitative research. On the other hand, it has been observed that mixed samples were collected in most studies including individuals with cerebral palsy, autism or intellectual disability. It has also been noted that quantitative studies are predominant. In this qualitative study, it is thought that limiting the participant population to children with DS fathers is a valuable study not to overlook their unique experiences, and this aspect is a strength of the study.

Despite these strengths, the study has some limitations. According to the results of the study, most of the fathers were satisfied with most of the issues related to their children and it is thought that the fathers who are not satisfied with the development of their children may not have accepted to participate in the study from the beginning. In addition, all interviewees are registered members of the Dost Yaşam Foundation, which was founded by the families of children with DS and was formerly actively working with children with DS and their families. All families started and followed the education of their children in this foundation on a

completely voluntary basis, with personal curiosity about DS. Most of them are families who have started their children's education earlier than the average. Because of these unique characteristics, it is thought that this is one of the limitations of the sample. The sample may not be representative of all fathers of children with DS, since fathers who are not satisfied with their child's development or who have complaints about their living conditions might have chosen not to participate in the study. On the other hand, the fact that they knew the researcher as a psychologist-teacher might have prevented them from sharing some of their personal experiences openly and created a concern that they might have acted with performance anxiety. It is thought that working with a researcher who does not know the participants in future studies may produce different results. In addition, considering that most of the participant profile is middle-income and men who were raised in a patriarchal order, it is thought that the gender of the researcher may also change the sharing of the participants.

Both face-to-face and online interviews were conducted with the participants. Due to the pandemic period and busy working hours, most fathers preferred to meet online. This preference caused their families to participate in the study from the room they were in, and it was thought that some participants could not share their experiences comfortably in the presence of their family members. While this difference may be due to the personal differences of the participants, it was observed that the fathers shared more easily in one-on-one interviews. In future studies, participants can be informed in advance and offered to join the interview from a place where they can attend the interview alone, and participants who agree to meet face to face after the pandemic can be encouraged about these meetings.

When the demographic characteristics of the family were evaluated, the fact that all participants, except one, lived in Istanbul, made a report far from diversity in order to see the effect of living conditions. At the same time, the fact that the spouses of the interviewees did not work was a factor that prevented us from seeing the experiences in homes with working mothers. When the demographic characteristics of the children are evaluated, it is seen that they are between the ages of 5-14. While it may be a good situation to create diversity in experiences, it is

thought that it may cause to miss some experiences spesific to a child's age and developmental level. Likewise, the fact that children have different diseases accompanying DS may have differentiated their experiences. Because with every change in children, changes occur in fathers' experiences as well. Therefore, the study represents the experiences of fathers in a limited sample. In future studies, keeping the age ranges of children more limited will be useful for more in-depth analysis. In addition, interviews can be conducted with families whose child with DS is accompanied by different diseases, as well as the age limit, and their lives can be tried to be understood more deeply.

It was observed that some fathers were reluctant to participate in the research. Some participants were reached through their spouses, and the spouses' view of the research greatly affected their participation. In order to avoid difficulties in finding participants, the research can be explained more broadly to participant candidates, and the research can be conducted with both parents. In addition, the effect on the spousal relationship and the effects on other children in the family were not investigated in this study. It is thought that interviews with both parents and other children will be beneficial in order to develop family-based understanding and to hear a deeper expression.

CONCLUSION

The current study sought to understand in-depth the experiences of fathers with children with DS in the context of Turkey. The research results obtained through thematic analysis have been an important step towards understanding the experiences of fathers and their relationships with their children with DS. It is thought that children with DS can help determine the needs of fathers and the content of clinical practice and intervention studies to be developed in the future. It can be said that this study is one of the first studies conducted with fathers of children with DS in the context of Turkey. It is thought that the image of being strong placed on men in Turkish society may prevent fathers of children with DS from understanding their own negative experiences, and that they may be deprived of this support while they may be able to receive it. The current study focuses on fathers' experiences, emphasizing both the joys and difficulties they experienced. The results of the study showed that most of the fathers suffer from a lack of support and are happy to have these issues discussed. This suggests that more research should be conducted with fathers, especially fathers of children with disabilities. It is hoped that this research will pave the way for future studies.

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APPENDICES

APPENDIX A. DEMOGRAPHIC INFORMATION FORM

DEMOGRAFİK FORM

1. Yaşınız:

2. Mesleğiniz/İşiniz:

3. Eğitim düzeyiniz:

4. Ekonomik durumunuz:

Alt

Orta

Yüksek

5. Kaç yıldır evlisiniz?:

6. Eşiniz çalışıyor mu?:

7. Eşinizin yaşı:

8. Eşinizin eğitim düzeyi:

9. Evde kimlerle birlikte yaşıyorsunuz?:

10. Çocukların bakımında yardım alıyor musunuz? Evetse kimden?:

11. Kaç çocuğunuz var?:

12. Çocuklarınızın yaşı ve cinsiyeti:

12. Down sendromu olan çocuğunuzun yaşı ve cinsiyeti:

13. Aile olarak psikolojik hizmet alıyor musunuz? Alıyorsanız nereden?

APPENDIX B. INFORMED CONSENT FORM

Bilgilendirilmiş Onam Formu

Araştırmanın Yürütüldüğü Kurum:	İstanbul Bilgi Üniversitesi
Araştırmanın Adı:	Down sendromlu bir çocuk yetiştirmek: Babaların deneyimleri üzerine nitel bir araştırma
Araştırmacının Adı:	Eda Cesur
Araştırmacının E-mail Adresi ve Telefonu:	
Araştırmanın Danışmanı:	Dr. Öğr. Üyesi Anıl Özge Üstünel Balcı
Danışmanın E-mail Adresi ve Telefonu:	

Bu çalışma, İstanbul Bilgi Üniversitesi Klinik Psikoloji Yüksek Lisans Programı öğrencisi Eda Cesur tarafından Dr. Öğr. Üyesi Anıl Özge Üstünel Balcı danışmanlığında yürütülmektedir. Bu araştırmanın amacı, engelli çocuk sahibi olan babaların deneyimlerini, yaşadıkları güçlükleri ve bu güçlüklerle nasıl baş ettiklerini derinlemesine anlamaktır. Araştırmanın; gelişimsel engeli olan çocuklar ve babaları arasındaki ilişkileri anlamamıza yardımcı olması ve bu ilişkileri destekleyecek çalışmalara katkı sağlaması beklenmektedir.

Bu araştırmaya katılmayı kabul ettiğiniz takdirde, yaklaşık 50-60 dakika sürecek bir görüşmeye katılmanız beklenecektir. Bu görüşmede, çocuğunuz ile ilişkiniz hakkında düşüncelerinizi ve gözlemlerinizi öğrenmek için sizden bazı sorulara yanıt vermeniz istenecektir. Yanıtlarınız, sonraki analizlerde kullanılmak üzere ses kaydına alınacaktır.

Bu araştırma bilimsel bir amaçla yapılmakta ve katılımcıların kişisel bilgilerinin gizliliği esas alınmaktadır. Verdiğiniz tüm kişisel bilgiler gizli tutulacaktır. Ses kayıtları araştırma süresince yalnızca araştırmacının ve danışmanının erişimi olan bir harici bellekte muhafaza edilecek, araştırma sona erdiğinde silinecektir. Görüşmede paylaştığınız görüş ve deneyimlerinize ilişkin örnek cümlelere ortak bulguların raporlanmasında yer verilecek, bu cümleler isminizle ilişkilendirilmeden anonim bir şekilde bilimsel yayınlarda kullanılacaktır.

Bu araştırmaya katılmak tamamen isteğe bağlıdır. Görüşmeye katılmanın üzerinizde herhangi bir olumsuz etki yaratması beklenmemektedir. Ancak görüşme sırasında yanıt vermek istemediğiniz, size kendinizi rahatsız hissettiren sorular olursa bu soruları yanıtlamadan geçebilirsiniz. Görüşme sırasında dilediğiniz zaman kaydın durdurulmasını isteyebilirsiniz. Görüşme başlamadan önce, görüşme sırasında veya sonrasında dilediğiniz zaman soru sorabilirsiniz. Katılmayı kabul ettiğiniz takdirde çalışmanın herhangi bir aşamasında herhangi bir sebep göstermeden araştırmadan çekilme hakkına sahipsiniz. Araştırmadan çekildiğiniz durumda verdiğiniz bilgiler değerlendirmeye alınmayacaktır.

Görüşmenizin sonuçları, araştırma sonlandırılmadan önce gözden geçirmeniz için sizinle tercihinize bağlı olarak telefon, mail yoluyla ya da yüz yüze bir görüşmede paylaşılacak ve geri bildiriminiz doğrultusunda gerekli değişiklikler yapılacaktır. Burada amaç, sizin görüşlerinizin ve deneyimlerinizin en doğru şekilde anlaşılmasını sağlamaktır.

Araştırmayla ilgili bilgi almak, soru sormak veya yorumlarınızı paylaşmak isterseniz, araştırmacı Eda Cesur ile …. adresinden ya da …. numarasından iletişime geçebilirsiniz.

Yüz yüze görüşmeler için

Araştırmaya katılmayı kabul ediyorsanız, lütfen aşağıya isminiz ve soy isminiz ile tarihi yazınız ve imzalayınız.

Bu çalışmaya tamamen gönüllü olarak katılıyorum. Bana anlatılanları ve yukarıdaki açıklamaları anladım. Çalışmaya katılmayı ve verdiğim bilgilerin bilimsel amaçlı yayınlarda kullanılmasını kabul ediyorum.

Katılımcı Adı Soyadı:	

Tarih:	
İmza:	

Online görüşmeler için

Araştırmaya katılmayı kabul ediyorsanız, lütfen aşağıdaki metni araştırmacıya mail yoluyla iletiniz.

Bu çalışmaya tamamen gönüllü olarak katılıyorum. Bana anlatılanları ve açıklamaları anladım. Çalışmaya katılmayı ve verdiğim bilgilerin bilimsel amaçlı yayınlarda kullanılmasını kabul ediyorum.

APPENDIX C. INTERVIEW GUIDE

I. Giriş

a. Başlangıç olarak kendinizden biraz bahseder misiniz?

- Günlük yaşamınız? Ne işle meşgulsünüz? İş yaşamınız nasıldır?
- Ailenizden biraz bahseder misiniz?

II. Baba olmak ve çocuklarla ilişkiler

a. Evlilik süreciniz nasıldı? Kısaca anlatabilir misiniz?
b. Eşinizle olan ilişkiniz nasıldır? Nasıl tarif edersiniz?
c. Ne zaman baba oldunuz? Nasıl bir süreçti sizin için?
d. Sizce nasıl bir babasınız? Kendinizi nasıl bir baba olarak tanımlarsınız?
e. Çocuklarınızla ilişkiniz nasıldır?
    - Birlikte neler yaparsınız?
    - Neler konuşursunuz?
    - Nasıl vakit geçirirsiniz?

III. Engeli olan çocuk ve teşhis süreci

a. Çocuğunuzun engelini ilk ne zaman fark ettiniz? Nasıl bir süreçti?
b. Çocuğunuz Down sendromu teşhisi aldıktan sonraki süreç sizin için nasıldı?
    - Neler düşündünüz? Neler hissettiniz?
    - Kimseyle paylaştınız mı? Paylaşabildiyseniz, nasıl?
    - Siz nasıl tepki verdiniz? Eşiniz nasıl tepki verdi?
    - Tepkileriniz zaman içinde değişti mi? Nasıl?

IV. Engeli olan çocuk ve babalık

a. Çocuğunuzun Down sendromlu olması sizin için nasıl bir deneyim?
    - Bir baba olarak size neler düşündürüyor? Nasıl hissettiriyor?

- (Başka çocuğu varsa) Engelli çocuk sahibi olmak, baba olmakla ilgili düşüncelerinizi, duygularınızı değiştirdi mi? Değiştirdiyse nasıl?

b. (Down sendromu olan) çocuğunuzla ilişkiniz nasıl?
    - Çocuğunuzla nasıl vakit geçirirsiniz?
    - Çocuğunuz ile günde/haftada ne kadar vakit geçiriyorsunuz? Bu size nasıl geliyor?
    - Çocuğunuzda geçirdiğiniz vakitte zaman içinde bir değişim oldu mu? Nasıl?
    - Çalışma düzeniniz çocuğunuzla olan ilişkinizi etkiliyor mu? Nasıl?
    - Çocuğunuzla ilişkinizde farklı olmasını istediğiniz şeyler var mı? Nasıl?
c. (Down sendromu olan) çocuğunuzun bakımında neler yaparsınız?
    - Bunları yapmaya nasıl başladınız?
    - Çocuğunuzun bakımı için yaptıklarınızda zaman içinde bir değişim oldu mu? Nasıl?
d. (Down sendromu olan) çocuğunuzla babalık deneyiminizde yaşadığınız zorluklar nelerdir?
    - Bu zorluklarla nasıl baş ediyorsunuz? Bu zorlukların üstesinden nasıl geliyorsunuz? Yaşadığınız bu zorluklarla baş etmeyi nasıl öğrendiniz? Bu yöntemleri nasıl geliştirdiniz?
    - Bir baba olarak, kendinize destek olarak gördüğünüz şeyler var mıdır? Bunlar neler?
e. (Down sendromu olan) çocuğunuzla babalık deneyiminizde hoşnut olduğunuz şeyler neler?

V. Geleceğe dair beklentiler ve umutlar

a. Gelecekte çocuğunuz ile nasıl bir ilişki hayal ediyorsunuz?
    - Bu ilişkiyi geliştirmek için neler yapmayı hayal ediyorsunuz?
    - Çocuğunuzun geleceği ile ilgili nasıl hayalleriniz var?

VI. Kapanış

a. Konuştuklarımıza eklemek istediğiniz bir şey bulunuyor mu?
b. Sizin sormak istediğiniz bir soru var mı?
c. Son olarak; bu görüşmeyi yapmak, bu konuları konuşmak size nasıl geldi?

APPENDIX D. INSTITUTIONAL PERMISSION FOR RESEARCH

T.C.

MİLLİ EĞİTİM BAKANLIĞI

ÖZEL TEK METOD ÖZEL EĞİTİM VE REHABİLİTASYON MERKEZİ

02.12.2021

Dr. Öğretim Üyesi Anıl Özge Üstünel danışmanlığında Psk. Eda Cesur tarafından yürütülen "Down Sendromlu Bir Çocuk Yetiştirmek: Babaların Deneyimleri Üzerine Nitel Bir Araştırma" isimli yüksek lisans bitirme tezi araştırması kapsamında kurumumuzda "araştırmayı duyurması, katılımcıları bilgilendirmesi, katılımcılar ile görüşme yaparak veri toplaması" uygundur.

S.SERNUR KÖSE
Kurum Müdürü
02.12.2021

ETHICS BOARD APPROVAL

Ethics Board Approval is available in the printed version of this dissertation.