

EXPERIENCES OF FATHERS  
RAISING A CHILD WITH AUTISM SPECTRUM DISORDER:  
A QUALITATIVE STUDY



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DATE  
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DEDICATION

This dissertation is dedicated to all fathers  
who made it possible for this research to come into the daylight;  
and those who became the bridge  
for me to reach out each and every one of them.

Special thanks to Nancy Molho and Soner Gül,  
for their time spared and concern.

### Abstract

The purpose of this study was to describe the experiences of fathers who have an only-child with Autism Spectrum Disorder (ASD) using Ambiguous Loss framework. Sample was consisted of 10 fathers, one father being the pilot of the study. Main foci of the research were whether ambiguous loss is a contributing factor in relation with stress levels of fathers raising a child with ASD. Moreover, whether their personal experiences of ambiguous loss impacted family systems through boundary ambiguity was also explored. Semi-structured interviews were conducted with each father. The qualitative method of thematic analysis gave rise to 2 super-ordinate themes, 9 themes and 10 subthemes. First super-ordinate theme “Process of Acceptance” included 5 themes and 8 sub-themes: 1) “konduramama”: straining self to accept ASD; 2) incomprehensibility of ASD; 3) emotional processes, 3a) feelings of guilt, 3b) pendulum of hope, 3c) concern for future; 4) receiving proper education, 5) making peace with ASD, 5a) increasing knowledge of disorder, 5b) reframing the situation, 5c) solution-orientedness, 5d) maintaining stability, 5e) attributions to something greater. This theme explained the stress increasing factors that fed fathers’ inner conflict regarding the acceptance or rejection of the ASD and the ambiguity it brings. Moreover, those factors helping fathers to deal with the stress was explained. It is seen that most fathers were resilient enough to learn to live with the stress that their ambiguous loss brought. The second super-ordinate theme was “Impact on Family Life” and it included 5 themes and 2 sub-themes as follow: 6) shaping the world around ASD; 7) impact on couple relationship, 7a) emotional turmoil, 7b) positive emotional shift; 8) father as an outside support system; 9) estrangement of relationships. The fathers’ experiences confirmed that ambiguous loss has increased their stress on their acceptance process of the disorder as well as

on their family lives. Moreover, the boundary ambiguity was seen to be the main stressor on the impact on family life. It created an ambiguity on the roles and identities of the family member by changing the structure of the family in various ways. Ambiguous loss provides a unique understanding to the losses that are hard to capture. The results can inform interventions in couple and family therapies such as normalizing and externalization of the stressful father and families' experiences. Future studies can focus more on social relationship component of ASD from a paternal and familial context. Limitations and further information is discussed.

*Keywords: ambiguous loss, Autism Spectrum Disorder, father, family, systems theory, relationships*

## ÖZET

Bu çalışmanın amacı Belirsiz Kayıp çerçevesini kullanarak çocuğu Otizm Spektrum Bozukluğu (OSB) olan, tek çocuklu babaların deneyimlerini anlatmaktır. Örneklem 10 babadan oluşmakta olup, 1 baba çalışmanın pilotudur. Araştırmanın ana odaklarından ilki, belirsiz kaybın ASD'li bir çocuğu yetiştiren babaların stres düzeylerine katkıda bulunan bir faktör olup olmadığıdır. İkinci odağı ise, belirsiz kayıp deneyimlerinin sınır belirsizliği yoluyla aile sistemlerini etkileyip etkilemediğidir. Her baba ile yarı yapılandırılmış görüşmeler yapılmıştır. Nitel bir araştırma yöntemi olan tema analizi ile 2 üst düzey tema, 9 tema ve 10 alt tema ortaya konmuştur. İlk üst düzey tema olan “Kabul Süreci”, 5 tema ve 8 alt temayı içermektedir. Bunlar sırasıyla: 1) “konduramama”: ASD'yi kabul etmek için kendini zorlama; 2) ASD'nin anlaşılmazlığı; 3) Duygusal süreçler, 3a) Suçluluk duygusu, 3b) Umut sarkacı, 3c) Ggelecek için endişe; 4) Uygun eğitimi almak, 5) ASD ile barış yapmak, 5a) OSB bilgisini arttırmak, 5b) Durumu yeniden çerçevlendirmek, 5c) Çözüm odaklılık, 5d) İstikrarı korumak, 5e) Daha büyük bir şeye atıflar. Bu tema, babalara ASD'nin kabulü veya reddi ve getirdiği belirsizlikler ile ilgili iç çatışmaların besleyen stress faktörleri ile beraber, strese yardımcı faktörleri açıklamaktadır. Çoğu babanın belirsiz kayıplarının getirdiği stresle yaşamayı öğrenecek kadar dirençli olduğu görülmektedir. İkinci üst düzey tema olan “Aile Hayatı Üzerindeki Etki” ise 5 tema ve 2 alt tema içermektedir: 6) Dünyayı OSB çevresindeki şekillendirmek; 7) Çift ilişkisine etkisi, 7a) Duygusal kargaşa, 7b) Olumlu duygusal değişimler; 8) Dış destek sistemi olarak baba; 9) İlişkilerde uzaklaşma. Babaların deneyimleri, belirsiz kaybın, OSB'nin aile yaşamları üzerindeki stresini de arttırdığını doğruladı. Ayrıca, sınır belirsizliğinin aile hayatı üzerindeki etkisinin ana stres unsurlarından

olduđu grlmektedir. Sınır belirsizliđinin ailenin yapısını eřitli Őekillerde deđiřtirerek aile yelerinin rolleri ve kimlikleri konusunda bir belirsizlik yarattıđı ortaya konmuřtur. Belirsiz kayıp, fark edilmesi zor olan kayıplara benzersiz bir anlayıř sađlamaktadır. Sonular, babaların ve ailelerin mcadelesinin normalleřtirilmesi ve dıřsallařtırılması gibi, ift ve aile terapilerinde sıklıkla kullanılan mdahaleleri Őekillendirebilir. Gelecekteki alıřmalar, baba ve ailesel bađlamdan ASD'nin sosyal iliřki bileřenine daha fazla odaklanabilir. Sınırlılıklar ve daha fazla detay yazının geri kalanında tartıřılmaktadır.

*Dizin kelimeleri: belirsiz kayıp, Otizm Spektrum Bozukluđu, babalar, aile, sistemler teorisi, iliřkiler*

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## 1. CHAPTER A – INTRODUCTION

### 1.1. Autism Spectrum Disorder

According to American Psychiatric Association (2013), diagnostic criteria of Autism Spectrum Disorder (ASD) proposes three main deficits for a person to be diagnosed with ASD. First cluster of symptoms is related to social communication and interaction with others. These symptoms are generally observed as impairments in social-emotional reciprocity which ranges from having difficulties in social approaching to others. Also, initiating or responding in reciprocal conversations with others as well as to decreased sharing of personal information such as emotions, affect and interests is also identified.

Secondly, observable deficits in social communication, nonverbal deficits are also expected to have deficits individuals with ASD. Nonverbal deficits result with difficulties displaying bodily and facial expressions as well as comprehending these non-verbal expressions and inability to maintain eye contact with others. Deficits in integration of verbal and non-verbal components of a social communication is also a common feature seen in individuals with ASD. Lastly, forming, maintaining and understanding social relationships are also affected. While it is difficult for individuals with ASD to show flexibility in changing social contexts, they show no interest in forming relationships with peers and show diminished interest in imaginative play.

#### 1.1.1. Prevalence and Onset

Today, the prevalence rate for autism diagnosis in U.S and other countries consists almost 1% of general population (APA, 2013). Even though there are no reliable statistics for Turkey, it is estimated that approximately half million individuals are diagnosed with an ASD and it affects more than 2 million people countrywide considering families (ODFED, 2013). The symptoms

are generally recognizable during the second year of life (APA, 2013). During these years, the onset can manifest itself through developmental delays in speech production, no sign of interest in social communication or having unusual social interactions and playing habits such as dragging people around by their hand without looking at their face or carrying specific toys around without playing with them. Occasionally, the onset of ASD might present itself in a typically developing children by a gradual decline in their social and speech abilities starting around 24 months of age. However, in cases where developmental symptoms are severe or quite subtle, it is possible to recognize the symptoms earlier than 12 months or to realize developmental delays later than 24 months of age.

#### 1.1.2. Comorbidity

There are also variety of comorbid features in ASD. It is common for individuals with ASD to either have intellectual impairment that can be accompanied speech disorders such as slowness in talk or understanding of speech more than articulation (APA, 2013). Adolescents and adults with ASD are more inclined to develop mental health problems such as depression or anxiety disorders. Along with these, impairments and unusual behaviors in motor abilities such as clumsiness or walking on tiptoes are also common features in ASD. According to APA prognostic factors, best prognosis is thought when intellectual and language impairments as well as mood disorders are either non-existent or do not interfere with functioning. Even individuals showing lower levels of ASD impairment might be vulnerable to these features. While males are four times more likely to be diagnosed with ASD, females are more likely to have worse prognosis since language and intellectual impairment are more common. Still, it is possible for individuals with ASD to adjust to social and work life with compensations provided by variety of treatment method since ASD is not a neurodegenerative disorder. However, it is important to



underlie that symptomatology and prognosis in individuals with ASD are not uniform; meaning that situations of symptoms that are easily handled in one child might not be handled in another (APA, 2013).

### 1.1.3. Treatment

Today, treatment options for ASD is growing in number (Roch, Bush & D'Angelo, 2018). There are variety of treatment options each having different focus during the education process. While some of these methods such as dolphin therapy or sensory integration are not proven to be effective with research, remaining methods such as applied behavior analysis (ABA) are most widely used treatment options for ASD and many of its interventions are empirically validated and currently used (Vismara & Rogers, 2010). ABA is an umbrella term for a group of interventions such as functional behavior assessment, social skills training or functional communication training and modeling (Wong et al., 2014); that are behaviorally rooted, and involving parental participation as well. The target in ABA is to identify any behavior that impedes individuals' adaptation to their environment or is harmful for themselves and change the behavior in ways that are either adaptive to their environment or harmless to themselves (Baer, Wolf & Risley, 1987). Along with various forms that these treatment modalities are delivered ranging from 40 hours of specialized interventions to shorter and intermittent interventions in different settings such as school or home environments, they are shown to be effective for desired change in individuals in general (Reichow, Barton, Boyd & Hume, 2012).

Effectiveness of these methods among which are applied in Turkey are supported by meta-analysis conducted by Sucuoğlu and Demir (2012). The researchers selected 14 single-subject studies with experimental design that are conducted with children and adolescents with

autism from Documentation Center of Higher Education Council. The effectiveness of treatments provided to 114 participants is measured. The studies in the meta-analysis used ABA techniques such as errorless teaching method, direct teaching, offering choice and teaching activity schedules and controlled the participant for any development including inappropriate behaviors such as noncompliant behaviors or walking around; basic social skills such as alone-time activities, responding to questions; and motor behaviors such as bicycle riding or play skills in water. The average effect size of intervention methods included in the study are shown to be .85 which is considered to be a large effect size.

Another technique, pivotal response training focuses on more vital skills necessary for accomplishing a developmental period with more in-depth trainings in larger set of skills. However, due to methodological limitations necessary for efficacy of treatment method, it is not considered as an effective treatment method (Vismara & Rogers, 2008). Lastly, relationship and developmentally focused trainings are considered to be more individualized treatment options based on the developmental stages of children. Even though in these treatments, foci of interventions aim to strengthen the parent-child relationship, they are yet to be shown their efficacy with more empirical data (Karst & van Hecke, 2012).

## 1.2. Theoretical Framework

### 1.2.1. Systems Theory

The systems theory which is an umbrella term for theories derived from General Systems Theory developed by von Bertalanffy (1950) recognizes the importance of the context when interpreting the behavior itself. The application of this theory to the family is called family systems approaches. Family systems approaches takes families as a unit with unique set of interactional patterns, which later turns into values, rules and goals (Parker & Molteni, 2017).

According to family systems approach, boundaries have utmost importance to understand how the family of concern functions within its own system. They are thought to be imaginary barriers that separate family from its environment. Consequently, families start developing a group identity that separate them from other families. Families have also internal boundaries.

Boundaries inside the family serves the function of either including or excluding members in which they create “subsystems” within the family. For example, “parental subsystem” refers to the internal systems consisted of parents and children.

The extent that boundaries function with and within the families is understood with their permeability. Permeability refers to the way the information generated in an interaction as well as how the individuals in the systems cross through the boundaries. Namely if the boundaries are open, information and people can cross very easily. While openness in boundaries are preferred to some extent for families to be able to adjust themselves to the changes occurring in life, creating a balance between open and closed boundaries is shown to be a habit of optimally functioning families (Seligman & Darling, 2007). Research also showed that most resilient families with ASD-diagnosed child are the ones that can show flexibility in their roles and responsibilities and can have open conversations about their needs (Bayat, 2007).

There are many studies focusing on the needs of families with ASD but many of those research lack the necessity to understand family by adopting an inside-out perspective (Seligman & Darling, 2007). While there are studies elucidating the needs and type of support that families should receive, how these family members can provide each other with the necessary support for each other using their own resources is scarcely researched. To be able to understand how family members can find ways to support each other inside the family, it is required for researchers to understand within-family functioning through subsystems and boundaries as constituents of

subsystems. For example, results of a preliminary study suggested that parents are different the way they provide support for the family (Seligman & Darling, 2007). While mothers were more prone to provide emotional support, fathers were more inclined to provide practical support. Understanding the functioning of interpersonal boundaries within families with ASD would be critical in order to help family members to show more flexibility by softening the dichotomization of the support they receive within the family.

### 1.2.2. Ambiguous Loss

Ambiguous loss is a theory that was first proposed by Boss (1999). The theory derived from the family stress theory suggesting that any change occurring in the family system creates a stress. According to Boss, changes with not well-established boundaries are more distressing than those changes marked by clear-cut boundaries. Considering that loss is a form of change, losses that are not processed with a definitive ceremony can arise feelings of incompleteness; and therefore, grieving process is stunted. This can be experienced in one of two ways. First, the loss might be physical yet, the loss in psychological sense might not be experienced. An example of that could be when families are not informed about the physical well-being of a lost family member. Second, the loss might only be experienced on the psychological level, yet it is not physically experienced. Referring to original work of Boss, caregivers of Alzheimer's patients can experience the second type of ambiguous loss (Caron, Boss, & Mortimer, 1999).

Ambiguity around the loss explains to define the degree of trauma through perceptions of ambiguity and resources that the individuals, families and communities have (Boss, 2006). When perceptions of those suffering from ambiguous loss is congruent on physical and psychological levels and if they have the resources to cope with the loss, their stress level is lower and their ability to "bounce back" from the adverse events – resiliency, remains intact. For those who are

resilient, the pain caused by their loss is a mobilizing source for them to change in the direction of growth. On the other hand, those who do not have an overlapping image regarding what they have in mind psychologically and what they experience in their everyday reality are said to have lower resilience in the face of stressors, especially when they do not have the resources to cope with them. This situation might lead those people to be preoccupied with their losses in order to look for meaning and react with immobilization response in the meanwhile. This is also related with the incongruent perceptions such as boundary ambiguity regarding their situation. Boundary ambiguity is further explained in the discussion section.

Boss and Couden (2002) explained five components that elevates the stress in families with Alzheimer's due to ambiguous loss. The stress in ambiguous loss caused by a chronic illness like Alzheimer's disease can also directly be experienced in ASD (O'Brien, 2007); therefore, identified principles contributing to elevated stress in Alzheimer's will be applied to ASD here. Firstly, the process of having a diagnosis in ASD is not straightforward. Despite the etiology in ASD regarding neurobiology, families may not fully capture the causes of the behavioral or social deficits of ASD; consequently, lack of clarity in diagnosis is a factor that contributes to their stress levels. Secondly, unpredictable nature of ASD prognosis due to great variability of the symptoms displayed by different individuals. For parents, not being able to foresee their children's future is a distressing experience.

Third reason is identified as day-to-day variability in the functioning of the child. While some days children seem to show improvements, on the days their symptoms might worsen. This conflicting situation might keep families in between in terms of the child's intention, whether the children are doing what they are doing on purpose or not. Moreover, worsening days might interfere with family's daily schedule and make it harder to make plans for themselves. Fourth

reason, the healthy appearance of the children with ASD creates a discrepancy for the parents' perception of their child forcing them to change their views regarding their children with the diagnosis. Furthermore, the reactions coming from external family members and from their social circle might reinforce the parent's ambiguity igniting their thoughts if they are exaggerating the situation (O'Brien & Daggett, 2006). Lastly, the loss of established relationships with the children as a consequence of the ASD is a source for ambiguity for parents. Considering that they spend considerable amount of time and effort for their daily care and treatment and not being able to establish a relationship with the child in a traditional sense creates a feeling of ambiguity in the loss of the parents.

Considering the components that contributes to stress levels of families experiencing either type of ambiguous loss, families are expected to display flexibility around their boundaries shaping their daily routines, roles and values in order to be less affected by the increased stress. The flexibility around boundaries might especially be challenging for the boundaries that are poorly established. Families that have such boundaries might experience "boundary ambiguity" which is a key component of ambiguous loss within families (Boss, 1999). According to Boss (1999), boundary ambiguity can occur when it is hard to decide who consists family members and who does not. It can also occur within the family regarding the identities of family members. In that case, the decision process for the roles and identities of the individual within family becomes blurred.

According to O'Brien (2007), boundary ambiguity is especially important for families with ASD. Boundary ambiguity in such families can occur when there are caregivers of a child with ASD from external family (i.e., grandparents or aunt) or outside of the family (i.e., nurse) and the boundaries that indicates whether the member is from inside or outside of the family is

confused. Consequently, it becomes harder to distinguish who belongs to the nuclear family and to treat individuals accordingly. Another component of boundary ambiguity also applies to interpersonal relationship of the caregiver and the child with ASD. After the diagnosis, the relationship between the child and parent might change in a way that a parent taking all the responsibility of the child and being included in every part of their children's life, resulting with an inefficacy regarding setting clear boundaries between themselves and their child. ASD becomes an important integral part of their self. This process "identity ambiguity" for their research with ASD-diagnosed families (2007).

The study conducted by O'Brien (2007) included 63 mothers. About half of their children has ASD diagnosis, while the other half has ASD related symptoms yet did not meet the criteria in all domains of ASD. All mothers who participated to the study were interviewed semi-structurally about their children's diagnosis and they talked about their concerns and needs. The questions were to promote insight about their children's condition, rather than directly assessing components of ambiguous loss experienced by the mothers. In the second part, mothers completed the Impact on Parent Subscale of Illness Perception questionnaire (Weinman, Petrie, Moss-Morris, & Horne, 1996) for the extent of the impact their children's situation had on themselves and the Parent Control subscale of the Health-Specific Locus of Control measure (Rau & Ware, 1981) to measure how much they thought they can control the outcomes of their children's situation. Moreover, they completed the Depression Scale of Center for Epidemiological Studies (Radloff, 1970) and the Parenting Stress Index (Abidin, 1970).

The aim of the study was to find out whether the mothers showed indications of identity ambiguity and whether their depressive and stress symptoms were related with the construct of identity ambiguity and symptom severity. The qualitative results showed that more than half

mothers' of children with ASD showed signs of ambiguous loss based on the interviews. The secondary interview analyses combined with parental symptomatology and demographics of the mothers and the children showed that even though identified identity ambiguity of the ambiguous loss increased the mothers' stress and depressive symptoms in both groups of children with different levels of symptom severity; the stress and depressive symptoms did not get affected by the symptom severity. As a result, identity ambiguity has a direct link with maternal stress. Even though this finding is compatible with the literature, research's suggestion that identity ambiguity and mothers' depressive and stress symptoms might not be directly related with each. There are some reasons for this argument. First, the interview questions were not directly assessing ambiguous loss, and specifically identity ambiguity. Second, the fact that ambiguous loss and identity ambiguity are used interchangeably throughout the paper must be approached with skepticism concerning validity of the measures.

Blankenship (2015) also explored the impact of ASD on families from the perspective of ambiguous loss. Using qualitative methods, 16 participants involving range of family members (i.e. parent, sibling or elderly in the family) are interviewed using semi-structured interviews. The children with ASD should be at ages of 7-18 in order to be included in the study and the family should be living with child for at least two years. While participants having a risky psychological condition such as risk of suicide or psychosis is excluded from the study, no other health condition for the child is also required for participation for the study.

The results of the study give rise to themes that families of children with ASD experienced anxiety and uncertainty about future, uncertainty or confusion about child's diagnosis; variability in day to day functioning; feelings of hopelessness, helplessness, loss of mastery and self-blame. Moreover parents reported expressions of grief and loss; concerns about



humiliation due to outward appearance of their children's health status, and conflicting feelings thoughts and feelings.

As a result of sub-themes, the researcher identified themes. It is reported that roles are more defined in the family household, their concern for safety tended to increase and they started to revolve their lives around the child's autism. Moreover, the family changed their priority from their marital relationship to their children's autism as well. While there was a continuing denial of their children's ASD, families accepted an increased need for their partners' support and changes in the expectation regarding their children. Also, it is reported that there were positive sides of having a child with ASD in their family. Lastly, even though they experienced stigma from outer world, families found their extended families supportive in their journey. The researcher reported that families were experiencing ASD as a form of ambiguous loss to conclude. Even though this study had a strong methodology, the fact that children with ASD had also other non-ASD siblings might confound results with other processes. Namely, the expectations regarding the non-ASD child is also changed as with the child with ASD; therefore, it would create another layer to the ambiguous losses that families experience.

## 2. CHAPTER 2 – LITERATURE REVIEW

This chapter will present body of research regarding the impact of ASD. First, how the family relationships are effected from ASD is going to be reported. Second, the way the couple relationships are impacted is going to be outlined in two seperate subsystems which are parent and couple subsystems. The differents underlines the difference between presence and absence of the child in the subsystem. Lastly, father research is going to be presented in order to provide further understand paternal perspectives for raising a child with ASD.

### 2.1. Impact of ASD on the Family

While having a chronic illness can be considered as a stressful situation for the individual who has the diagnosis, its effects is not only limited to the with the individual. The quality of life, adaptation, and the opportunities in an individual's life are affected by chronic illness or disease (Dell Orto & Power, 2007). The families that those individuals have are also impacted (Dell Orto & Marinelli, 1999). Consequently, by the time the child receives the ASD diagnosis, it is expected that the whole family is to be influenced by these various factors and both family members and the child receiving the diagnosis experience a process of adaptation.

In order to elaborate how diagnosis of ASD impacts the family, Brown, Mac-Adam-Crisp, Wang, Iarocci (2006) examined 3 groups of families living with either typically developing children, a child with Down syndrome, or a child with ASD. The primary aim of the study was to describe the perception of family quality of life of the participants. Respectively, 18 families with typically developing children, 33 families with Down Syndrome and 16 families with ASD agreed to participate and completed the Family Life Quality Survey (Brown, Neikrug, & Brown, 2000). When compared with other groups, families living with a child with ASD scored significantly lower in six out of nine domains. The domain they reported as the most satisfying for them was family relations, while the least satisfying was the civic and community involvement. Yet in both domains, the satisfaction percentage was significantly lower than the other groups. Thus, the impact of autism on family life quality was more established than other developmental delay disorders.

### 2.2. Impact of ASD on Parents

Even though treatment options can provide behavioral change, 85% of the individuals with ASD do not acquire the necessary skills to live independently from a caregiver who may be

a parent and/or sibling (Volkmar & Pauls, 2003). Having a child with ASD may also have adverse effects on the parent functioning. Regardless of the child characteristics or features surrounding the process of getting a formal diagnosis, the difficulties parents experience starts long before an actual diagnosis of ASD (Pottie & Ingram, 2008). Studies report that most families start observing differences in social, motor, and play behavior; and communication skills as early as 6 months of age, but they explicitly start stating their concerns at about 18 months of age (Bolton et al., 2012). Still, the average age to receive a formal diagnosis for the child is around 3.1 years (Mandell et al., 2005).

Immediately following a formal diagnosis, parents reported feelings of loss and grievance due to the change of dreams and hopes built for the child into new expectations based on new information; feelings of shock, guilt, denial, and even clinical depression (Altiere & von Kluge, 2009). Furthermore, these reactions may even be perpetuated due to confusion based on lack of information and resources regarding the disorder and how to cope effectively (Meadan et al., 2010). One study reported that this period where families learn about the diagnosis was the most stressful time of the process (Kuhn & Carter, 2006).

### 2.2.1. Parenting stress

Literature regarding family stress demonstrates that raising a child with ASD is more stressful than raising a typically developing child regardless of the symptom severity and timing of diagnosis (Johnson, Frenn, Feetham & Simpson, 2011), as well as children who are diagnosed with other types of developmental disorders (Schieve et al., 2011). In a study, 43 mothers who had children with ASD completed the Questionnaire on Resources and Stress (Brobst, Clapton & Hendrick, 2009). Results showed that mothers whose children showed more severe impairments experienced more stress than mothers with higher-functioning children (Konstantareas &

Papageorgiou, 2006). However, contradictory findings were reported in a another study conducted with 15 high-functioning children with autism whose parents completed the Parental Stress Index (Abidin, 1995). In-group difference for the level of distress in terms of symptom severity, between parents of children with higher-functioning ASD and lower-functioning ASD was reported to be similar (Rao & Beidel, 2009); showing no indication of better outcomes for less severe symptoms when the two groups were compared. Consequently the child characteristics such as cognitive impairment, language difficulties or behavioral problems in ASD did not seem to be solely responsible for the parental distress according to the latter study. Considering these discrepancies in the literature, the topic should be researched with an understanding that symptoms of ASD comprise only a layer of difficulties experienced by parents.

Parenting a child with ASD was also found to be related with decreased overall well-being of parents in terms of mental and physical health. Studies showed that parents who raise a child with ASD have increased levels of psychological problems when compared with parents whose children follow a typical developmental path without any disorder or disability (Carter, 2009); are with high-functioning ASD (Allik, Larsson, & Smedje, 2006); are diagnosed with intellectual disability without ASD and Cerebral Palsy (Mugno et al., 2007). These results indicated that emotional and behavioral features that are peculiar to ASD have more adverse impact on parental health. The most common problems among these parents were depression and anxiety. While 33% of mothers met the criteria for clinical depression, 17% of the fathers did, and both groups were similar (6%) in terms of anxiety symptoms (Davis & Carter, 2008). However, in an ongoing longitudinal study with 67 parent dyads, these mental health problems

were shown to be ameliorated by lower parenting stress; and consequently, fewer symptoms of depression.

The research regarding physical health problems yielded results that are parallel to mental health problems regarding the comparison between mothers with typically developing children and children with ASD. Higher levels of physical health problems and exhaustion were reported among parents who raised a child with ASD and severity of their physical problems were higher compared to mothers whose children had intellectual disability (Mugno et al., 2007). Even though there is no study demonstrating a causal effect between child ASD and parental physical health problems, maladaptive coping strategies used by parents to deal with child-rearing stress might mediate the relationship with poorer physical health among the parents. One study with 2388 participants showed that externalizing behavior in children with ASD measured by Child Behavioral Checklist (Achenbach, 1991) was related to tobacco use in both parents and illegal drug use among mothers based on the Parent Substance Use History Form (Wade, Reeve, Cox & Hull, 2014). This finding might explain some of the variance between ASD and parental physical health.

### 2.2.2. Parents as Couples

One of the main areas that having a child with ASD impacts is the couple subsystem. The parents who raise a child with ASD are adversely affected from this on-going process as couples due to increased levels of parenting stress, parental conflict or worsening parental health (Pottie & Ingram, 2008). Couples raising a child with ASD are approximately twice as more likely to divorce when compared with couples raising a typically developing child (Hartley et al., 2010). When compared with control groups, parents having a child with ASD report decreased marital satisfaction in their relationship through increased parental conflict and decreased positive

affective expression (Gau et al., 2009). Furthermore, ASD symptom severity is adversely related to the couple conflict in ways that increased marital conflict worsen the child symptomatology (Hartley et al., 2011) and sibling relationships among children that are typically developing and developing with ASD (Rivers & Stoneman, 2003).

There are studies with contrary findings. Hartley et al. (2016) examined how couples interacted during their daily problem-solving conversations. One hundred seventy-six couples raising a child with ASD participated to the study. Couples recorded their most important problem-solving interactions and the level of negative affect to a diary for 14 days and these interactions were sub-coded based on subjects of interactions that were either ASD-related or couple related. Results showed that the level of negative affect couples experienced during their conflict interactions regarding their children's ASD was lower than their level of negative affect in their interaction regarding issues such as couple behaviors or couple intimacy or closeness. Considering that issues of commitment, communication or personality in relationships are also distressing for the couples in general population (Cummings, Goeke-Morey & Papp, 2004), the researchers suggested that having a child with ASD was not the sole reason of the increase in negative affect in the couples.

Even though, parenting to a child with ASD is explored in various studies, the intra-familial factors that influence both parents was unclear. McStay, Trembath and Dissanayake (2014) conducted a study with 196 parents whose children were 3 to 16 years old using a Double ABCX Model of family adaptation. In a cross-sectional design, researchers explored factors some of which were possibly affecting parenting stress, coping, and sources. Marital adjustment was measured with the Dyadic Adjustment Scale (Spanier, 1979). Counterintuitively, results showed that marital support did not predict the variance in parent outcomes as a couple.

Researchers explained this discrepancy due to their methodological differences. The variance marital support explained itself among other resources may not be found to predict parental stress.

### 2.3. Impact of ASD on Fathers

From 1970s on, despite continual small increments, the average time father spend for child care has been increasing steadily (Craig & Mullan, 2011). Increase in the time spent in the household also changed fathers participation to child-rearing practices. Even though mothers have higher levels of parenting stress, the stress level is elevated regardless of parental gender (Davis & Carter, 2008). In a more recent qualitative study; the experiences of eight fathers of children with ASD were shown to be similar to the mothers (Frye, 2016). In this study, while all the family members explained how they adjusted to the challenges that come with the diagnosis, specifically fathers explained their needs and experiences. The needs were related to; a) financial hardships regarding the treatment of their children, b) sharing of the responsibilities as a team rather than taking over the whole responsibility of childcare that comes with fatherhood role, c) challenges around getting involved and reaching trustworthy information in the treatment process, and d) to create time to follow-up with all these needs. The researchers also reported that the fathers' emotional reactions around these needs during ASD treatments were similar to grief and loss which are also experienced by mothers. Thus the study suggested similar experiences surrounding ASD for the mothers and fathers.

Other studies on ASD and fathers accentuate the unique processes that lead the fathers to have increased levels of stress. One study such study by Axup (2003) concluded that fathers' experiences were different than those of the mothers and the fathers' experiences were generally unheard. In order to look deeper for father's experiences, Axup (2012) conducted another

qualitative study with Interpretative Phenomenological Analysis method. Nine fathers took part in the study whose children had Asperger's Syndrome. Results showed 6 themes that were particularly important for giving a voice to the fathers' experiences and their needs in relation with their unique experiences.

The first theme "self in time" in which fathers reflected on their own childhood and the parenting they received was important in relation to their current relationship with their son. The second theme "selfhood and syndrome" showed that children's diagnosis has changed nothing about the fathers' views concerning their children and it was merely seen as a name. Yet, "self and the world" theme pointed out that father did struggle to find and work with professionals whom they can trust. Moreover, they experienced hardship in order to find a school that can support their children's processes especially during transition times.

It was hard for fathers to balance their relationship to their son considering the societal expectations within the realm of masculinity and fatherhood. Wanting to be accepted without experiencing isolation from others was found in the "self and identity" theme. Moreover, the other theme "self and the family" provided more insight regarding fatherhood role as well as the husband role. The fact that mothers do develop enmeshed relationships to their children with Asperger's by taking up all the responsibility of their children impacted most fathers' coping. First way was to relate other children with no syndrome which provided them with a sense of "normality" and a way to protect siblings who bear the responsibility of carer from time to time. Second way was to provide more support to their wives in order to take care of the child responsibility instead of taking care of the child.

For fathers who struggle with their children's caretaking, parental support alternatives were either quite limited or non-existent and they had to develop alternative strategies on their



own while observing the mothers as role-models. This theme was found as “parenting an evolving practice” also explained fathers’ decision to stay in the couple relationship through the quality of father’s relation to their wives and their children with ASD, especially at times the relationship distress related to child treatment issues had elevated. When external family’s and societal expectations were combined with rather positive relationships with their children and wives, escaping the family was not an option and seen as irresponsible. Moreover, they felt guilty of escaping the family through other strategies such as going to work or going to sports.

Financial support as reported in Frye (2015) was an important support for factors in this process.

As the child with ASD grows older while the mothers’ stress level gradually decreases, the paternal stress remains at the same level (Bebko et al., 1987). The researchers explained this discrepancy in experiencing stress with acceptance of ASD symptoms. Mothers accepted the problem behavior in their children more than the fathers did. This is thought to be helpful for the mothers to overcome the distress related with problem behaviors in ASD. Based on this finding, one of the hypotheses put forward regarding parenting stress was related to parental gender and parental involvement (Tehee et al., 2008).

In a different study by Hay (2016), the researcher conducted semi-structured interviews with 12 fathers whose ages ranged between 21-60. The objective of the study was to identify the possible factors that impact the time spent in caregiving of the child with ASD by fathers using qualitative and quantitative methods. Data were also collected through The Brief COPE Inventory and The Parental Authority Questionnaire-revised in order to understand their coping skills and parenting styles and cultural backgrounds, respectively. According to the emerging themes, results are categorized into two categories as active and passive involvement of the fathers. The distinction was about whether the fathers actively spare time to performing activities

with the child or passively making monetary contribution in addition to general presence in child's life. According to the themes of the study, actively participating fathers a) had higher levels of healthy coping skills such as engaging in recreational activities with their children, b) exerted authoritative parenting in which they are good at setting rules yet they set rules from a democratic stance and less quick to punish the child was the dominant one among father who were active, c) showed significant levels of love, care and acceptance. Consequently, they had lower levels of parental stress than fathers who were passively involved. However, the level of acceptance displayed to their child was an important factor for fathers who were both actively and passively involved with the childcare. While it is important for the fathers to participate to childcare, the quality of participation were also an important factor. This study might provide an insight regarding the causes of continuing paternal stress compared to declining maternal stress through time.

In the study of autism and its relation to family members in current domestic and foreign literature, most of the quantitative studies mainly focuses on mothers for pragmatic reasons. The research including the fathers tend to attempt to understand the fathers' experiences compared to the mothers, putting the mothers' experiences more upfront and taking their explanation as the "representative of the whole family" (Smith et al., 2010). When it comes to qualitative research, only one study took ASD as an ambiguous loss and looked for the impact of ambiguous loss on family members. For fathers, some studies focused on understanding the underlying processes through parental involvement (Tehee et al., 2008), manhood and fatherhood (Axup, 2012), social support and financial issues as well as focusing on their emotional world accentuating a resemblance between fathers' emotions and grief responses (Frye, 2016). Even though these studies focused on explaining the strains that fathers experience an overarching explanation

focusing on the process that fathers experience regarding how these strains start at the beginning and continuously contribute to the presenting problems that fathers have is often overlooked. This study, as the first endeavor solely focusing on fathers' experiences with ASD in the Turkish context, aims to understand and contain father's experiences to illustrate an overarching mechanism that will help finding new ways dealing with strains of fathers living in families with ASD.

#### 2.4. Statement of The Problem

Hartley et al. (2010) reported that parents who have a child with ASD are almost twice more likely to divorce compared to a representative sample of parents. Families that have children with ASD report elevated divorce rates due to deterioration in their well-being and increased levels of stress as well as limited sources to cope with the stress. Moreover, this divorce rate remained consistently higher until early adulthood. However, there are no statistics in Turkey regarding the divorce rates of families with ASD.

The quality of the parent-child relationships influences the children. Differences in parenting practices between mother and father shows that children are most likely to conform with their father's values and abilities regarding psychosocial adjustment and achievement, if they have a warm and close relationship (Radin, 1981).

The absence of fathers in general have deleterious effects the contexts of children. Studies focusing on the absence of fathers with single-mothers demonstrated that the single mothers' parenting skills were undermined due to a variety of reasons; losing a co-parent (Hetherington & Kelly, 2002), elevated economic stress (Pearson & Thoennes, 1990), increased emotional stress due to social disapproval of a single mother in the society (Hetherington et al., 1982), increased emotional stress in children due to feelings of perceived abandonment by the parent (Kelly &

Lamb, 2000) and continuing inter-parental conflict (Kelly, 2000). However, it is also reported that children have better outcomes if they have lasting relationships with both their parents in the absence of high inter-parental conflict (Kelly, 2000). A qualitative study by Burkett et al. (2017) with both single- and two-parent African-American families of children with ASD also corroborates these findings for families with atypically developing children. Single mothers reported different experiences than the two-parent families in terms of finding consistent social support by people surrounding them and within their community, unlike the two-parent families supporting each other. Therefore, considering the beneficial effects of having a father (or a co-parent) in the parental subsystem of the family, even when the parents are divorced, it is important to understand the father's experiences in families with ASD. The current study is therefore important to add up to the current literature in terms of increasing relationship satisfaction and lowering divorce rates.

Inclusion of fathers in childcare has unique normative and non-normative influences on children such as their social, linguistic, intellectual and cognitive development (reviewed in Lamb, 2004), which are important areas for development among children with ASD. Even though father inclusion to studies for normative development is increased over the last 40 years, a similar pattern is not observed in childhood psychopathology and in medical settings (Phares, 2004). Considering paternal impacts can also benefit the children in ASD setting, more research for father inclusion is needed in order to increase father involvement in the family. Moreover, research indicates having a child with ASD primarily impacts mothers in Turkish context (Koydemir-Özden & Tosun, 2012) because mothers cannot receive the support they actually need within their family settings (Johnson & Simpson, 2014). Thereby, understanding stress

increasing factors for fathers would provide insights for increased involvement in childcare which in turn will help with the child development and maternal stress.

Previous research focusing on families with ASD has scarcely explored the interactions among the subsystems of the family (Cridland, Jones, Magee & Caputi, 2014). The relations between and within the subsystems affect the family functioning (Meadon & Stoner, 2010). Considering that, focusing primarily on the fathers' experiences in relation to the other subsystems in the family would be significant. By doing that, paternal perspectives in the family would not be merely compared with within-system experiences of the mothers. Paternal perspectives in itself would provide us with valuable insights into the fathers' needs to build a relationship with their children and the increased rate of divorce in families with ASD. Considering the consequences of having and not having a father in a family system, this research will inquire whether fathers are affected by the experience of ambiguous loss in relation with their increased stress levels; and if they are, how this situation impacts their family system.

### 3. CHAPTER C - METHOD

This study has explored the experiences of fathers who have children with ASD. The purpose was to understand and interpret the fathers' experiences using the systems perspective and ambiguous loss theory.

#### 3.1. Thematic Analysis

Thematic analysis is a method used in qualitative research in order to identify and interpret themes in qualitative data. In this process, the researcher first familiarizes themselves with the data, starts coding the underlying meanings and track the deriving themes in the codes. Use of thematic analysis provides a great deal of flexibility to the researcher. This is because

contrary to other qualitative methodologies which provide a theoretical framework concerning data collection and analysis, thematic analysis provides the researcher with the method for coding and theme development around interviews. However, the fact that thematic analysis is a method and not a methodology does not mean that it does not have a theoretical background; it means it has a theoretical flexibility (Braun, Clarke & Terry, 2015). Based on that, while none of the philosophical stances or the theories that the data will be grounded (i.e. social constructivist epistemology) is going to guide how the analysis is going to be made, the data of the study will be grounded in Ambiguous Loss Theory proposed by Boss during theme consolidation (1999) and the systemic perspective (Minuchin, 1998).

### 3.2. Interview Guide

The main instrument used for the interviews were the interview guide. It is used in order to collect the data for analysis and prepared prior to interviews. The questions were either composed by the researcher based on the theoretical assumptions of Ambiguous Loss or Systems Theory, rest of the questions reviewed and adapted from earlier qualitative research for the ambiguous loss (Çelik, 2013). For example; the question for the definition of their “family in mind” directly came from the theory of Ambiguous Loss. Rest of the questions for ambiguous loss such as “How was your relationship with your own father? In what ways is this relationship similar / different to your relationship with your own child?” was retrieved and adapted from the study of Çelik (2013).

### 3.3. Sample

In this study, 10 fathers were interviewed on their experiences of having a child with ASD. One father’s interview is used as a pilot; therefore, it is not transcribed and included in

coding. The data collection continued until data saturation was reached which was evident when dominant themes started to occur. Inclusion criteria for participating fathers were as follows:

- a) To have only one child with ASD and no other children in their family considering the fact that having a second non-ASD child might ameliorate indications of ASD,
- b) To give consent to participate in the study.

Exclusion criteria for participating fathers were identified as follows:

- a) Not to have fluency speaking and understanding Turkish,
- b) To have been divorced,
- c) To have a cognitive or physical disability that would impair the fathers' ability to form complete sentences.

The fathers in the study were selected through criterion-based purposive sampling. Criterion-based sampling is effective when all the participants experience something in common (Bloomberg & Volpe, 2012). The nature of the study required to select participants based on a criterion on its own accord since it is about fathers who have a child with ASD. Fathers who met the criteria described above were accepted to the study on the basis that they had new information to provide regarding their increased stress. It was important for the researcher to include the fathers who had a story to tell about their children with ASD, not the extent of their story in terms of its content.

### 3.4. Procedure

After the study had been approved by the ethical committee of Özyeğin University, the recruitment of the fathers were conducted from a variety of domains. First, an announcement of the study was posted in the social media support groups for families who have child with ASD.

Those who returned to the post were reached via instant messaging through their social media accounts and they were given a demographic form and consent form. The communication was maintained either through social media or phone contact information.

Secondly, managers of special education centers located in İstanbul were informed about the study, asking for cooperation. Contact was made via phone calls and those who agreed to cooperate were sent consent forms through regular mail. Those who consented either directly communicated with the researcher or they notified the researcher through the centers and contact was made through the center. Lastly, an application for research cooperation to Tohum Autism Foundation and Turkish Autism Federation had been made. Necessary documentation and the materials including the consent forms, demographic forms and the interview questions were presented to their scientific councils. As they accepted to cooperate, the researcher continued with similar procedures of data collection. Fathers who had children with ASD contacted with the researcher either through contact information on the consent form or via the foundation.

Use of experiential interviewing conducted through face-to-face interaction was preferred. The meetings took place upon predetermined locations, preferably in a quiet environment in the absence of children. The locations included father's house when the child is not around and/or cafés outside rush hours. The interviews were semi-structured including use of close- and open-ended question in order to allow for probing, so that the interaction could be rich enough to explore the personal accounts of the participants. All of the interviews were recorded using voice-recorder feature of a phone. Points that are seen important to the researcher to follow by probing afterwards were simultaneously written by hand. Also, these handwritten notes included nonverbal observations that the researcher made.



After the interviews, the voice recordings were transcribed to a document in order to reach participant data more easily using MAXQDA which is a qualitative data analysis software. Any handwritten notes were also included in the participant transcripts. Confidentiality of the documents were ensured using a code assigned for each participant and the codes were matched with any data and identifying information. These documents were stored in lockers manually and kept using external memory devices digitally, while any identifying information and handwritten notes were kept in a file in another location.

### 3.5. Credibility of the Study

One of the main issues concerning the maintenance of credibility in thematic analysis is ensuring the researcher's ability to be aware of their own biases (Clarke, & Braun, 2013). The researcher should refrain from these biases so that they do not interfere with the analysis procedures implicitly. This necessity for the method is considered to be especially important for researchers if they have a personal connection to the narratives they explore. Having a personal connection to the narratives would obscure the way they deal with the narrative in ways that can interfere with the emerging themes. Ensuring credibility heavily relies on unfolding and explicitly documenting the thinking processes through self-reflexivity. Audit trail, a known method used in qualitative research in order to provide self-reflexivity, informs the audience. This method refers to the transparent explanations of the development of research steps from the first day of data collection until the research results are reported.

This study was inspired by a couple and family therapy master's student and their impressions and experiences regarding ambiguous loss. During the process of my training, seeing clients in a facility that also served couples and families was one of the requirements to be a specialist. Working there, with each client/s and their families, who were either present in the

therapy room or were there symbolically, allowed me to observe endless variation in their stories and their family dynamics. Yet having close or enmeshed relationships with mothers and contrarily, having distant relationships with fathers was a recurrent theme in almost every client.

In an interdisciplinary symposium combining family therapy and medical approaches, it was mentioned that after having the ASD diagnosis, fathers were more strained to welcome the diagnosis according to the experiences medical specialists. Seeing that fathers were harder to reach in both events (i.e. therapy and disorders), I had started to contemplate on the possible reasons such as not being able to tolerate the frustration and regulating emotions as in ambiguous loss as an underlying phenomenon. My personal narrative does not include any family or relative who has ASD diagnosis. Yet, taking struggling fathers into consideration, I aim to contribute to the literature of ASD with regard to experiences of fathers.

Another way of ensuring credibility in qualitative research is through the collaborative analysis of multiple researchers and interpretation of some parts of the data to see if they are to conclude their results in a similar manner with each other. Purpose of this procedure is to make sure that the researcher minimizes their own biases in addition to self-reflexivity. In this research, rather than using multiple researchers for theme coding, method of expert checking was used. While the main researcher coded and defined the themes, one of the academic mentors of the current research Assistan Professor and Couple and Family Therapist Fehime Senem Zeytinoğlu-Saydam checked the results regularly in order to ensure that the process was developing on its own accord.

Lastly, the method of member checking, also known as respondent validation, was used as a measure of credibility. In this way, raw data in the form of transcription or results belonging to the participants were returned to them in order to check for the accuracy of what the respondents



ALC	56	Foreign trade	Bachelor's degree	Upper middle	No	No	Yes – Volunteer
KEM	43	Tradesman	High School	Lower	No	No	Yes – Social media
ADN	40	Software Engineer	Bachelor's degree	Upper middle	No	No	No
HAR	41	Accountant	High school	Lower	Yes	Yes	Yes – Volunteer
SUK	50	Sales and Marketing	Primary school	Middle	No	No	No
MET	53	Mechanical Engineer	Bachelor's degree	Upper middle	No	Yes	No
CUM	49	Health Sector	Bachelor's degree	Middle	No	No	No
OGU	45	Hairdresser	Primary school	Lower middle	No	No	No
LEV	47	Architect/ Designer	Master's degree	Upper middle	No	No	No

Table 1. *Father Characteristics: Name codes of fathers, age, level of education, socio-economic status (SES); prior psychological, medical and/or social support status.*

Table 2. *Child-related Characteristics: Name code of fathers, age of children, number of children, sex of the child involved in the study, timing of the diagnosis, current medical problems and any other relatives with ASD.*

Name Code	Age of children	Number of children	Sex of children (Involved in study)	Timing of diagnosis (years ago)	Another current health problem of children	Any prior relatives diagnosed with ASD
ALC	24	1	Male	21	None	No
KEM	12	2	Female	9	None	No

ADN	10	1	Male	7	None	No
HAR	15	1	Male	13	Epilepsy	No
SUK	22	1	Male	19	None	No
MET	15	1	Male	13	None	No
CUM	8	1	Female	6	None	No
OGU	12	1	Male	9	None	No
LEV	25	1	Male	22	None	No

#### 4.2. Vignettes of Participants

Vignette sections involves researcher's personal impressions, insights and observations mainly about participants as well as themselves throughout the interview process. Father acronyms are going to be presented with their age, their children's age and sex and father's occupation respectively within brackets in the rest of the paper.

##### 4.2.1. Interview 1: ALC (56, 24 year-old son, foreign trade)

From the first moment I contacted the father, I felt an overall positive mood and a motivating style to engage with. Initial moments of the face to face interview affirmed what I have expected on the phone conversation. As it was my first interview, I was hesitant to talk about a topic that I do not know how well they manage or if they are somehow sensitive on any regard. The father being pretty humorous, smiling and cheerful until the end of interview, helped me overcome my hesitance from the first moment.

ALC was involved in an organization for the rights for children with ASD. They worked on visibility of ASD in the society. Interviewing with an activist father was both an advantage

and a challenge for me. It was an advantage since the father was very articulate. He was able to elaborate on his ideas and talk with striking phrases that convey the essence of his experiences. Throughout the interview, I thought this father could be a great example of how to live with ambiguous loss in an adaptive manner. Some of the phrases that the father used such as “always having a gray area about knowing their situation” was almost verbatim definition of ambiguous loss. Some of the other concepts such as not being able to take action, having unmet expectations from the child provided me with a hope about my research question.

On the other hand, father’s ability to articulate his thoughts sometimes got ahead of my ability to guide the interview since there was a lot of content that he wanted to share. Whenever I tried to interrupt the conversation in order to paraphrase what the father said or to ask follow-up questions, father ignored my attempts and kept talking. I could not insist on interrupting more because I was afraid that I would seem insincere or disrespectful. After a certain point, I realized I was drifted by my anxiety regarding the length of the interview because it almost approached to two hours when I expected it to last around an hour. Moreover, as I could not lead the conversation, I felt ineffective which led me to feel angry about the interview. At those times, even though there might be topics to uncover further for the sake of the interview, there is a possibility I have missed some of them.

#### 4.2.2. Interview 2: KEM (43, 12 year-old daughter, tradesman)

Before and upon meeting as first impression, I thought the father seemed very tired and lacked energy. Based on my first impression, I started to think about to what extent I should try to get answers and push the father, concerning about their possible sensitivities. As the interview progressed, my prior impression that he might be tired has turned into father being a benign and relaxed person. Comparing with the ALC, KEM provided me with less content; therefore, that

was an advantage in terms of elaborating the process of the conversation. On the other hand, the father repeatedly focusing on different details of his personal experiences (i.e. speaking about governmental policies instead of what is asked about him) led me to feel ineffective. Similar to my first experience, I realized I was drifted away with my concern regarding not to elongate the interview and thought some topics should have been covered more in depth.

One exception that should be mentioned about KEM is that he has two children and both of them are with ASD. Considering that having a second child with ASD can also be similar with having an only child with ASD, father was accepted to study to talk about his first-born child. However, despite the frame of the interview was indicated based on the first-born child, the father mentioned back and forth between his two children. The father compared the two siblings at times. Even though I guided him to keep his focus, he confused the questions and experiences of the first-born child sometimes with the second child. At those times I asked clarification questions.

The discourse of the father has vaguely reminded me of the theory of ambiguous loss throughout the interview. Even though he repeatedly stated that he accepted his child's situation completely and there is no chance that she will meet her father's expectations, the father struggling to keep her in a better condition was a reminiscent of ambiguity around the loss.

#### 4.2.3. Interview 3: ADN (40, 10 year-old-son, engineer)

One of the first things that attracted my attention about the father was that he certainly avoided to have eye contact with me. My endeavor of trying to warm the atmosphere in the room did not seem to have an impact, seeing that father spoke as if I am not in the room. Despite this led me thinking behaviors of a person on ASD spectrum, later on I reminded myself to see this

behavior as a mere sign of nervousness that anyone could experience upon meeting someone, especially if someone to talk on personal issues with.

Another thing that was striking was the amount of guilt the father had took on. Unlike the first two fathers, ADN did not talk about researching about the ASD. Without an endeavor for being informed about the situation, this process reminded me of a denial of the situation not adapting to the new reality as a part of their lives. Similar to other fathers, he touched upon the fact that ASD is not visible to the eye. Moreover, throughout the conversation the negativity and positivity of the conversation went back and forth very powerfully. Both of these examples led me to think that the father was in an unstable position of accepting the diagnosis as it is. This was evidenced by the father's mentioning about their limited ability to deal with the situation, and in fact, the father repeatedly said that he was burnt out. This seemed to be confirming their ability to deal with the ambiguity and hardships that situation brings.

Similar to the first two fathers, ADN also mentioned that they became distant with their family members. Also, similar to the second father that they had no couple relationship and that their life was built only around the child. One striking point was that the mother became distant from the father-child relationship and had an increasingly blurred role in the family. They could not cope as a couple; the father took most of responsibilities on himself.

#### 4.2.4. Interview 4: HAR (41, 15 year-old son, accountant)

Upon first contact on the phone, the father left an impression that he is a person with anxiety. He could not hold back explaining a point at least three of four times. If not interrupted, he kept going. Even though this made me a little bit anxious not knowing how the interview was going to take place, first face to face contact changed my perception of him to an extent. He



seemed to be not as repetitive as on the phone. He seemed to be open to proceeding in a cooperative manner.

One thing that enabled the conversation to go well was the father's ability to clearly point out the source of his experiences. On the other hand, this clarity sometimes went off during the conversation as the father could not gather the overall timeline on his head, which left with an overall confusion despite all my endeavors of clarification. This situation reminded me of my negative mood before and upon first contact with the father and at times I felt like I being was drifted away from the core of our conversations. However, he was relatively clear with his answers, he remained hesitant in terms of elaborating on the details of his process. While the details did not add up at some points (such as the times he seemed hesitant to talk about his child's official autism diagnosis), he "confessed" that he did not tell his wife about our interview since she got angry with his activist agenda outside the household. I attributed the lack of organization in his answers to the fact that he is meeting with me for this interview without telling his wife. After this point, I felt a little bit more relaxed and curious to understand his experiences. Seeing that these feelings of helplessness and ineffectiveness might be related with partly due to the father's process helped me at that point. After that, I felt more present in the conversation.

However, I realized that I had an overly optimistic and unrealistic stance of what the father was saying. This might be due to the way that the father stood and spoke (shoulders and eyes down to floor) seemed and expressed signs of being burnt out. Countless times, he stated that they were completely alone and they waited for a hand to realize and help them. Even though I knew I was not there at the moments as a therapist to intervene with the situation, I felt an urgency to lift the father's mood up with such interventions. Basically I realized I felt sorry

for the father and his discourse made me think I have to do something, as I reflect on it. At more than once, the father emphasized a concern regarding not being able to express himself clear enough and that was also striking. The father explained a strain of relating to his child. He stated that the families of children with ASD also have hard times expressing themselves and organizing with each other – there were fathers that thought otherwise – I also found myself trying to soothe the father’s concern on that regard as well. It manifested itself as me paraphrasing and summarizing our conversation maybe more than necessary. The interview was finished with questions on whether each party had understood each other good enough, yet with an overall positive mood.

#### 4.2.5. Interview 5: SUK (50, 22 year-old son, sales)

As the only father who took the initiative and reached to me via phone, SUK was very motivated to participate in the study. While the father and I were on our short way to the meeting point walking together, he started talking about how their relationship was currently affected by their child. Before we started the interview, he attempted three times to talk about his relationship to his wife. I see this as an indication for his need or eagerness to share. When the topic was the couple’s relationship during the interview, the father seemed hesitant to talk about it. This was perplexing. Even though there was not a moment where I felt drifted away from the interview, it was confusing for me not to be able to understand the father’s couple relationship thoroughly. This confusion partly related with not getting clear answers from the father, or me not being able to understand what he meant to say.

#### 4.2.6. Interview 6: MET (53, 15 year-old son, engineer)

When I arrived at the meeting point with the father MET, I was a little bit nervous because I was almost late for half an hour due to traffic jam. However, he politely ensured that it was OK for him to wait. Seeing his sincerity, my nervousness turned into a curiosity of the father's story. For me, the father was a person easy to talk. His answers were almost always direct and to the point, which I thought could be because he is an engineer. I felt effective and having the initiative in order to set and keep the frame of the conversation because I thought he was open to dialogue in that respect. At times when I felt confused, I believe I was able to clarify.

I realized that I started to listen to the father with more compassion and understanding at times when he started talking about not being able to spend more time with his son. The fact that he became restless because he cannot spend time with his son; even if he spends time he cannot be tolerant and gets angry; consequently, he started using anti-anxiety medication to increase his tolerance level made me more understanding towards the father. I believe the challenge of having lower tolerance for something or someone is somehow familiar to me. That is why his personal experience of having low tolerance might have opened my compassionate ear and made the atmosphere more easy-going and relaxed for me.

#### 4.2.7. Interview 7: CUM (49, 8 year-old daughter, health sector)

This father was very eager to participate in the study when I first told him. The father's daughter was also attending play therapy sessions with me; therefore, the father and I knew each other from another relationship other than the participant-researcher relationship. While this could be a disadvantage in terms of role confusion, I saw that it was also an advantage throughout the interview considering the trust in the relationship we have established previously. He provided very sincere details regarding his life. What I have paid attention to was not to

formulate my questions considering the father's spouse whom I know from therapy sessions as well. I believe knowing the mother as opposed to other participating fathers would be a pitfall in terms of having a bias in favor or opposition of the mother. However, I think I managed to keep my focus on the father. At the end of the conversation, I felt that I covered the questions with enough details.

I realized the anecdotes and details provided by the father evoked compassion while I was listening to him. I think this was related with the father's unconditional support and love – as he reported in the interview- that were striking for me as a researcher. Rather than feeling a familiarity with what the father felt, what I felt at the moment was sort of a yearning that came from somewhere personal.

However, I also realized that the father started answering the questions by what he did not mean rather than what he actually meant. When I summarized what he said, I felt he became defensive and tried to make amends with what he said. Normally, in this condition, I would hesitate not to make the father defensive which could inhibit me to ask further details and clarification. Yet, I think I was not hesitant with the father.

#### 4.2.8. Interview 8: OGU (45, 12 year-old son, hairdresser)

The overall interview was conducted in a positive and constructive mood. One of the first impressions as the interview progressed was that the father had a very graceful perspective of his journey and had the ability to insightfully articulate his experiences. The reason for this impression was because the father was able to answer the questions within the realm of what was asked. Unlike other interviews, he gave enlightening examples of experiences when I asked rather than talking about a variety of subjects in one monologue. However, I did not have the

impression that we were not flexible on the topics either. When one subject was finished, the father moved on to another other which allowed me to deeply elaborate and understand the subjective experience behind.

One of the reasons I felt comfortable in this interview was that the comfort was mutual. This led me to think that the father was being sincere and honest with positive as well as negative aspects of his experience. While he avoided eye contact in the beginning, towards the end he did not need to hide his small tears in his eyes keeping his contact with me. Despite emotionally loaded moments, his experience made me think that the father was in a good shape in terms of dealing with the situation. He explained some strategic ways of thinking that helped him to shift his focus from the problem to the solution. Even though he knew that this situation was permanent, he was trying his best to improve his child's life or whatever decisions made he consulted his wife. These were some of the things that made me think of possible indicators of ambiguous loss. Rather than source of ambiguity of the loss, these were his coping strategies with the ambiguity in their lives.

#### 4.2.9. Interview 9: LEV (47, 25 year-old son, architect/designer)

I did not have any impressions about this father at the first phone contact or initial face to face contact. I was rather neutral both intellectually and emotionally. As the conversation progressed with the participant, I started to form my overall image about the father. He was a creative director at many different companies specialized in data visualization. Also, considering the other fathers, he had the highest level of education. Overall my views of the father were distinguishingly different than the rest of the fathers' both in terms of their insights and the meanings attached to those insights. For example, this father used the term "mixed feelings" and "role confusion" naming what he experienced at the time of diagnosis which are basic

components of ambiguity around the loss based on the theory. Moreover, the father seemed to have a unique understanding of his son's speech in terms of how it lacks abstraction and what that missing abstraction refers to in his son's overall speech. Even though this is an innate feature of the fathers participating to the study, LEV seemed to be the only father who had a theoretical understanding of his child's speech, indicating a thorough understanding of ASD combined with his expertise. These were striking moments for me.

On the other hand, LEV also touched upon the issue of being left alone and/or isolated either in the family or society from a unique perspective as well. Even though this was a similar experience of many of the fathers, LEV was able to distinguish being alone in the family or in the social environment and being left alone by them. He made almost a verbatim commentary about the irrational nature of ambiguity around some of the losses that created tension in either personal or relational systems. People could not stand to be around them due to the tension created by the constant ambiguity around ASD, according to the father. Overall the father seemed to be well-adjusted to live with this ambiguity by putting every component into a process in his head, which I think may be partly related with his intellectual capacity.

#### 4.3. Thematic Overview

For the purposes of this research, nine interviews were conducted with fathers and their answers were coded separately. Among their transcription codes, the ones that recurrently manifested were gathered under the same themes. This grouping process was led by the main research question of "What are the factors contributing to paternal stress in fathers raising a child with ASD?". Among those factors, are there any one that are particularly related with boundary ambiguity?

The codes that were created based on the fathers' answers gave rise to two super-ordinate themes: a) *process of acceptance*, to sequentially touch upon the stress generating factors before during and after ASD and to elaborate how the fathers came in terms with their children's ASD; and b) *impact on family life*, in order to explore how the boundaries and relationships changed within the family as well as how families situated themselves with these changing boundaries and relationships outside. Table 3.1.a, table 3.1.b. represent an overview of the themes identified under the super-ordinate theme of "Process of Acceptance". Under this theme, there are four main themes. On the other hand, table 3.2 represents the super-ordinate theme of "Impact on Family Life" and four main themes identified under it as well. Further information regarding super-ordinate themes is provided in the related subsequent sections.

Table 3.1.a. *Theme, sub-themes and reoccurrence counts for the super-ordinate theme of Process of Acceptance*

	Theme	Subtheme	Name	Reoccurrences in the 9 father
Process of Acceptance	1		Konduramama: Straining self to accept ASD	8
	2		Incomprehensibility of ASD	8
	3		Receiving proper education	7
	4		Emotional processes	
		401	Feelings of guilt	6
		402	Pendulum of hope	8
		403	Concern for future	6

#### 4.4. First Super-ordinate Theme : Process of Acceptance

Interviews which are coded for their both latent and semantic meanings and analyzed based on the first research question which was whether fathers are affected by the experience of ambiguous loss in relation with their increased stress levels, gave rise to four themes in the super-ordinate theme of “process of acceptance”: a) *konduramama: straining self to accept ASD* for the initial hardships that the fathers experience; b) *incomprehensibility of ASD* to explain how fathers cannot conceptually engage with ASD; c) *emotional processes* for explaining shared emotions among fathers in the acceptance process; d) *receiving proper education* to underline the hardships during special education of children with ASD, e) *making peace with ASD* to elaborate on the fathers’ acceptance of their situation and helpful factors at this phase.

#### 4.4.1. Process of Acceptance - Theme 1: “Konduramama”: Straining Self to Accept ASD

This theme reported by 8 fathers out of nine is named as “Konduramamak” in order to describe the fathers overall experience during the times when they started to see peculiarities in their children and try to make meaning of it - mostly choosing not to see them as peculiarities. They frequently used the term “konduramamak” in order to describe not being able to associate their children’s situation and its name, which similarly is also described as “yakıştıramamak” and/or exaggeration. This situation was explained by the father CUM’s (49, 8 year-old daughter, health sector) commentary on his reactions to his daughter’s peculiarities when he was asked “How ASD has gotten into your lives?”:

*“I thought that was ridiculous, and she [the wife] is exaggerating. Then as she researched more, she started saying our child might be autistic and again, I could not say the word autism out loud [“konduramadım”] as I look at her. Because at the time, the way I see autism only included severe cases of autism such as when children cannot*



*control their movements. At first, inability to speak made us think about dyslexia. Even though younger children started speaking, she could not. I stayed still and did nothing. It was exaggeration....”*

His comments on her daughter’s delay in speech indicate an obscene denial regarding the possibility of ASD to the extent that he had to be tricked into getting a formal report for ASD. In here, father’s difficulty to accept was due to his prior knowledge of ASD that is based on lower functioning cases in ASD. Although her daughter’s situation is obviously different, connotations attached to this situation strained the father emotionally and he refused the possibility of ASD.

Another response to this situation that indicated to the fathers’ strains about the peculiarities was anger, as it is put by ALC (56, 24 year-old son, foreign trade):

*“It was a young special educator who first articulated her observation for the possibility of our child to be with autism. Somehow we were referred to her; and probably because we were referred to her, she reluctantly shared her observation with us. Even though we said ‘OK, thank you’, I remembered feeling so pissed off as we left. I mean, you are not a doctor. How could you say something like this?”*

Here, the father remembered feeling anger toward a person indicating to a possibility of autism rather than just refusing to accept. The strain here shows itself as an emotion that is hard to experience in itself.

When the same question was asked to the father SUK (50, 22 year-old son, sales), his experience of being strained corresponded to the time right after their child was diagnosed with ASD rather than before receiving a formal diagnosis. His experience was as follows:

*“After we learned about this, it was hard for us to accept. We could not share this with anyone in the family. Rather than not being able to share, we just did not share... Because we did not know that it was something like this. We could not say the name of autism out loud [“konduramadık”] for our children because we did not know what it is exactly... with the intention to protect him, we kept this as a secret so that people would treat him normally. I mean if I were to tell my mother, she would have started baby-treating him. We did not want him to be sugar-coated by his actions. We wanted him to face real consequences so that he could feel normal.”*

The fact that their child was diagnosed with ASD was hidden by the father SUK from the external family members in order to maintain their child’s normalcy in their lives despite his peculiarities. Here, the strain was more stratified considering the father was actively trying to keep this information from others while having a hard time to accept the child’s condition.

#### 4.4.2. Process of Acceptance - Theme 2: Incomprehensibility of ASD

Eight out of nine fathers reported that they did not know the cause of the disorder, even though they embraced an explanation that seemed most meaningful for them. Living with a cause unbeknownst to them also interfered with their perception of the disorder in terms of not being able to comprehend the true nature of the disorder and categorize it schematically within their mind. This inability to comprehend ASD was explained by the father ALC (56, 24 year-old son, foreign trade) when he was asked “How has the meaning of autism changed for you?”:

*“Actually, it means nothing. I cannot attribute it to anything basically. We were living everything about autism. We have learned that in a short time: Each and everyone’s autism is unique! Despite similar stereotypes that everyone shares, everyone’s experience of autism is different. Not an easy task to define and group the experience of*

*it. That is why there is always a grey area left (in our minds). We were never able to say that we understood autism completely.”*

Here, the father mentioned a grey area which acted as a barrier for them to group their experiences and understand completely. In relation with that, this incomprehensibility is perpetuated by a discrepancy between how ASD looked and how it is experienced. The discrepancy interfered with the father's meaning making to find a cause for the ASD. When the father ADN (40, 10 year-old-son, engineer) was asked how his opinions regarding ASD have changed so far, his answer portrayed this experience as follows:

*“This (disorder) is so repulsive that you cannot get him educated by accepting him as a spastic. If he had a physical disability, you can say that so that he has to sit down all the time. This handicap is so confusing that he creates wonders at times; he learns striking things from the most unexpected sources. [Child] Surprises you. You see that he has no problem with his intelligence. Bodily, you can see that he has no disability. When you direct him to a sport, he can do sports too.”*

Since the father could not entirely categorize the disorder as either physical or mental, he described ASD as something “repulsive”. While his child can create miracles using his mind and accomplish bodily activities, the fact that he cannot comprehend how ASD becomes a problem for them.

Similarly, fathers think that this discrepancy was also the cause in which other people could not understand ASD in the society. Upon the same question, father HAR's (41, 15 year-old son, accountant) answer shed a light on this situation as follows:

*“Perhaps, it is because there is no deficiency in his appearance. They were saying things like ‘It will pass...’. When you look at leukemia, for example, the physical peculiarity is apparent. Other people may come to support. However, the child we have is good-looking; maybe a bit-spoiled or have behavioral problems [as others think]. We cannot get support.”*

HAR was explaining that the discrepancy which made it harder for them to comprehend the nature of the relationship, was also causing others to misinterpret their child’s condition; therefore, illustrated that people could not schematically categorize the children with ASD as someone that needs help based on how they look and act. This illustrated that the discrepancy which is peculiar to ASD complicated comprehending the nature of the disorder for both the fathers as well as others based on paternal perspective.

#### 4.4.3. Process of Acceptance - Theme 3: Receiving Proper Education

This theme presents the issues regarding a fundamental need which is special education for children with ASD. Seven out of nine fathers reported that they have experienced some kind of a problem at different points in their journey starting with ASD. Opportunities provided by the state government, expertise of teachers, efficacy of teaching methods, institutions prioritizing financial matters at the expense of providing healthcare, and lack of guidance by diagnosticians were some of the issues mentioned by the fathers. In addition to problems covered above, father HAR (41, 15 year-old son, accountant) points out another facet of the hardship they face, which is accepting their children into some schools because their school formation was not inclusive and not able to commingle children with disabilities with children with typical development:

*“Preschools and kindergartens were not accepting our child... Rehabilitation centers were very ineffective and they could not support as well. Many branch teachers were not*

*participating to the classes... We end up continuing with one of our relatives who is also a special educator.”*

At a larger scale, for opportunities provided by state government, father ADN (40, 10 year-old-son, engineer) explained that they would benefit a lot, if a certain level of quality in special education is met:

*“Neither families of ASD community nor our family do not feel confident within the current situation of our country. It is governments job to make parents relaxed, as they do in Western countries. Child receives education from experts under the guarantee provided by governments and we could still make parents to our child feeling much better. However, we as a country, do not fit to such conditions.”*

Lastly, father OGU (45, 12 year-old son, hairdresser) criticized the diagnosis systematic until age of three of his children with the following sentences:

*“They do not diagnose with ASD before the age of three. However, a family who is sure that their children have something different that needs special education cannot start government assisted education even though it is the very same doctors who say it is best to start trainings as soon as possible. I ask to myself: ‘Have I received my child a proper education until now?’”*

#### 4.4.4. Process of Acceptance – Theme 4: Emotional Processes

This theme was composed of paternal experiences during and after their children got formally diagnosed with ASD. The diagnostic process in ASD required in-depth evaluations and regular follow-up appointments with a diagnostician; therefore, having a finalized diagnosis might be prolonged and was not always clear-cut. Even when the diagnostic process was straightforward, fathers reported experiencing a range of emotions and thoughts during the

process. Within this process, prominent experiences common to most fathers gave rise to three subthemes; a) *feelings of guilt*, to describe father's search for a guilty in terms of the cause of ASD; b) *pendulum of hope*, to portray the situation in which conflicting emotions pent up after the diagnosis; and c) *concern for future*, as an ongoing restlessness in terms of their children's future.

#### 4.4.4.1. Subtheme 401: Feelings of Guilt

Six out of nine fathers reported feelings of guilt just as they learned about their children's ASD. These feelings of guilt presented themselves in one of two ways. One way was to whether it can be traced back to anyone in the family including themselves. Here, there was a guilt that should be taken over by someone. This was exemplified by SUK (50, 22 year-old son, sales) when asked about his first reaction upon learning about the diagnosis:

*“How did it happened to us? Is it genetics? Is it me or the uncle of my child? Because the uncle had been very into counting and numbers as a child... When I started to inspect me and my wife, I saw that she is a perfectly normal person. When I look at myself, I start to suspect something about me such as when I could not memorize the multiplication table. I had always bad grades at school. You get to see it as you keep looking for it. It is like feeling the clouds yet not being able to tell what they look like.”*

Here the father was searching for possible explanations in order to find a link between the ASD and a person, as was depicted by a metaphor of clouds since each option seems equally feeble. This process of finding a scapegoat indicated presence of a free floating guilt that needs to be addressed in the father's perspective.

The other way of dealing with the guilt was to directly take it entirely on oneself. The father ALC (56, 24 year-old son, foreign trade) explained this process upon the question of “To what do you attribute the cause of ASD?”:

*“People laugh at me when I say this but ‘apple never falls far from the tree’. I do not think this is independent from us. They definitely have something from us as I can see that my son is a copycat of mine in some characteristics such as indulgence ... I blamed myself about that. Well, maybe not blamed myself but it kept me thinking. Back in my college days, I participated in a psychotic drug trials for money. A doctor friend of mine reassured me that drugs were safe to be used. However, I thought whether it affected this situation somehow ... Now, I do not contemplate about it that much knowing that my other friends had not experienced such a situation.”*

The use of proverb ‘apple never falls far from the tree’ in this context told about how the father held himself accountable after his child’s ASD, considering the similarities between his and his son’s personalities. While this resemblance kept the father contemplating for a period of time, some of his prior actions contributed to his self-blaming tendencies. Despite quitting blaming himself with reasoning to an important extent today, the guilt for the father eventually was still there.

#### 4.4.4.2. Subtheme 402: Pendulum of Hope

The content of this theme captured two opposing sets of emotions that are simultaneously experienced in a cyclical manner. The cycle included hope and hopelessness as two interrelated sets of emotions both of which has an impact on the other. On the one hand, fathers were hopeful that their children are going to improve symptom-wise and/or miraculously be cured one day.

Until then, they were determined to undertake whatever actions are necessary to make their children's conditions better, so that they could keep dreaming and making plans for their children in a foreseeable future. When he was asked about "How did your perspective change about ASD so far?", the father MET (53, 15 year-old son, engineer) summarizes the feelings of hope in which eight out of nine fathers had shared various parts of his hope as follows:

*"You always have a hope inside. OK, now he will be unclogged and he will start speaking. You hide a hope inside. OK you accepted the situation but there is an ongoing hope for him to suddenly speak or understand. He will be better starting from this point on and yet, you say that it will continue as it is ... It is something we are not familiar with. We feel like he is going to take a pill and everything will be over ... There is science on one hand that says it is a disorder while there is superstition on the other hand that makes you still believe in miracles ... We have done everything we can just to make sure you prove it to yourself if not for anyone else. Say it education, say it pharmaceuticals..."*

This passage illustrates the hope that father carries inside in which most fathers shared. An aspiration for a miraculous change of events and trying to accomplish everything for their children is laid out by the father. In another example, the father SUK (50, 22 year-old son, sales) make a remark on hope from another facet as follows:

*"I always tried to make him do things that he can even though he always came to a deadlock. He could not learn how to tie his shoe laces despite hundreds of repetitions. The same for taking the garbage out too. But I do not develop a system one in which it can solve all his problems on purpose. I am pushing him so that he can learn."*



SUK mentioned about his determination as an indicator of his hope. Since he insisted on the idea that his child might be able to learn, he consistently and patiently waits for his son to learn about some fundamentals that could benefit the child for his own care-taking.

On the other side of the pendulum, as opposed to the eight fathers who remained hopeful, eight of the nine fathers reported feelings of hopelessness at the same time. Their hopelessness was due to the thoughts that their children were going to remain the same in terms of their compelling symptoms for the rest of their lives. These thoughts were accompanied by feelings of despair, inadequacy and powerlessness considering the room for development is relatively narrow in ASD despite being promising. Even though the fathers struggled to meet their children's need to provide utmost care, factors such as finances, allocating time and energy remained as the source of hopelessness. As a result, imagining a future or make plans for the child became impossible. As a response to the question how his perception of ASD has changed, the father ADN (40, 10 year-old-son, engineer) replied:

*“We are still powerless. At least on my part, I am still powerless. I am an extraverted person, so I may not make it obvious that I am powerless when we think of me in relation with my child because I have a fear of not being good enough. This is constantly laying inside... But where did we come so far? We could not go as far. Maybe, did we overcome anything? I am not so sure about that as well ... He likes car rides and music instruments. We cannot do it; we cannot meet his need on that regard both financially and educationally ... Even if you have plenty of commodity such as the best car or best mansion, it does not have any value for you.”*

AND's hopelessness about the situation was related to his constant fear of not being able to meet his child's needs which consumes his energy. The fact that he did not think he can meet his

child's needs makes him question about how far they came; consequently, he made a remark on how not being able to improve the child's ASD trivializes what they already have.

At times where father's hopelessness manifested itself in the form of inability to think, imagine or plan ahead is explained by father the HAR (41, 15 year-old son, accountant) as follows:

*"I do not know whether I say these because I am under tragic impact of the situation or the fact that it is reality... I cannot think, compare these two because we are in a dark lantern. We have no dreams. It is all dark. 'What can a person think' is what we think I guess. We have no enthusiasm, no plan or expectation regarding the future."*

#### 4.4.4.3.Subtheme 403: Concern for the Future

Six participants reported a concern about the future of their children. The concern shaped around the term future had variety of meanings some of which overlapped. Mainly, the fathers expressed that they were contemplating constantly about what their children's situation will be after they are gone. The fact that this situation was disturbing for the fathers had different motives. Firstly, it included meeting the general needs of the children and having people around the child to take care of them. LEV (47, 25 year-old son, architect/designer) mentioned what would change in their lives if their son would not have ASD with the following words:

*"You would have felt the cycle of life yet our child's life is not cyclical. A person becomes young, middle aged, gets married with kids and you become a grandparent. We do not have such a cycle in life. We have a kid and we have a kid for life. That is why we are trying to live as long as we can. What will happen after we are gone? Unless there is a revolution, I pity my son's future... That is why we are trying to live as long as we can."*

The fact that their children is stuck at a developmental level in which he depends on his parents for vital needs, the father had thoughts for later stages of the process of caretaking which included anticipation of his child’s need of being taken care of like a child. Another father who was aware of the fact that they brought their child into life based on their own will and not their child’s, SUK (50, 22 year-old son, sales) expressed his concern for their child’s solitude – not having another sibling in the world:

*“I thought ‘What is he going to do when I am gone?’ at first instance. He will not be able to make eye contact, he will not be able to ask a girl out ... What I have thought about my entire life was about how my son’s life is going to be after I am gone ... He does not have a sibling either. At least he would have been supported by his siblings, if I knew it better back then because I am already worn out ... We brought him to this chaotic world. We do not know what sort of a world he is going to live in. I hope they can live alright...”*

Table 3.1.b. Theme, sub-themes and reoccurrence counts for the super-ordinate theme of *Process of Acceptance*

	Theme	Subtheme	Name	Reoccurrences in the 9 father
Process of Acceptance	5		Making peace with ASD	7
		501	Increasing knowledge of disorder	9
		502	Reframing the situation	7
		503	Solution-orientedness	6
		504	Maintaining stability	8
		505	Attributions to something greater	5

### 2.1.1. Process of Acceptance - Theme 5: Making Peace with ASD

The last theme of process of acceptance is about accepting the disorder in the way that fathers make their peace with it. Seven fathers reported that they were able to reach to an understanding where they felt a transformation regarding their approach to their children's ASD and were fine with it. Among those who did, KEM (43, 12 year-old daughter, tradesman) expressed contentment about his daughter current situation despite he knows she will always be with ASD:

*“My daughter can now express herself. There will always be remnants of ASD. Does she have remnants now? She does. Ninety percent of children with ASD have nail biting obsession. She has it too. We could not give her up whatever we did. She is now very agreeable and can integrate into society very well. She is fine now. I am very contented with my daughter.”*

Based on his speech, father asserted his acceptance towards permanence of ASD. As distinct from KEM, what some fathers described as they accepted was the ambiguity that comes with ASD rather than the ASD itself. ALC (56, 24 year-old son, foreign trade) describes it in the passage below:

*“Grey area is still in our lives but I do not know, it is not something of a concern as it used to be for us... it became a part of our lives ... One day, while I was giving money to doorman, he knocked TV over in saloon. Luckily, these days TVs are built much stronger (chuckles). At first, you have nervous laughter but then, you consolidate TV into wall with steel wires. One day, he came to me smiling sneakily as if he has done something. When*

*we go inside and he saw that he could not manage to knock over the TV due to wires, his smiled has frozen on its mouth. Each small victory strengthens.”*

What ALC mentioned as ‘grey area’ is what they do not know about ASD. While the ambiguity surrounding the unknown was disturbing to the father until recently, he described series of events just as is read above that made him able to feel like a ‘winner’ over the disorder. By having victories over the hardship of ASD, father described the ambiguity as something that is easier to bear.

Most fathers have either consciously searched for or instinctively adopted helpful strategies that made them able to facilitate the process of acceptance as mentioned in the case of ALC above. Five strategies that were common to more than half of the participants and known to facilitate this process were: a) increasing their knowledge of ASD, b) reframing the situation, c) solution-orientedness, d) maintaining relationships and e) attributions to something greater. Even though these strategies do not explain the stress generating factors in fathers, they are to be used to alleviate the stress. All these strategies were explained in the following paragraphs.

#### 2.1.1.1.Subtheme 401 – Increasing the Knowledge of Disorder

All of the nine fathers described that learning more about the ASD as a situation either previously unknown or wrongly known helped them to accept the situation and anticipate the aftermath. CUM (49, 8 year-old daughter, health sector) explained learning more in detail about the disorder and its impacts as follows:

*“Since I could not adapt to the idea of ASD, my wife researched a lot and explained it to me. Even though I thought it was exaggeration at first, I started to pay attention slowly and peculiarities caught my eye too. As I started consulting my wife, she informed me*

*about all the details and I was able to differentiate my daughter's ASD was on a higher functioning spectrum, which helped me a lot afterwards."*

Even though the increasing knowledge was aided by mothers for some fathers who identify their wives as the 'resilient one', some other fathers reported that self-education was helpful in terms of understanding what to expect in later courses of the disorder:

*"We searched ASD online like crazy about what it is and what it is not ... We tried to educate ourselves on that matter ... We learned that it can become a part of our lives."*

#### 2.1.1.2.Subtheme 402 – Reframing the Situation

Eight fathers reported that reframing the situation in the sense that focusing on the brighter sight of a fairly pessimistic picture helped them cope and accept the situation. Father SUK (50, 22 year-old son, sales) walked me through his way of reframing the process with the following metaphor:

*"I guess this is how my logic works: I was a sales-person. I know how to see a product. I took a cup and I fancy it out and sell it in one way or another. Now, the product is my product. You have to accept this fact at this point. You cannot return it just because it seems off. You accept and eventually, you are more relaxed."*

Father SUK (50, 22 year-old son, sales) accentuated the importance of brighten up the desirable features in the overall situation. Father LEV (47, 25 year-old son, architect/designer) has shared a more direct way of this strategy with an explanation leading to this strategy whilst he was mentioning how his relationship to his wife grew stronger after their child's ASD. Here, father did not directly reframe the situation of ASD, but he chooses to focus on the positive impacts of ASD rather than negative:

*“Unless you do not trust each other as couple, you cannot make your child feel the trust as well. Our son has felt that feeling a lot and he recognizes it well. As differently, he can communicate as opposed to his counterparts with ASD. I identify my child’s situation as ASD with social and emotional abilities. Distinguishingly a different relationship we do share with him.”*

In another, father ALC (56, 24 year-old son, foreign trade) used a funny nickname that externalizes the seriousness of a hefty situation. Here, he reframed it in their favor by focusing on how he perceived his son’s ability of lying as an extra-ordinary situation distinguishing him from other people with ASD. As a result, a former disadvantage turns into an advantage in a different context:

*“We call him “AUTI” which is a prettier abbreviation for ASD. In fact, we call him “AUTI-CAT”. Among all the children, an anti-cat that has the ability to lie fell to our share (chuckles). He lies sometimes. He is a witty boy with devil’s feather on it. You would adore him as well.”*

#### 2.1.1.3.Subtheme 403 – Solution-Orientedness

Six fathers found it more helpful to focus on the solution rather than the source of problem itself. When father CUM (49, 8 year-old daughter, health sector) is asked “What is your explanation of autism?”, his response directly summarizes his mindset:

*“I did not look for why it happened. It just did. It is the point of no return. Let’s say it is my wife’s or doctor’s fault. What are we going to do? Bite each other’s heads off? What is important is what lies ahead.”*

While most of the fathers did search for a meaning and explanation to the ‘why’ of the disorder, the father CUM said he never needed to ask why it is happened. In his views above, he shares his opinion on solution-orientedness and his views are also shared by other fathers almost identically. This can be exemplified by father HAR (41, 15 year-old son, accountant) explaining on what he invests his energy to keep himself together for his child as follows:

*“I cannot solve problems if I contemplate on my son’s condition. Psychologically, I need to stay strong. If I focus on a child who constantly depends on us with no future, I would collapse ... What is my role on this lane? To spend more time, to be there more.”*

#### 2.1.1.4.Subtheme 404 – Maintaining Stability

Seven fathers reported that having stability in their life helped them deal with the stress they have. Most people among the participants reported that they have been isolated from their immediate social environments and families. This matter is going to be elaborated in the last theme. However, even among those families who had lost contact with a part of their lives in terms of people or activities and/or have impoverished relationships with those and things around them, maintaining a type of stability helped them alleviate the stress. The stability was considered as any enduring activity in fathers’ lives ranging from meeting regular people to going sightseeing at the same time each week. This is exemplified by father ALC (56, 24 year-old son, foreign trade) as followed:

*“They helped in terms of food [if nothing else]. The people on my mother-in-law side also wanted to be involved in caretaking of our child. She always cooked for us and fed us. We still keep bringing food from her house to ours three times a week. Despite our oppositions, she still continues to cook because she likes doing that. It meant that she is still is a part of the family for her. I understand and respect that. When we are invited*



*over, she cooks whatever our child likes as well. This became a ritual at Thursdays for us.”*

Father ALC (56, 24 year-old son, foreign trade) described that their family provide support in term of daily life necessities and it is indeed cherished by the father as well. Having routines shaped around family meal times created a perception of support and maybe not being alone which is reported to be helpful by father himself. Apart from this, other fathers reported stable relationships in their lives were also means of other kinds of support including financial or psychological support. Father CUM (49, 8 year-old daughter, health sector) explained how his enduring relationships from the past mitigated his stress through perceiving their support by their side as follows:

*“Even though I have cut-off relationships with my nuclear family, I have always had solid relationships with my two uncles living in other cities. Today, they still would not let me stay anywhere else but their homes if I ever visited their city ... They always provided moral support. Apart from their helpful attitude that soothes our anxiety, they offered financial support if we ever need it ... We have never used their money, yet you say to yourself ‘Even if I ever need money and do not have enough, I always have an alternative’. Knowing that helps a lot.”*

#### 2.1.1.5.Subtheme 405 – Attributions to Something Greater

Five fathers out of nine made attributions regarding the cause of their children’s condition considering a higher-order power that cannot be subject to control by a power any less than itself. These included explanations such as life, destiny or luck either in their spiritual sense or overall meanings not based on any systematic belief system. In relation with that, father ADN (40, 10 year-old-son, engineer) has described his views as follows:

*“Autism is hard ... I mean, I do not know. This could be the only thing that I could say about this handicap. You see how meaningful and meaningless life is, both at the same time. It tames you beautifully ... Some people do not like when I say say but I think autism is one rotten egg among thirty solid ones. That rotten egg has fallen to our share ... Some are lucky that the shell of their egg is thinner. Then, their life is easier. In some other, their shell is much thicker; they cannot adapt their child into their lives. Their lives are ruined. The only recipe is to be patient.”*

Father ADN as one of the fathers who claimed that they could not learn how to manage ASD and his response above is to the question of “What would you recommend to other fathers?”. He asserted that the only reason their child is with ASD is because the odds were against them on the larger perspective. With this pre-acceptance, father was motivated to be patient so that he can be there to adapt their son into his life.

Table 3.2 Themes and sub-themes for the super-ordinate theme of Impact on Family Life

	Theme	Subtheme	Name	Reoccurrences in the 9 father
Impact on Family Life	6		Shaping the world around ASD	7
	7		Impact on couple relationship	
		701	Emotional turmoil	6
		702	Positive emotional shifts	6
	8		Father as an outside support system	6
	9		Estrangement from relationships	6

2.2. Super-ordinate Theme 2: Impact on Family Life

The second research question of the study which was whether their personal experiences of ambiguous loss impact family systems through boundary ambiguity informed the themes

occurred in the second super-ordinate theme. In the “impact on family life” four main themes emerged from the data: a) *shaping the world around ASD*, to describe how fathers take their child’s disorder into center making adjustments of their lives, b) *impact on couple relationship*, to illustrate the positive and negative impacts of ASD on couple relationship, c) *father as an outside support system*, to describe the processes in which father’s became the third pillar of the primary mother-child relationship, and d) *estrangement of relationships*, to understand how external family and immediate social circle becomes distant to the fathers raising a child with ASD.

### 2.2.1. Impact on Family Life - Theme 6: Shaping the World Around ASD

This theme covers the shaping impact of ASD on fathers’ and their family’s lives in terms of how they accommodate themselves according to disorder. Six of the fathers reported that they take ASD to the center of their lives and make their adjustments in the way that will facilitate their children’s as well as their lives. Father ADN (40, 10 year-old-son, engineer), for example, described the mindset that they have grown throughout the process of disorder when started talking about the things that ASD has changed in their lives:

*“We struggle for our son exist in life. We look for how to contribute to his life after we are gone. Living in luxury or having a comfortable life is not our priority at this point. We can only have priorities concerning him ... We live according to our son, not the other way around ... As he keeps growing up, his problems have also grown. Probably I will start working home-office in the following years to support his domestic requirements and moving into a rural area out of the city with necessary facilities. I am going to take on that responsibility as well. I will see how it will turn out.”*

According to AND, his wife could not cope with the stress that comes with caretaking of their children. As the member of the family whose resiliency is higher than the mother, father tried to support both his child and wife who does not come into terms with their children's condition. Even under these extreme circumstances, his main agenda was still trying to attune his living conditions up the necessities of his child's condition.

Another example was given below by father LEV (47, 25 year-old son, architect/designer) from his sayings when he started talking about 'What would their life be if it were not for ASD?' :

*"We would not be in this position where we are at right now. We have made a decision to retreat in our lives when our child was 12. We see this as a fight. You cannot fight a war from the forefront all the time. It is about winning from the front you fight from. For example, we moved from another place in hope for our son to have more social support. My wife started to work in a place where it is 6-7 minutes away from home, by walk. I have quitted from my job when I was in my prime time of my work and started to other home-office works. My first shift starts with my son when he wakes up and the second one starts during the night as he fell asleep."*

Having a "war" metaphor in mind, father took his life accommodations as a strategic move in order not to win the combat, but to win the bigger war. Looking from a larger perspective, father may seem to lost parts and pieces from their prior life as a person or family, yet at the end of the day, his war still continues from back fronts, indicating their awareness about their child's ASD may require lifelong and continuous adjustments.

#### 2.2.2. Impact on Family Life - Theme 6: Impact on Couple Relationship

This theme addresses the impact of ASD on couple relationships from fathers' perspective. It is seen that most of the father's relationship have been subject to changes attributed to ASD in terms of feelings of intimacy and communication among couple. Among all fathers, three trajectories have been reported: a) three of them reported an increased couple discord and did not mentioned any improvement afterwards, b) the other three fathers portrayed a trajectory in which they were able to transform their relationship into a more from a conflicting situation, c) remaining three of the fathers did report increased feelings of intimacy and yet, no increased discord whatsoever. These changes are categorized under two themes: a) emotional turmoil, to explain the aftermath of the diagnosis process; b) positive emotional shifts, to underline the positive transformation that couple relationship underwent after the discord. However, the last trajectory did not come up as a theme. Below, possible trajectories are illustrated.

#### 2.2.2.1. Subtheme 601: Emotional Turmoil

Six fathers reported an increased conflict, decreased quality of communication and lack of intimacy during and after the time in which the child is diagnosed with ASD. When father reports were looked in detail, the dominant theme among those who have a turmoil was lack of couple time in the absence of child. Three fathers reported that even when the child was not around, couple cannot spend time together since their mind is preoccupied with their child. Father MET (53, 15 year-old son, engineer) explained how ASD impacted their couple relationship as follows:

*“If affects adversely. For example, he sent me away from the bed. He runs before me to get the bed instead of me. Other times, I see him already sleeping in my bed while I was in saloon watching TV. You cannot wake him up and send him away to his own bed. Since*

*I leave early in the morning, I let him sleep in my bed. Sometimes we still sleep with my wife too when we send him to his bed for one or two weeks ... Other than that, you cannot go to movies or hang around together. Even when we did, the child is the only thing we think about ... I accepted things the way they are now. I am so used to this that I cannot think of anything else when I am not without him. At the end, we keep him with us all the time, instead of concerning about him when he is not with us."*

Father indicated their child consists of their relationship to the extent that they cannot share a couple time within the same bed with their wife. Despite their attempts to share couple time in their own bed, the pattern in which the child dominating the couple relationship returns. Moreover, the father's reaction to the fact that they cannot spend time together with his wife resembled to learned helplessness reaction in the way that he has no hope for their relationship to change at all.

Similarly, father's expressed a hopelessness regarding their couple relationship in areas other than physical and emotional intimacy. Communication was another area increasing couple discord. Communication about the roles in the family was reported by father SUK to be a field of discord in their relationship. He elaborated on how he and his wife start arguing about nourishment of their child. Father pointed out to the fact that his wife has the last word in caretaking of the child because they spend more time together. He elaborated on how he cannot intervene to relationship between his wife and his child and expresses feeling of helplessness about it as follows:

*"It impacted our relationship negatively with my wife. For example, our son is physically weak due to the medications he takes regularly. My wife tries to feed him with junk foods since that is what he wants to eat. In this situation, he cannot eat during the dinner since*

*he is already stuck himself up with junk food. When I tell her he can eat whenever he gets hungry and not to buy junk food and feed him that way, she cannot hold herself back doing all these thing over and over again. That sort of a disagreement creates tension between us. When we disagree, we go with what she says. Since they are the two people that live in the same house, I am compelled to accept as she pleases. Otherwise, she is coming to get back at me. There is nothing to do about it.”*

#### 2.2.2.2. Subtheme 602: Positive Emotional Shifts

Six fathers reported that their relationship has reached to a state in which they have feelings of increased intimacy towards each other. Half of these fathers did not report any significant deterioration in their relationship from the period they were diagnosed with ASD onwards, whereas, the remaining half reported a recovery from an increased discord between the couple. Illustrating the former group, father CUM (49, 8 year-old daughter, health sector) explained how his already positive feelings towards his wife increased as follows:

*“There were times where my stubbornness became a strain in our relationship but it was not something as negative. My feelings toward my wife has changed. Sometimes, I say to my wife ‘If one of us has die, I hope would be me.’ Because if she stays, I cannot manage our child the way she does. That is what comes from the bottom of my heart. Whatever happens to me, I hope she remains safe. At this point, I can say my love and respect for her has increased. My wife is modest, down-to-earth and a contended person which were the reason I loved in her and got married. After all this, her attitude dealing with all the situation increased my love towards her even more.”*

Reminding of his wife’s desired qualities in the beginning of their relationship, father reported increased positive feelings including gratitude that comes with the caretaking of their

child. For the latter group those who deteriorated and managed to transform their feelings towards each other, ALC (56, 24 year-old son, foreign trade) explained their experience. In their relationship, father reported feelings of loneliness in terms of dealing with the child's ASD, which led him to act harsh while communication to his wife. However, reminding that their common enemy is ASD rather than themselves with the remark of his wife, couple were able to break out of their negative emotions led them remind how they see each other in the absence of stress caused by ASD. This process is explained as follows:

*“There were times that our relationships shaken from its ground in the sense that I used ultimatums to her by saying ‘Pull yourself immediately. I have limits too!’ It was harder for her, she was not able to manage and she seemed defeated which I could not handle very well. I was thinking that she has no right to be defeated. ‘Ok, let’s stop crying and see what we can do. We can solve as much as we can and adapt for those we cannot.’ ... As I said, we adapted. We rasped some parts of ours too. We remembered what we meant for each other, even though we have always known. This value we have for each other grounded when once my wife said in the midst of an argument: ‘I do not have a problem with you. I still love you the way I love you.’”*

### 2.2.3. Impact on Family Life - Theme 7: Father as an Outside Support System

Based on the interview questions to capture structure of the family, six out of nine fathers are seen to be situated in a position where their primary role was to support relationship built between the mother and child. This process was executed in one of two ways. Firstly, the supportive role of the father fulfilled by creating an environment in which family's in and out-of-household caretaking needs including special education and life expenses are met; consequently,



fathers provides mother-child dyad with the necessary environment to caretaking and meet child's needs. As a result, fathers kept their role as the provider so that caretaking of the child can sustain. KEM's (43, 12 year-old daughter, tradesman) answer illuminated how he construct a niche for his wife and two children with ASD so that they can maintain their lives when he is asked how to support his role as a father as follows:

*“First and foremost, money. Without it, life does not go on. Rent, food... Those are what I fulfilled as a father. I have to work so that I can provide to my family. After all, our landlord is not going to say that he will set us free from this month's rent merely because I have two children with handicap.”*

On another instance, CUM (49, 8 year-old daughter, health sector) described how they share responsibilities in the way that they enable the sustainability of the caretaking niche of the child by supporting his wife's responsibilities in the household as follows:

*“On percentage, I take twenty of the overall responsibility. In cases of emergency, we can swap in our responsibilities. However, we have an agreement as such: I can manage household chores yet, it is hard for me to manage the child. As a result, we agreed upon her taking care of child altogether, while I take care of cooking, dishes and shopping etc. and it went on this way. Our daughter also started to manage herself. Despite that, when she starts crying I cannot soothe her. When I failed soothing, I start panicking. Then voices get louder in the house. At the ends, she has to come for the child which doubles her responsibility and would complicate things. Wife better knows to deal with the child. As a result, she gives 100% of her energy to child. It was a win-win deal for both of us.”*

Even though there were a pre-conceived role division between parents, it was clear father CUM thinks taking care of the child should be eventually on mother's share. Since as a child

who grew up without a father himself, CUM put forward that he does not know to soothe his daughter as well.

Secondly, in a built-up relationship for family and mother-child dyad, fathers had to sacrifice their position in their relationships to their wives, so that the interaction between mother and child can maintain properly. Instead of being the primary caregiver of the child, father became a part of the caretaking dyad of mother and child by supporting them through 'taking some of the load off mother's shoulders since there is an already conceived role division between parents. HAR (41, 15 year-old son, accountant), for example, exemplified this process when he described how decisions are made within the household and following passage is important in the way that it will shed light on this process as follows:

*“Honestly, mother has more responsibility in house since she stays at home. Generally, we are in supportive position. We cannot be in decision-making process since she is the one struggling more. Whatever she needs, I support from outside. I cannot speak up my mind since she is already psychologically worn out. That is why she has more impact in every decision we make. She is in harder position because she has all the load piled up on her. It is like taking care of I-don't-know-how-many-child to take care of one child with ASD. I cannot dare to ask for anything extra unless it is something trivial.”*

What HAR was saying is that he does not ask for anything extra from the mother since he took over the mission of not being a burden for the mother. For other fathers along with HAR – total of six fathers, this mission was also accomplished by taking the child to his/her special education classes and/or to outside activities to socialize and create vacancy for the mother. Even then, what fathers should do was guided by mothers in five of the nine fathers. Father OGU (45, 12 year-old son, hairdresser) used the term “minister of interior” to illustrate the extent that he

relies on his wife in the sense that he follows her instructions rather than having initiations for child's ASD related requirements.

In the rest of the three fathers' families, this structure had not been prominently observed because fathers either were; a) working from home and that gives them the edge to be more involved with child-caretaking and building a sound relationship with the child, and b) father was more "resilient one" in their current situation; consequently, even when they did not work from home, they performed two roles as if they were working "two shifts" one in household and the other is outside.

#### 2.2.4. Impact on Family Life - Theme 8: Estrangement of Relationships

This last theme, which was mentioned in six fathers' interviews, described the processes in which they estranged from their families and immediate social environments. This experience generally concerned with social support while the family take care of their children with ASD. The estrangement process had different motivations and impacts on fathers per se as well as on their lives in more general sense. For example, among six fathers who described an estrangement, five of them described an experience where they are left alone or isolated by others, while for one father it was a deliberate choice since the social support they received from their family does not meet up to their expectations. In the passage father ADN (40, 10 year-old-son, engineer) described, his family's and friends' reaction to their child being diagnosed with ASD and its aftermath is given as an example:

*"As people learned about the handicap, most of them did not stand by our side. First they say we are going to heal your child and become a family and then you see that you are left alone as parents in this process. Everyone support when you are healthy, but no one is there when you are not. We became isolated. This was not caused by us. People*

*isolated themselves from us. We are alone to be exact ... We could not go to movies for the last 5 years. We have no one to leave the child. Even when we do, we are concerned leaving him behind ... Imagine living with your mother-in-law in the same building and she is not being able to tolerate what taking care of our child demands. When you look at, he [the son] is her daughter's child."*

The aftermath of their situation left them with inability to socialize and spend time in the absence of ASD due to lack of social support from family and/or friends. The reason for people to put a distance leading to an estrangement and isolation from environment is explained by father LEV (47, 25 year-old son, architect/designer):

*"When people see that our child's behaviors and communication of the child is restricted, people start hesitating to get in contact even though no matter how educated and loving people they are. This creates a distance. After a certain age [of the child], you face with an attitude everywhere as if you are with a plague ... Since we have so much to bear, people do not want to share our burden; as in the spiritual sense, not only financial burden ... People do not want to become your burden-sharing partners, even if they are your family, aunt, uncle or sibling..."*

LEV explained how spiritual burden of caretaking of the child with ASD aside with financial burden combines into estrangement of immediate social circle in relation with their children symptomatology. The distance occurring in the relationships impact family life in terms of isolating family members and lack of social support.

### 3. CHAPTER E – DISCUSSION

This qualitative work has studied the experiences of fathers raising a child with ASD from a systemic perspective, exploring the question of whether the fathers are affected by

experience of ambiguous loss in relation with their increased stress levels. If their elevated stress level was due to their experience of ambiguous loss, whether this stress is related with changes in their family structure was another question of concern. In relation to that, main research questions were: a) What are the stress generating factors in relation with ambiguous loss? b) What are the changes occurring in the family structure in relation with ambiguous loss?

Before describing fathers' experiences of ambiguous loss, it must be clear that what is being lost in ambiguous loss. According to family life cycle theory of families, each family have different developmental needs moving forward through the time in their family cycle (McGoldrick, Preto & Carter, 2015). Birth of the child, growing-up of the child, leaving the child corresponds to developmental stages that families experience in this journey. Their developmental needs in these stages prompt families to follow series of structural changes such as broadening, retracting or realigning relationship patterns within the family. Many of the difficulties families face aligns with these transition periods.

In families with ASD, as one father described, their life is stuck at a specific developmental stage, mostly at the having a child. Here, their children might physically grow, but their family life cycle mostly do not change as they cannot move from one to another. Even though families might have the expectancy of their children growing up, leaving the house, get married and have their own kids; now they have a life-time of a child in most cases. The fact that these families cannot move forward through developmental stage in time, the development in its normative sense is now lost. Even though families have children, the lost normative sense of moving forward complicates the process and thereby, obscures the loss.

In order to see this process, nine fathers who have been raising a child with ASD were interviewed with a semi-structured method. The interview questions were generated based on

ambiguous loss theory in order to understand how ASD is related with increased stress in fathers and their changing family structure. The interviews were transcribed and analyzed with thematic analysis method and the analysis yielded two super-ordinate themes consisted of eight themes and 18 subthemes.

In this chapter, the results presented above are going to be discussed in order to elaborate on the research questions by examining 9 themes and their related 10 subthemes. What is found with regard to themes are going to be explained within line of current literature, by providing both supporting and refuting evidence from research. Also, how these findings make meaning based on the theory of ambiguous loss are going to be explained in detail. As the research question suggested, the stress generating factors for fathers and how family structure is impacted by increased stress are going to be referred to the theory of ambiguous loss in this part. It is expected to enable the readers with an overall framework regarding the individual and family functioning from a systemic perspective by referring to novel and existing findings.

### 3.1. First Super-Ordinate Theme: Process of Acceptance

#### 3.1.1. Process of Acceptance – Theme 1: “Konduramama”: Strain to Accept ASD

“Konduramamak” in this theme captured the strain that fathers generally experienced during the earlier times of their children’s journey of ASD. Since an exact translation of this experience was not found in the English language, Turkish name was kept as the situation is explained as fathers straining themselves to accept their children have something different than other children. This strain was mainly related to the fathers’ either denying and/or ignoring the fact that their children has something different than other children as well as trying to minimize the importance of either their children’s symptoms and their long term consequences. This was

due to several reasons including lack of knowledge, elderly in the family persuading parents that peculiarities were normal and/or ignoring the signs because it was distressing for the fathers.

As mentioned earlier parents who had a formal diagnosis for their children with ASD, reported feelings of shock, denial and even clinical depression which are also shared characteristics of feelings of loss and grievance (Altiere & von Kluge, 2009). This is thought to be due to the change in the dreams and hopes built for the child into new expectations based on new information. As a result, the situation of “konduramama” as a difficulty for fathers might be thought as a difficulty in emotion regulation that is associated with the loss because prior expectations of fathers are going to subject to a thorough accommodation. This finding brought another perspective to the idea of denial comparing to the prior body of research.

According to Boss (1999), denial is one of understandable reactions when there is ambiguity around the loss. By denying, minimizing, calling others to stop exaggerating and struggling not to see what others see in their children, fathers try to ease themselves from the negative impact of contemplating on the worst case scenario. In doing so, fathers find a chance to remain hopeful in the beginning processes of ASD. Even after diagnosis, as they became more knowledgeable with the disorder, they might succumb immediately to accept the disorder. In doing so, they had a time interval in order to get used to the idea. As a result, “konduramama” helped them stall in order for them to regulate the intense emotions that arouse with the diagnosis. In a way, it is an adaptation process to the newly emerging emotions. This process is eased by accompanying hope of fathers that an alternative explanation is possible; therefore, it helped them with ambiguity that came with the diagnosis around their loss.

Other research has put forward another claim for this situation. In a qualitative study conducted among 24 Palestinian mothers, a theme emerged by reports of 16 mothers indicating

that they were either unfamiliar with ASDs prior to diagnosis and/or misunderstood the diagnosis (Dababnah & Parish, 2013). Of the fathers in the current study three out of eight reported that they did not know anything about ASD prior to the diagnosis. This research informing the process of “konduramama” provides an alternative explanation for a possible cause of denial. However, the fact that study was conducted with only mothers might make it harder to draw conclusion for paternal context.

### 3.1.2. Process of Acceptance – Theme 2: Incomprehensibility of ASD

This theme emerged out of the experiences of fathers trying to assign a meaning and/or provide an explanation to their children’s situation by constantly struggling to reveal a cause of disorder or trying to dichotomize it as either a bodily or mental disorder. The fact that the cause is unknown for ASD makes it harder for the fathers to experience a sense of mastery in which they feel control over their situation. This was evident by the discourses of some fathers reporting a wishful thinking of a desire for their child to have apparent and/or well-known disorder such as cancer or mental retardation. They would have still a disorder or diseases; nonetheless, they would know the reason or classify it as bodily or mental.

Boss (1999) stated that “lack of mastery over one’s life increases not only perceptions of helplessness but real helplessness” in the long-term ambiguous losses. Considering that having an ASD diagnosis is reported to be the most stressful period in which families with a member of ASD had experienced in their lives (Kuhn & Carter, 2006), it is longitudinally demonstrated that parenting stress hinders perceived mastery during parent-child interaction in families with typically developing children (Farmer & Lee, 2011). For families raising a child with autism, parental self-efficacy is shown to be moderating the impact of child problem behaviors on



fathers' anxiety (Hastings & Brown, 2002). Fathers who have higher sense of self-efficacy were less stressful in the face of child problem behaviors. Fathers who did not have the chance to increase their perceived self-efficacy in the domain of knowing what caused the disorder were more likely to experience helplessness and despair due to the ambiguity around the nature of the disorder. Our results also confirm these findings where fathers who report a lack of mastery over their children's ASD reported signs of distress in their lives.

How others reacted to their situation was another hardship for fathers under this theme. The way others treated and responded during their interactions with their child were identified as social factors that perpetuated the paternal stress as well as lack of clarity regarding their situation. This phenomenon was also identified in other qualitative studies with fathers. For example, in one study, researchers found that because there might not be a physical manifestation of the disorder with ASD, children's problem behaviors were seen as a result of bad parenting (Neely-Barnes, Hall, Roberts & Graff, 2011). Being labeled as a "bad parent" can be stress-inducing due to its negative connotations. Even though none of the fathers expressed a fear of being labeled, the idea of conflict with the others were the main reason their increased stress. This can be partly related with the fact that lack of ASD awareness in the society. Instead of fighting endless fights with others, some fathers adopted alternatives such as using humor in public with their childrens symptoms.

In terms of ambiguous loss, the outcome heavily relies on attributions regarding the situation. Boss (2006) indicated that attributions coming from the community may have more impact than the attributions of the individual or the family. The fathers reported being blamed for spoiling their child or as if they lacked the ability to parent their child when the children acted out or showed stereotypies in the public. Four fathers who have developed positive relationships with

their neighbors were grateful for their neighbors' understanding throughout the whole process they went through with their child. After all, it is not possible to develop positive relationships with the community unless the community validates fathers' situation as traumatic as is.

### 3.1.3. Process of Acceptance – Theme 3: Receiving Proper Education

Many fathers accentuated different types of concerns, criticisms, and hardships regarding their children's treatment in the post-diagnostic process. These obstacles on the way to receive proper education-as-treatment ranged from financial considerations to more systematic issues such as governmental policies, quality of education, and training processes. While problems regarding the former can be dealt by fathers as a result of their personal endeavor of trying to increase their income or by familial support, problems regarding the latter remained as more chronic and harder to impact.

Tissot (2011) in their study collected opinions of parents and local authorities regarding their experiences of either receiving or providing educational services in England. For the parent part, the results obtained through questionnaires showed that despite parents chose to send their children to local government-assisted facilities, this was primarily because of their financial motivations rather than a thinking of what is the best for their children. This result is in line with the current study. Fathers sent their children to government-assisted training as it is free for a certain amount of classes per month. Those who chose to use private centers complained about the income-driven policies. Even though the parents reported that admission to schools were bureaucratic and stressful, according to Tissot (2011); no fathers reported such an experience in the Turkish context. On the contrary, one father shared an anecdote in which he shared his

gratitude for the Ministry of Education regarding the way they handled a complaint he delivered about a special education center.

The dilemma that the many families dealing with ambiguous loss face can be exacerbated by the wrong-doings of officials in the larger systems. The ambivalence around the ambiguity caused by two opposing sets of emotions about whether they should keep trying to improve their children's situation or leave it altogether, can be intensified in an environment where they struggle to receive a high-quality education. From this point on, father's insistence on the quality of education and pushing the governmental authorities to do more can be seen as a creative way of solving a situation that seems unresolvable. By doing their best, they aim for their children to achieve their best. The underlying process of ambivalence as stress-increasing paternal factors is explained more in detail under the theme of "Impact on Couple Relationship".

#### 3.1.4. Process of Acceptance – Theme 4: Emotional Processes

Having a child with ASD elicited a range of emotions among fathers including anger, despair, and helplessness. Towards receiving the diagnosis and afterwards, the fathers reported miscellaneous emotions. However, based on the reports of many, these were shared experiences among the fathers regardless of their background.

##### 3.1.4.1. Subtheme 401: Feelings of Guilt

Immediate reaction of many fathers as they learned that their child has ASD was to look for who is responsible whether it is themselves or anyone in the family. Most of the time, seeing themselves as the cause of the disorder in a self-accusatory manner was distinguishable. For example, the fathers reported observing similarities between themselves and their children's personality or behaviors. At times, the fathers were inclined to load the guilt onto some other

member in the family such as their wives or relatives, similarly by observing similarities or remembering some patterns specific to ASD.

A number of qualitative and quantitative studies provided mixed results compared to this finding of the current study. For example, in one study fathers had the tendency to either blame their wives or to blame their external family members (Neely-Barnes, Hall, Roberts & Graff, 2011). Our study has confirmed this finding partially. While there were three fathers that explicitly reported that they blamed their wives, majority of the fathers reported blaming themselves. In another study, Pisula and Kossakowska (2010) compared two groups of 26 fathers and mothers of children with typical development and children with ASD. The findings showed that the parents of children with ASD tended to self-blame, as they experience more parenting stress and lower sense of coherence in their lives. But, the other group that have child with typical development have no such tendency.

According to the ambiguous loss theory (Boss, 1999) how people view the world has an impact on the meaning they assign to their ambiguous loss (Boss, 1999). Those who have a just-world view tend to tolerate ambiguity worse than those who do not. Believing in a just-world mean that if adversity happened, it is only because one deserved it or because it was their fault. One possible explanation underlying the fathers' self-blame may be holding such a view, however we did not measure their world view in the current study. In addition, while it is a common experience for people feel a need to allocate guilt in times of traumatic events, self-blame can be dysfunctional if it leads to immobilization (Boss, 1999). For example, rumination as a reaction of immobilization indicates a lack of closure which inhibits grief. In the current study, after a certain period of time the fathers neither blamed themselves and nor blamed others. The fact that, they were no longer in search for someone to place the guilt on indicates a

resiliency and not an immobilization; therefore, even though feelings of guilt stressed them out in the beginning of ASD process, it became irrelevant as they coped well with ambiguity.

#### 3.1.4.2.Subtheme 402: Pendulum of Hope

There was an evident pattern in the interviews with the fathers in this study that they experienced hope and hopelessness intermittently, much like a pendulum swinging. On the one hand the fathers were hopeful as if their child was going to recover by “taking a miracle pill”; consequently, this hope motivated the fathers to do anything to improve their children’s symptoms at the expense of their physical and psychological sources. Seeing that little or no improvement took place at the expense of disproportionate sources spent on the child led to hopelessness. Then, as the fathers managed to regulate the downward spiral of hopelessness, they were again able to receive satisfaction from taking care of their child or cherishing the tiniest accomplishment their children made. Once again, they felt hope before their next episode of hopelessness. Going back and forth between the two ends of this hopefulness-to-hopelessness-spectrum, the fathers reported mixed feelings due to raising a child with ASD.

Post-traumatic stress disorder (PTSD) and ambiguous loss are not identical traumatic experiences. Long-term consequences of ambiguous loss can give rise to symptoms such as anxiety, depression, guilt or dissociation which are shared by symptoms of PTSD. The distinguishing factor for ambiguous loss is conceptualized as a roller-coaster model of family stress by Boss (1999). The name captures the alternating nature of ambiguous loss in which the families had ‘up’s where they feel hope and ‘down’s where they feel hopelessness throughout the processes. Since what is lost is not always clear for fathers when they learned that they are going to raise a child with ASD probably for the rest of their lives; repeated exposure to this prolonged

and gradual loss regarding the situation of their children creates a roller-coaster type of stress. They had both hope and hopelessness regarding their children's situation and it may be traumatizing in the long run.

This phenomenon is also found in other studies. In a qualitative study, Broderick (2009) found that the parents of children with ASD discursively positioned hope in opposition of hopelessness. The researchers reported that the parents represented autism as a hopeless and tragic event and the only hope in the situation was inextricably linked with the desired end that comes with ultimate recovery. This is also parallel to the reports of the four fathers in the current study when they talked about their devastation upon learning their children's ASD.

However, at the end of the day, fathers needed to balance between the two extremes in the roller-coaster of emotions. This process is called "family gamble" as the ultimate that a person can reach whilst experiencing ambiguous loss (Boss, 1999). In the current study the family gamble was actualized between the two extremes of "hope" and "hopelessness". Fathers need a position that will make them stay motivated for doing what they can do for their children and keep believing that their child will eventually get better, yet their despair in remaining times would not interfere with their daily life routines and caretaking. After all, people can choose to act out on two extremes: hope as if nothing is lost and hopelessness as if everything is already lost. However, these two extremes might not be functional because the reality in everyday life is far from that. This required fathers to find a point in which they can merge extreme versions of hope and hopelessness. In other words, fathers needed to gradually let go of their otherwise-imagined child, while at the same time, keep their present child that is diagnosed with ASD.

#### 3.1.4.3.Subtheme 403: Concern for the Future

Most fathers explicitly described an overall concern regarding their child's condition in upcoming years. Fathers were contemplating on how long they are going to be able to meet their children's needs. It is related to the fathers' concerns on "...will I be around?" Underlying this motive, fathers were implicitly concerned due to uncertainty whether they have enough time to teach their children to live independently. This implicit anxiety is evidenced by fathers second type of concern in which they are contemplating on whether there is going to be anyone around such as a sibling, external family member or facility residents to take care of their children's vital needs in their absence.

In a study by Pisula and Kossakowska (2010) families including fathers and mothers of children with ASD were found to score lower in their sense of coherence compared to families with typically developing children. Sense of coherence was defined in three levels one of which was the manageability of their situation. Families of children with ASD were found to score lower on manageability because their confidence was less in terms of their resources to meet the necessities of their situation. Moreover, no gender differences were found. Therefore, fathers' constant concern for the future was shown elsewhere in the literature too.

According to the ambiguous loss perspective, the impact of uncertainty around the losses can pile up (Boss, 1999). So, the expected life transitions (i.e. children becoming adults and leaving the house as they find a partner in life and getting married) or unexpected life transitions (i.e. diseases, disorders, divorces) can add on to one another. Considering the ASD diagnosis as an unexpected life transition early in life, it will certainly require the fathers to adjust themselves with a series of following unexpected life events such as their children's ability to earn money, leave for college, and get married. Their adjustments prior to the diagnosis is to be re-adjusted. Moreover, this is an adjustment process with lack of confidence regarding the future for their

children in an atmosphere of uncertainty. Even though the future is not certain for many parents, those who do not know what to expect or hope from the future of their children might be especially preoccupied with the thought of the future, with the hope to decrease ambiguity surrounding their loss.

### 3.1.5. Process of Acceptance – Theme 5: Making Peace with ASD

This theme converges the experiences of the fathers where they were able to figuratively “make peace” with their inner conflict concerning their children’s situation. The resistance that comes with “yakıştıramama” – strain of acceptance for their children’s condition, was ameliorated in many fathers. There appeared to be two types of reality for the fathers to accept. Firstly, fathers were able to accept their child without denying, ignoring or minimizing the disorder in any way. Secondly, fathers were able to accept the ambiguity that comes with the unpredictable prognosis of the disorder. The fathers who were able to accept uncertainty around ASD were more resilient – able to show flexibility in the face of uncertainty surrounding ASD.

Neely-Barnes, Hall, Roberts and Graff (2011) reported that mothers of younger children with ASD hope to “cure their children’s autism” as opposed to mothers of older children with ASD who switched to “learn to live with autism”. In their study the fathers were also included yet it was not clear how inclusive this theme was for the fathers as well. This process is also indicated as the goal for individuals dealing with ambiguity. Boss (1999) invites individuals and families to find a way to change to learn to live with ambiguity. At this point, the process of family gamble is the mean for families to position themselves at a gradation on the spectrum of hope and hopelessness. Considering that the loss is irretrievable in ASD, changing their expectations about the ongoing course with ASD may provide the fathers with an acceptance of the disorder into their lives as opposed to fighting with it in order to fit it to their prior



expectations. At the end of this process, fathers did not change the fact that their children are with ASD, but they did change what to expect along the way.

Among those father who were able to make peace with their children's ASD, some common themes also manifested. These themes were not the stress increasing factors for fathers; on the contrary, they were the stress reducing factors. Following themes are thought to ease and facilitate the process of acceptance among the fathers of children with ASD.

#### 3.1.5.1.Subtheme 501: Increasing the Knowledge of Disorder

Increasing their knowledge regarding ASD provided the fathers with an increased sense of mastery over their situation. This happened mainly because the fathers were able to foresee and prepare themselves to the necessities of the disorder as they re-shaped their expectations for their children. This helped them come into terms with their situation and facilitated their acceptance process. This process was either initiated by fathers themselves or aided by their views. Regardless of that, the initial process of increasing knowledge serves as a psycho-education for fathers and increased resilience.

In the literature, lack of information is reported to be a contributing factor to the stress reactions given to the ASD diagnosis as the fathers were faced with the fact that the hopes and expectations are to be re-built (Meadan et al., 2010). In relation with that, the confusion based on lack of information hindered fathers' ability to cope with this process effectively.

This type of psycho-education for the fathers is helpful because it releases them from guilt, mostly self-blame. The reason that the fathers blame themselves is likely because they think they have done something wrong or something is wrong with them. Learning about the disorder helps the fathers to become free of these thoughts by internalizing the idea of not all bad

things happens due to their wrong actions or due to something wrong with themselves. By breaking the cycle of self-blame that is fed by that type of linear thinking through increasing knowledge, fathers reported being better able to be comfortable with the discomfort that arouse with the ambiguity in this study.

#### 3.1.5.2.Subtheme 502: Reframing the Situation

Reframing is a therapeutic technique used in order to create a shift in the perception of individuals concerning a situation, event, or relationship through assigning them a new meaning (Clark, 2014). In the study, the fathers accomplished forming reframes through focusing on their children's personal strengths as well as the positive impacts that ASD brought into their relationships and lives. This shifted their perception of their children's situation from a pessimistic (e.g.: helpless, deficient, despair) to a more optimistic view (e.g.: hopefulness, a gain, strength) since it helped to elicit new meanings. A situation in a brighter light facilitated fathers' acceptance of their situation.

The qualitative study by Bayat (2007) had identical findings with these findings. They reported that most families did attribute positive meanings to their children's disability as well as gaining a sense of growth mostly a year after the diagnosis. Parallel to these results, in the current study many fathers also reported that they were more sensitive and helpful to people and incidents around them and cherish smaller accomplishments with more positive regard to life in general. Transforming a component of a situation that is not likely to change is also a creative way of dealing with ambiguity. Not knowing what to expect from the certain loss can push individuals and families to transform their expectations of their situation. This is realized by fathers focusing more on the components that could be easily neglected by most and turn them into something to be cherished.

### 3.1.5.3.Subtheme 503: Solution-Orientedness

Many fathers reported to be more invested in the solution rather than the problem itself. While their personal motivation showed great variability involving avoiding arguments or avoiding feeling upset; the underlying process was the preservation of their sources such as time and energy. Considering that children with ASD requires constant caretaking, they chose to invest their mental energy to solve the problems that their children might encounter throughout the day.

This is also shown in other qualitative research with the fathers. Gray (2003) reported that most common two coping mechanism regardless of the sex of the parents were: a) planning a reasonable solution beforehand, b) dealing with the problems subsequently as they occur. However, the fathers reported to engage in solution-focused coping more than mothers did. Even though the fathers' solution-focused coping was reported to be useful in dealing with the stress, the strategies they embraced in the current study were not homogenous enough to collect under one theme; therefore, they were not reported in the findings. However, dealing with problems as they occur was one of the forefront strategies reported by a couple of fathers.

Principles of family gambling (Boss, 1999) can apply to the fathers' use of solution-focused coping during the process of acceptance of their children's situation. The fathers who were able to find a balance between extreme hope and hopelessness experienced fluctuations in their balanced emotional states in relation to the day-to-day variability of their children's condition. Becoming closer to the negative side of the two extremes would be understandably painful for the fathers. Igniting hope in order to return from painful experiences of hopelessness is a protective and rightfully defensive mechanism. As a result, keeping their focus on the

solution facing in the direction towards hope can be considered as one of the stress reducing factors most fathers shared.

#### 3.1.5.4.Subtheme 504: Maintaining Stability

Despite fundamental changes have occurred in the fathers' lives as they learned that their children have ASD, some type of ritual helped them cope with their stress for many. Stability provided by the rituals included a wide spectrum ranging from having weekly family dinners or family trips to cherishing and maintaining a strong personal bond that is revisited regularly. While rituals helped the fathers with a sense of normalcy as they were still connected to their lives before the diagnosis, it also provided them with a sense of control over their lives that they had restricted control on. As a result, a situation that is normal and controllable became easier to accept rather than the contrary.

Psychiatrist deVries (1996) define rituals as “mechanisms that allow individuals to reorganize their often catastrophic reactions to losses” (p. 401). These processes enable individuals to make meaning out of their experiences even when they face extreme challenges. Moreover, individuals who are able to process such experience can experience ‘posttraumatic growth’ in which they have an increased personal strength that is likely to benefit others as well (Tedeschi & Calhoun, 2004). Considering that long-term impacts of ambiguous loss can mimic the impacts of PTSD, having a ritual in their lives that can help maintain their sense of normalcy can temper long-term traumatic impacts of ambiguity for the fathers.

Even though ambiguity of the loss can lead people to be immobilized since it freezes the grief processes, stability as an “immobile” factor leading to decrease in stress among fathers might seem counter-intuitive. One goal for people experiencing ambiguous loss is to break out of

the immobility response. However, stability, as opposed to numbness, can be a dynamic and effortful process to maintain; therefore, people experiencing ambiguous loss can break loose of their immobilization response as they move forward within the mist of ambiguity. As a result, their demand on stability decreases through time (Boss, 1999) and spontaneity that will allow them to come up with novel coping methods.

#### 3.1.5.5. Subtheme 505: Attributions to Something Greater

When there is an ambiguity regarding the cause, fathers knowingly or unknowingly attributed it to higher-order cause of their situation. This cause was generally spiritual such as “life”, “existence” and “faith”, while more rational attributions such as “luck” or “possibility” were also mentioned. However, it does not mean that fathers embraced these causal attributions as the primary explanation. All fathers were knowledgeable enough of the etiology of ASD. They firstly embraced the etiology as a partial explanation of the disorder. The remaining gap, “grey area” as one father named it, was filled with indefinite concepts as indicated above. Since these are the ultimate explanations, it eased externalization of the cause and helped with the acceptance.

Other studies also indicated that parents of the children with ASD experience their situation as a meta-experience. According to Bayat’s (2007) findings, the indefinite concepts that are indicated above are regarded by families of children with ASD from a philosophical stance, indicating a sense of unity and/or an in-group identity. In the current study, even though indications of developing an in-group identity was found in four fathers, this was not listed as a theme.

The fact that the fathers made such attributions can be considered as an indication of their acceptance of ASD. While most fathers blamed or considered blaming themselves in the earlier

times of their post-diagnosis period, turning their blame into an external higher-order seemed as more functional than the former. Making such attributions when dealing with the blame caused by ambiguity is a way of making meaning in itself. This sort of meaning-making seemed to be helpful for the fathers. Spirituality was also found to be helpful for families dealing with ASD in terms of finding meaning and guidance in life (Plumb, 2011).

### 3.2. Second Super-Ordinate Theme: Impact on Family Life

#### 3.2.1. Impact on Family Life - Theme 6: Shaping the World Around ASD

Fathers of the children with ASD were cognizant of how post-diagnosis process have impacted their lives structurally. They explained re-structuring their lives in order to make life easier for their child as well as themselves. In this process, families reported an experience that can be called over-identification with ASD. This is due to ASD being a disorder that requires high maintenance and not leaving space for anything else in the families' lives.

This theme was parallel to the findings in the literature. The findings under this theme were explored under different terms such as 'family participation' or 'routine structuring'. DeGrace (2004; as cited in Boyd, 2014) highlights the situation where the world is shaped around the child with ASD, sometimes at the expense of priorities for the rest of the family. In their case study, referring to the same phenomenon of prioritizing the child when building up family routines, Larson (2006; as cited in Boyd, 2014) unveiled the reason for that as the inflexibility of the children as a result of ASD. Similarly, Marquie et al. (2011; as cited in Boyd, 2014) concluded that sticking to the routine as a result of inflexibility of the child, increased the structure of family routine which helped the child in return.

The earlier definition of identity ambiguity referred to a situation of enmeshment between the child and the caregiver. However, identity ambiguity can also impact relationships by a seizing the various identities of the family members (Boss & Greenberg, 1984). In the current study, those fathers who undertook various responsibilities in different domains of their children's lives started to have more permeable boundaries between their identities and their children's needs. Most fathers were both working outside the home as well as when they were home. They were the parents, bread-winners, caregivers, friends and sometimes special educator to their children. At the end, most components that made up their identities subsided into the ASD. That signifies a state of enmeshment between individual identities of the fathers and ASD. Since ASD requires extensive care and labor, those fathers who cannot able to open space for other identities than the ones subsided into ASD have their lives shaped around shaping ASD.

### 3.2.2. Impact on Family Life - Theme 7: Impact on Couple Relationship

This theme is going to be discussed combining two subthemes of emotional turmoil and positive emotional shifts. While some families were gravitated into an increased conflict situation, some others were able to ascend out of it reporting increased feeling of intimacy. Those fathers who reported deterioration in their relationship attributed this to increased conflict, decreased quality of communication and intimacy. The dominant discourse was lack of couple time that they were able to share with each other. However, some fathers reported that they were already in a loving relationship and that ASD only made them feel more intimate with each other. Those fathers stated that it was due to their relationship already being built in a solid ground and their gratitude to their wives in terms of their support for caretaking of their children.

Ambiguous loss and emotions have an intrinsic relationship. The word "ambiguity" means absence of clarity. In ambiguous situations, emotions may display ambivalence. The term

“ambivalence” refers to conflict situation among rationality and emotions. As mentioned in the concept of “roller-coaster of emotions”, ambivalence may cause conflicting thoughts, feeling and emotions to emerge either subsequently or all at once (Boss, 2006). That means a person who is in a situation of ambiguity as in the case of ASD, may feel and think many things that may be in the opposing direction towards a particular person. As a result, increased stress caused by the ambivalence of the feelings and/or thoughts may impact father’s couple relationships miscellaneously in the short and long term.

The impact of ASD on the couple relationship can follow three trajectories in relation with the ambivalence caused by ambiguity around the loss (as reported in findings, see the graph 1). The reason trajectory c) (i.e. have never experienced anything conflictual in couple relationship) did not come up as a theme might be due to fathers’ concern of their privacy. However, for those who experience conflict, especially in the beginning process after the diagnosis, might experience ambivalence towards their situation. Fathers may feel anger towards their wives since they look for someone to blame but at the same time they might feel love, gratefulness and relief since they know their wife will take care of their children or support them in the process. On another level, fathers may feel ready to undertake the extra responsibilities of caregiving role to a child with ASD, while on the other hand, they might experience moment where they find it overwhelming and suppress an urge to abandon it all and leave. Since it might take time to learn to tolerate and live with the discomfort caused by ambivalence, based on how well couples can tolerate stress of the conflicting perceptions and emotions might be a determining factor of their relationship trajectory.

The literature about relationships for couples raising a child with ASD presents evidence with regard to both deteriorating and empowered relationships between the fathers and mothers.



Hock et al. (2011) in their qualitative study conducted with 9 couples and one mother, reported stages of relationships that is highly similar to this study. Their findings suggested that ASD pressured couples to adapt to a new status quo in their relationship. This pressure firstly led couples to change their expectations from their relationships and they become more of a parents rather than couples. In the last stage, it is reported that couples started to create time and space for each other to share and understand each other to provide spousal and emotional support. Moreover, Myers et al. (2009) also reported that couples experienced both marital and couple strain as well as enrichment at different points in their marital lives. In another study by Garcia-Lopez et al. (2016), actor-partner meditation model unveiled that relationship satisfaction mediated couples' dyadic coping and their adaptation to parenting. Moreover, focusing on more positive dyadic coping strategies were more effective than engaging in negative dyadic coping behaviors (Sim et al, 2017). These results are significant since it provides a quantitative evidence for both Hock et al.'s study as well as the current study.

Brobst et al.'s (2008) study highlighted that couples raising a child with developmental disorder and typical development do not differ in terms of perceived support, even though the former group has lower relationship satisfaction. This finding is contradicting with Hartley (2017) covered in the literature review. As opposed to their finding that couples experience relationship stress primarily because of their negative affect during daily communication, the results of the current study conducted with fathers favors Brobst et al rather than Hartley.

### 3.2.3. Impact on Family Life - Theme 8: Father as an Outside Support System

This theme focused on how family life is impacted in terms of family structure. The data inferred that relationship between mother and children gradually become closer in the ways that will inhibit fathers to be cognizant of the interaction taking place in mother-child dyad. The

process explained here can also be regarded as the boundaries between mother and child is less permanent as opposed to boundaries that are more open between the couple. Even though those families who perceived themselves more enmeshed reported an increased self-efficacy in coping with their situation (Altiere & von Kluge, 2009), this lead to a family structure where primary caregiver role of mother is supported from outside by fathers who work in jobs outside the home. This is also evident for six fathers affirming their wife spend more time than they do. This way would help families maintain the status quo in a more pragmatic and traditional sense.

Moreover, fathers needed to give up their position in their couple hierarchy as a part of their supporter role of mother-child dyad. At the same time, this means fathers being stripped away from their spouse role. As a result, while the mother and father would function within the former couple subsystem, they are now can better function at the parent subsystem. Role division here is actualized in accordance with the families' prior needs. As long as roles and identities are distributed organically (i.e. not having a certain degree of convergence with other's perspective), a transition from a former normal to a new normal would surely create ambiguity and ambivalence around the question of "who is who in this family?". This theme would therefore be considered as a contributing factor to fathers stress level through the boundary ambiguity in families with ASD.

Even though no study directly put forward such finding in literature referring to this theme, there are study concerning division of responsibilities in families that can provide an indirect explanation. A more traditional role division is also mentioned in the Hartley (2014). Mothers are more actively involved in child care, when fathers' participation is through the paid work. In the study, in contradiction with their hypotheses, this type of arrangement is found to be linked with increased stress for fathers. In another study that reported similar findings, it is also

reported that mothers staying at home taking care of primary work for the child is enabling these established pattern of role division (Ogston-Nobile, 2014). These findings provide evidence for fathers being a secondary support directly to their children and indirectly to mother-child dyad. Considering that being an outside support to family might function as a way to release stress by having another identity that is based on paid-work, it might also increase work load and stress levels of fathers. In our study, fathers agreeing on either of these arguments were existent. This point whether fathers having an outside support to their families increase their stress level or not is currently unclear.

#### 5.2.4. Impact on Family Life - Theme 9: Estrangement of Relationships

Most of the fathers described an extinguishing relationship with their external family members and immediate social circle. For most, this was experienced as a social isolation which left them with restricted social, financial and emotional support. Fathers and nuclear families tended to rely on their own resources. Even though Blankenship (2015) study provided almost identical findings in terms of themes emerged out of their data, getting and perceiving support from extended family members were the only theme that differed from the current study. The reason that findings of two studies give conflicting results from each other could be due awareness of ASD at a societal level. The families in Blankenship (2015) study attributed the reason that they felt supported mainly because of they though “the stigma of having a child with autism-it’s probably not even there anymore”. It can be put forward that ASD needs to be further recognized in society. Fathers in the study also give voice to this concern making remarks on some TV shows that lately being aired on Turkish TV channels such as “Miracle Doctor”.

The concept of “psychological family” is an important aspect of ambiguous loss. It is defined as the family residing in mind as opposed to “physical family” that we are connected

through blood or legally related. According to Boss (1999), it has an utmost importance to have a degree of overlap between the two concept in order for an individual to function. As long as one can be certain that someone is going to be there in times of need is an intrinsic reaction that lessens ambiguity. However, especially in times of ambiguous loss, the knowledge regarding the overlap between psychological and physical families can also become blurred. This is explained as underlying mechanism leading to boundary ambiguity.

The reason that boundary ambiguity is related with estrangement of relationships with families of fathers is because it is hard to make sense. The beliefs of those external family members who should be the bearer of ambiguity around the loss are shaken fundamentally. The reason for that is because they are also reminded that the world may not always be just and rational because an ambiguous loss is hard to make sense of. Even though some families were well-intended, they did not know how to act or help around the child with ASD. Other external families avoided or refused to even talk about the child with ASD to the extent that will break off the relationship to the fathers. Regardless of the cause, ambiguity of the loss around ASD hindered fathers' relationship to others around, leading to an increased incoherence between their physical and psychological families and increased stress of not feeling supported.

The studies also report that parents of children with Asperger's require more social support (i.e. from family, friends and other sources) than their typically developing counterparts (Heiman & Berger, 2008). While structural models showing the relationships between perceived social support decreased depressive symptoms and overall well-being for mothers (Benson, 2012), other research showed that mothers and fathers differ from each other in terms of perceived support. It is shown that mothers perceive more family and friend support than fathers (Altiere & von Kluge, 2009). It is most likely because fathers generally tend to use strategies

providing regulation of emotion such as going to work or being solution oriented by suppressing emotions (Gray, 2003).

Similar results were also found in other qualitative research in terms of estrangement. It is suggested that parents of children with ASD experienced social isolation (Myers, 2009). The experiences that give rise to this theme was restrictions on preferences for socializing, losing immediate social support circle and negative reactions from environment. This experiences were also identical with our current study. What is intriguing is that these families could still feel isolated even though they are supported by their immediate social circles, even though social support help them alleviate couple problems (Dunn, 2001). This can be explained as social support and feelings of estrangement having a complicated relationship.

### 5.3. Clinical and Policy-Making Implications

This study explored whether having a child with ASD can create stress in fathers' lives as a result of the ambiguous loss. Within that, boundary and identity ambiguities were seen as processes observed in fathers and in their families. The findings showed that ASD can be seen as an ambiguous loss and this can generate stress in and of itself in fathers' lives. Consequently, it may be necessary to come up with solutions that can be integrated into therapeutic work, especially targeting fathers. Seeing ASD from an ambiguous loss perspective and acknowledging it as a loss that is surrounded by the mist of unknown can provide professionals with many advantages working with the effects of ASD with the fathers and their families. First and foremost, presenting this situation as ambiguous loss would help fathers to normalize their situation because it provides a rationale of their personal strains. Learning that other people also deal with conflicting emotions or obscured thoughts regarding their situation may be beneficial normalizing their reactions; consequently, the feelings release coming from acceptance of their

situation as a whole would free them from their personal stress. This would be the base that the therapeutic work is built upon.

Moreover, structural family therapists can help with fathers and their families with an array of tasks. As with the entrance of ASD into the life of the families, those families can be coached into new roles and routines. For example, the findings showed that fathers reported they had to shape the world around ASD. In times of adapting to arrangements necessary for their children for ASD new routines might be required. Another example could be worsening couple relationship due to not knowing their newly engaged roles or identities in the couple and parent subsystems. This might also require redistribution of roles and reconstructing identities. Most of the time, as some of the fathers also indicated, these changes would take place organically, without communicating with each other. However, using ambiguous loss as a phenomenon to externalize their problem as if it is not each other that is the problem, but ambiguity itself is the problem would also help to open space for necessary work to be conducted.

Therapists can also help families develop a social support system and facilitate relationships of families to their service providers. As the findings suggested many fathers experience estrangement and they have hard time getting proper education with their provider. In such cases, the family therapist can intervene to the relationship to the obstacles that is blocking the flow of social support or services. For example, working with the external family expanding the family system to reinforce the relationships that weakened as a result of ambiguous loss. Also, enabling the flow of information with the education provider in terms of families' needs and translating the information received from the provider could help maximize the benefit by decreasing dysfunctional perceptions towards the education system and increasing functional adaptations to their difficult emotions.

The findings in “Receiving a proper education” can prompt authorities to act accordingly with the needs of families with ASD. Developing a standard for the expertise of educators that work with groups with special needs and following-up their standard practice through repetitive examination system might provide a grip on the overall special education system. Also, the trainings given to educator team in primary and secondary schools can be more refined in terms of creating a more welcoming atmosphere for fusion classes. These should also be reinforced with complementary law and regulations that ensures the stability of such regulations within overall Turkish education system. “Autism Action Plan” as a law ensured many of these regulations and it is passed from the parliament in 2016. Prosecution of the law would make sure that many problems that are reported under this theme reach to a conclusion.

It is also reported that families with ASD experience a concern regarding their children’s and their future. A solution to this problem would be to create nurseries for people with ASD that will take care of them after their relatives are no longer be able to provide them with their lively necessities. Also, considering that families with ASD have increased levels of stress that is associated with situation, they would benefit largely from an external official support system that would be in assistance of them regularly. These finding can urge authorities to take necessary actions pursuant to social state principles.

#### 5.4. Limitations

The results of this study are not suited for generalization to a larger population due to the chosen qualitative method. The constructivist nature chosen to carry out the thematic analysis decrease the studies generalizability. The narratives that are collected for the purpose of extracting information belong to a very specific group; and therefore, their experiences are quite personal. Moreover, qualitative studies are generally conducted with small number of

participants. With small sample size, it is expected to have thicker and richer data of a smaller group, rather than larger groups. Considering these factors, generalizing the results of this study with other populations would be misleading since the experiences of other groups and underlying processes are different.

Second possible limitation might be due to alliance building with the fathers during the interviews. Considering the sensitive nature of the topic, it would be understandable for some individuals to find sharing details about themselves disturbing. Time allocated to building alliance with fathers has to be fairly short due to reasons concerning practicality; and therefore, they might not feel themselves secure enough to disclose their vulnerable emotions in front of a stranger. It must be taken into consideration that some fathers might not sharing their experiences with total transparency and choose to hide some content for themselves might impact findings considerably.

The type of research that is proposed in this paper requires researcher to be aware of their personal biases. Considering the researcher as the main instrument of research along with mentoring of an expert, researcher's personal way of seeing the raw data guides the results. At this point, results might be reflecting personal biases, beliefs or assumptions of the researcher rather than what the data suggests. Not being able to ensure credibility at a certain extent on that regard might be the third limitation.

Most of the interviews were conducted within a setting in which fathers may not feel completely comfortable such as a public café. Even though quiet and peaceful indoor spaces are preferred, it would provide more transparency to conduct interviews within a home setting. But for many fathers, concerns regarding child interrupting the interview was valid. Practical issues such as transportation was another obstacles dealing with this limitation.



### 5.5. Future Directions

Several reasons that hindered fathers' ability to accept their children's ASD were identified. Even though possible reasons are also identified in the overall literature regarding masculinity and manhood surrounding the role of fatherhood can be further understood specifically for Turkish context. The research conducted for this subject is based on more individualized cultures (see Axup, 2012). Considering that Turkish culture is thought to be more of a collectivistic society (Hofstede Insights, 2020), the meanings attached to fatherhood, manhood and parenting is likely to be different than those in highly individualized countries.

Moreover, in terms of shaping the life around the child with ASD might require further investigation in the same line of research. While it is also observed that families in individualistic culture prioritize their child's, the motivations underlying that could differ from each other. It would be necessary to differentiate whether the necessity to prioritize the child is about meanings attached to parenting (i.e. exerting all effort into parenting) or whether it is rooted in problems in bureaucratic processes (i.e. lack of social state understanding).

The needs of families in terms of socialization and having their children get a better special education can also be helpful in order to create more targeted interventions and develop regulations (i.e. Autism Action Plan). "What are some of the things that bothered families with ASD when they socialize in public places" was one of the questions in my mind as a researcher while I conduct the interviews. Likewise, "What are some of the needs that experts can pinpoint facilitating families' relationship to their service providers?" was another question that awaits to be answered for the Turkish context.

Future research should also include quantitative and qualitative research on fathers' emotional coping more in detail. Whether the individual factors or more dyadic factors within the

relationship help father deal with the stress of raising a child with ASD can be elaborated. While resiliency factors are identified, how they interact within couple relationship can also be another point of concern.

The current literature provides mixed results in terms of whether working in a job outside home help fathers alleviate with stress functioning as a buffer; or increasing their stress by increasing their vulnerability diathesis.

It is also mentioned that social support that families receive and the extent that they perceive they are being supported by their immediate environment has a complicated relationship. Possible factors explaining the discrepancy between social support and how well it is perceived as support can also be further explored.

#### 5.6. Conclusion

This qualitative study portrayed a picture of how ASD have an impact on fathers' personal, couple and family accounts in terms of their stress. The thematic analysis revealed two super-ordinate themes: process of acceptance and impact on family life.

Process of acceptance included 5 themes and 8 subthemes: 1) "konduramama": straining self to accept ASD; 2) incomprehensibility of ASD; 3) emotional processes, 3a) feelings of guilt, 3b) pendulum of hope, 3c) concern for future; 4) receiving proper education, 5) making peace with ASD, 5a) increasing knowledge of disorder, 5b) reframing the situation, 5c) solution-orientedness, 5d) maintaining stability, 5e) attributions to something greater.

Impact on family life included 4 themes and 2 subthemes: 6) shaping the world around ASD; 7) impact on couple relationship, 7a) emotional turmoil, 7b) positive emotional shift; 8) father as an outside support system; 9) estrangement of relationships.

Ambiguity around the loss that comes with ASD increased paternal stress during the process of acceptance of ASD. The father were reluctant to accept the diagnosis at first. Second, despite their willingness to learn, ASD was beyond their –and anyone else’s- comprehension. This situation create powerful emotions such as guilt, constant hope and hopelessness and future anxiety. Not being able to get an education they aspire for their children also add upon their stress levels. Despite all, by increasing their knowledge, changing their perspective, being solution-oriented, maintaining stability in life and make sense of what happened according to themselves; fathers were able to accept their children is with ASD and they are going to live with ambiguities surrounding this situation.

Moreover, ASD impacted families lives through the fathers. Fathers started to exert their power to adjust the life according to their children. While doing so, from the beginning of the diagnostic process on, they had couple problems of different level of importance. Some of the simpler couple problems were resolved for the better within the couple and more complex problems is remained stable. Independently, families go through a structural changes in which fathers relinquished from their positions in the couple hierarchy and have the role of support for mother-child rapprochement. As family and fathers, they had deteriorating relationships with people surrounding their immediate environment.

These suggest ASD can elicit a form of ambiguous loss in experiences of fathers raising a child with ASD. This form of ambiguous loss can increase stress level of fathers, even though fathers can learn to live with this special form of loss throughout their lives. Ambiguous loss is also impacted their families through boundary and identity ambiguities blending the boundaries between in- and out-of-family as well as identities of the members of families, respectively. Then again, families did learn to achieve homeostasis through extending their resiliency.

Overall, the two super-ordinate themes seem to have relationship with ambiguous loss. They both seem to converge at the point of what is lost in ambiguous loss: a sense of normalcy in its more traditional sense. In the first super-ordinate theme of process of acceptance, each theme can be seen as a layer of loss that pile up on one another. With each layer of loss, families diverge from their normal family life cycle experiences. The impact of these themes leads the changes in the family life in the second super-ordinate theme. Even though there is an ASD-driven change in the family structure, boundaries between what is lost and what is remained from the sense of normalcy is obscured. Even though many typically developing families can experience ambiguity around their family structure, these changes would still be predicted and expected. The impact of ambiguous loss on life cycle of families' with ASD can be a distinguishing experience for many families with ASD because it is unexpected. Eventually, it can be said that fathers raising a child with ASD experience a personal and relational stress that is related with ambiguous loss.

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## APPENDIX A: Informed Consent Form

Dear participant,

This research is conducted by Özyeğin University Couple and Family Therapy graduate student Psychologist Burak Savcı and Assistan Professor Senem Zeytinoğlu-Saydam and Associate Professor Nilüfer Kafesçioğlu. This research aims to investigate the experiences of fathers with a child diagnosed with autism. There is no right or wrong answer in the study. What we want from you is that you try to express yourself as clearly as possible.

This study is carried out for scientific purposes. The data collected during the study will be evaluated anonymously and no names will be used at any stage of the research. Each participant will be given a code name and that code name and data will be collected. The results will not be matched with your personal information, and no personal evaluation will be made as a result of the research. The information and data in the research will only be known to the researcher and will be kept in the researcher's encrypted computer and locked office.

Participation in the study is completely voluntary. Your right not to sign this form and participate in the study is reserved. Even if you sign the form, you can stop working when you feel uncomfortable.

At the end of the research, your experiences will be gathered under certain themes and you will be contacted via e-mail to get information about whether these themes reflect your experiences.

For more information about the study, you can contact Burak Savcı (e-mail: burak.savci@ozu.edu.tr). If you have questions, problems or suggestions regarding the ethical aspects of the research described in this form and / or research details, please contact Özyeğin University Ethics Committee on (216) 564 91 76.

At the end of this meeting, if you think you need support, you can contact Özyeğin University Couple and Family Center (ÖZÜÇAM) by phone (549) 810 86 25 or via Bilgi University Psychological Counseling Center (PDM) or pdm@bilgi.edu.tr or (212 ) You can contact by calling 311 76 74.

I have read the details of the above mentioned research project and my questions about this project have been answered. I agree to participate in this study voluntarily.

Name-Surname	Date
E-mail	Signature

#### APPENDIX B: Demographic Survey

- 1) Your age: \_\_\_\_\_
- 2) Your marital status:
  - Married  Single  Divorced  Other (Please specify: \_\_\_\_\_)
- 3) Your profession: \_\_\_\_\_
- 4) How would you describe your monthly income level, the range it is located in?
  - 2500 <2500  2500-3500  3500-5500  5500-7500  7500 >
- 5) Your educational status (the last school you graduated from):
  - Primary School  Secondary School  High School  University  Master
- 6) How many children do you have? Indicate by number: \_\_\_\_\_

7) When did your child get diagnosed with autism? Specify the time, in numbers: \_\_\_\_\_

8) Your child who is in the treatment process:

a) Age: \_\_\_\_\_ b) Gender: \_\_\_\_\_

10) Does your child have a serious health problem other than autism (eg. heart disease, epilepsy, etc.)?

Yes  No

9) Did you have psychological treatment experience for your child during the treatment process?

Yes  No

10) Did you have any psychological medication experience during your child's treatment?

Yes  No

11) Have you joined a support group or association with your child diagnosed with autism?

Yes  No

12) Did you have a relative who has been diagnosed with autism before?

Yes  No

13) If your answer to the previous question is yes, indicate your relation with this person:

\_\_\_\_\_

## APPENDIX C: Interview Guide

Autism = A

Ambiguous Loss Question = AL

Family / Systems Question = F / S

- 1) How did autism enter your life? When and how did you get the diagnosis? (A)
- 2) What did you think and what did you feel after getting the diagnosis? (A)
  - a. How was the process of getting the diagnosis and how was it after you received it?
  - b. How have your feelings and thoughts changed since you got the diagnosis?
- 3) What did your family members react positively / negatively during this process?
- 4) What was your role as a father in this process? (A)
- 5) There are many different explanations about the causes of this issue. What do you think caused this situation? (A)
- 6) How would you describe your own child to me? (AL)
- 7) How do you spend time together? (AL)
  - a. How much are you involved in the care of your child (food, cleaning, treatment, transportation, material)?
  - b. Who decides this period, how?
  - c. Are these different from what you want it to be? Would you like it to be more / less?
- 8) How was your relationship with your own father? In what ways is this relationship similar / different to your relationship with your own child? (AL)

- a. Do you have any information about your father's relationship with his father?
  - b. How would this affect you positively / negatively if your child had not been diagnosed with autism?
- 9) Who comes to your mind when you think of “family”? How was your family positively / negatively affected by this process? (F / S)
- a. What difficulties did you encounter in this process? How did you overcome them as a family?
- 10) How did you have a child with autism affect your relationship with your spouse positively / negatively? (F / S)
- 11) How are decisions taken at home? How are responsibilities at home divided? (F / S)
- 12) Who supports you when you encounter difficulties and how? (F / S)
- 13) What advice would you give to other fathers whose children have just been diagnosed in this process? (F / S)