

**NEAR EAST UNIVERSITY**  
**GRADUATE SCHOOL OF SOCIAL SCIENCES**  
**CLINICAL PSYCHOLOGY**  
**MASTER'S PROGRAMME**

**MASTER'S THESIS**

**INVESTIGATION OF THE MOTHERS OF CHILDREN WITH AUTISM  
SPECTRUM DISORDER IN TERMS OF CAREGIVING BURDEN, DYADIC  
ADJUSTMENT, PERCEIVED SOCIAL SUPPORT, EXPRESSED EMOTION,  
LIFE SATISFACTION AND POSTTRAUMATIC GROWTH**

**Güliz ÇETİNBAKIŞ**

**NICOSIA**

**2017**

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POSTTRAUMATIC GROWTH**

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**NICOSIA**

**2017**

**DECLARATION**

**APPROVAL PAGE**

## ABSTRACT

### INVESTIGATION OF THE MOTHERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER IN TERMS OF CAREGIVING BURDEN, DYADIC ADJUSTMENT, PERCEIVED SOCIAL SUPPORT, EXPRESSED EMOTION, LIFE SATISFACTION AND POSTTRAUMATIC GROWTH

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January, 2017, 167 pages

Examination of mothers who have children with autism spectrum disorder in terms of multidimensional perceived social support, dyadic adjustment, expressed emotions, burden of care, life satisfaction and posttraumatic growth.

**Purpose:** This study is conducted to evaluate the burden of care, dyadic adjustment, multidimensional perceived social support, expressed emotions, life satisfaction and the level of posttraumatic growth of mothers having children with autistic spectrum disorder (ASD), and to determine the factors influencing burden of care and life satisfaction, to examine the relationship between burden of care and the percentage of the child's disability, dyadic adjustment and posttraumatic growth.

**Material and Method:** The research which is descriptive and relationship-seeker was made with the mothers who have children with ASD and studying in Bursa Autistic Children Education Center and Special Education and Rehabilitation center. The research group established by mothers (S=62) who have children with ASD in the age range 4-21 and mothers (S=60) who have children with Normal Development (ND) in the age range 1-26 as the control group. Data were obtained using the Socio-Demographic Form, Zarit Caregiver Burden Scale, Dyadic Adjustment Scale, Multidimensional Perceived Social Support Scale, The Level of Expressed Emotion Scale, Satisfaction With Life Scale and Posttraumatic Growth Scale. In addition to the mentioned scales, Autism Behavior Checklist has been implemented to mothers who have children with ASD in order to determine the level

of their children's ASD. Statistics of the resulting data was made by using frequency distribution, mean, variance, regression and correlation analysis.

**Findings:** It has been found in research that mothers who have children with ASD have higher levels of expressed emotions and burden of care, while mothers who have children with ND have higher levels of life satisfaction and multidimensional perceived social support. There was no difference between dyadic adjustment and posttraumatic growth.

There's a positive relationship between burden of care and disability percentage of children with ASD and their expressed emotions; a negative relationship between disability percentage of children with ASD and subscale of post-traumatic change in perception of self; a negative relationship between multidimensional perceived social support and expressed emotions.

**Results:** Multidimensional Perceived Social Support that mothers who have children with ASD perceive is in a negative relationship with burden of care, dyadic adjustment and positive relationship with life satisfaction. Multidimensional Perceived Social Support systems are important for increasing the quality of life of parents who have children with ASD psychological, social and emotional support systems and units can be provided for parents who have children with ASD.

**Key Words:** *ASD, Mother, Burden of Care, Dyadic Adjustment, Expressed Emotions, Posttraumatic Growth, Perceived Social Support, Life satisfaction.*

## ÖZ

### OTİZMLİ ÇOCUĞA SAHİP OLAN ANNELERİN BAKIM YÜKÜ, ÇİFT UYUMU, ALGILANAN SOSYAL DESTEK, DUYGU DIŞAVURUMU, YAŞAM DOYUMU VE TRAVMA SONRASI GELİŞİMİ AÇISINDAN İNCELENMESİ

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Ocak ,2017, 167 sayfa

**Amaç:** Araştırma Otizm Spektrum Bozukluğu tanılı çocuğa sahip annelerin bakım yükü, çift uyumu, algıladıkları sosyal destek, duygu dışavurum, yaşam doyumu ve travma sonrası gelişim düzeylerini değerlendirmek, bakım yükü ve yaşam doyumunu etkileyen faktörleri belirlemek, bakım yükü ile çocuğun engellilik yüzdesi, çift uyumu ve travma sonrası gelişim ile ilişkisini incelemek amacıyla gerçekleştirilmiştir.

**Materyal ve Metot:** Tanımlayıcı ve ilişki arayıcı tipte olan araştırma Bursa Otistik Çocuklar Eğitim Merkezi ve Özel Eğitim ve Rehabilitasyon merkezlerinde eğitim gören ASD’li çocuğa sahip anneler ile yapılmıştır. ASD’li 4-21 yaş aralığındaki çocukların araştırmaya katılmayı kabul eden anneleri (S=62) ile kontrol grubu olarak normal gelişim gösteren (NGG) 1-26 yaş aralığındaki çocukların anneleri (S=60) araştırma grubunu oluşturmuştur. Sosyo-demografik Form, Zarit Bakıcı Yükü Ölçeği, Çift Uyumu Ölçeği, Çok Boyutlu Algılanan Sosyal Destek Ölçeği, Duygu Dışavurum Ölçeği, Yaşam Doyumu Ölçeği ve Travma Sonrası Gelişim Ölçeği kullanılarak veriler elde edilmiştir. ASD’li çocuğa sahip annelere sayılan ölçeklere ek olarak çocuklarının ASD düzeyini belirlemek amacıyla Otizm Davranış Kontrol Listesi de uygulanmıştır. Elde edilen verilerin istatistikleri yüzdelik dağılımlar, ortalama, varyans, regresyon ve korelasyon analizi kullanılarak yapılmıştır.

**Bulgular:** Araştırmada ASD’li çocuğa sahip annelerin bakım yükü ve duygu dışavurumu, NGG çocuğa sahip annelerinkine göre daha yüksek, yaşam doyumu, algıladıkları sosyal destek düzeyi ise NGG çocuğa sahip annelerinkine göre daha

düşük bulunmuştur. Çift uyumu ve travma sonrası gelişim düzeyleri arasında fark bulunamamıştır. Bakım yükü ile ASD'li çocuğun engellilik yüzdesi ve duygu dışavurumu arasında pozitif bir ilişki, engellik yüzdesi ile travma sonrası gelişim kendilik algısındaki değişim alt boyutu arasında negatif bir ilişki, algılanan sosyal destek ile duygu dışavurumu arasında negatif bir ilişki olduğu belirlenmiştir.

**Sonuç:** ASD'li çocuğa sahip annelerin algıladıkları sosyal desteğin bakım yükü, çift uyumu ile negatif ve yaşam doyumu ile pozitif bir ilişkide olması, ASD'li çocuğa sahip olan ebeveynlerin yaşam kalitelerinin artmasında sosyal destek sistemlerinin önemli bir yeri olduğu sonucundan yola çıkılarak ASD'li çocuğa sahip ebeveynlere yönelik psikolojik, sosyal ve bilişsel destek sistemlerinin ve birimlerinin oluşması sağlanabilir.

**Anahtar Kelimeler:** ASD, Anne, Bakım Yükü, Çift Uyumu, Duygu Dışavurumu, Travma Sonrası Gelişim, Algılanan Sosyal Destek, Yaşam Doyumu



*Kızım Begüm'e*

## ACKNOWLEDGMENTS

To be the mother of an autistic child is so difficult to understand just like understanding autism itself. First of all, I want to thank the mothers of children with autism spectrum disorder, who live the most special and difficult kind of motherhood, mothers with healthy children who participated with all the sensitivity when they learn about the purpose of the research. I would like to thank them for the support and patience.

I am very grateful to my precious adviser Assoc. Prof. Dr. Gülbahar BAŞTUĞ who provided all the support and contribution throughout the academic working process, have contributed to my research with patience and guidance, made me feel the importance and sensitivity at every stage of my research, always encouraged me and gave me the opportunity to progress on the “Autism Spectrum Disorder” issue. Thank you so much to Assoc. Prof. Dr. E. Tuğba Özel Kızıl for supports to our work and sharing information and support. I want to thank you to my thesis jury Assoc. Prof. Dr. Ebru ÇAKICI and Assist. Prof. Dr. Zihniye Okray for their participation and valuable contributions. Thank you to Nurdan Akçit, İpek Tadır Kızılloluk and Hazal Işık who were always by my side and empowering me with energy throughout all my graduate education. I am very thankful to many teachers and principals in Special Çekirge Doğa Anatolian School who supported me in the preparation of the thesis. I want to thank warmly to my mother Fecriye Güner who is always there for me in my educations, has infinite trust to me, every moment we feel each other's support, my father Erkan Güner who is the person I care about his appreciation, always directs me further, gives me moral support to take big steps and stay strong in life; my older sister Assoc. Prof. Dr. Deniz Ulusarslan who is always an example for me, gave me ideas the process of preparing the thesis; my little sister, very special person to me, Lawyer Yeliz Koçak who is always next to me in every difficult moment; my dear husband Kaya Çetinbakış, I feel his infinite support in every moment of my life.

I didn't know what my daughter experienced and the importance of what I experienced myself about it when I set the topic of my study as ‘autism spectrum disorder’. Being a mother of a child with autism spectrum disorder means being very busy. I want to thank you so much to my beloved daughter Begüm Çetinbakış for giving me permission and support because I used some of time to this study which

normally I spend with her. I could not live the most beautiful form of motherhood if Begüm wasn't next to me.

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## LIST OF ABBREVIATIONS

- *ABC*-autism behavioral checklist
- *ASD*-autism spectrum disorder
- *BC*-burden care
- *DA*-dyadic adjustment
- *DAS*-dyadic adjustment scale
- *EE*-expressed emotion
- *EES*-expressed emotion scale
- *LS*-life satisfaction
- *SLS*- satisfaction with life scale
- *SWLS* Satufaction With Life Scale
- *ND*-normal development
- *PSS*-perceived social support
- *MPSSS*-Multidimensional perceived social support scale
- *PTG*-posttraumatic growth
- *PTGI*-posttraumatic growth inventory
- *SS*-social support
- *ZCBS*-Zarit caregiver burden scale

## 1. INTRODUCTION

### 1.1. Preliminary Information

The family is the smallest unit of society and children are the most important part of the family. Each parents dream about their unborn child beyond the expectations of being healthy while in the process of bringing a baby into the world and make plans about how their life will be for themselves and their babies. If baby born with different characteristics than expected, it may cause deterioration of parent's plans for themselves and their babies.

While providing a new order is a source of stress by itself, experiencing the shock, denial, guilt and help-seeking efforts after the first diagnosis of disease is almost same in all family, but short or long duration of the process ending with acceptance varies for each family.

Family's learning that they have a disabled child is the beginning of a difficult process, a situation that brings important responsibilities and a traumatic life event because of feeling the sense of loss for them. New responsibilities of disabled child and care burden arising from lack of self-care are being concentrated on family, especially on mother. This may affect the mother's mental health, relationship with other family members and social environment, level of life expectation, feelings and development as an individual due to traumatic situations.

Temporary or permanent illness or disabled of one family member affects compliance of all member (Yörükoğlu, 1998) (Visually handicapped, hearing impaired, mentally disabled or physically disabled etc.) (Cited: Çakan and Sezer, 2010:163).

Autism Spectrum Disorders (ASD) defined as neurodevelopmental disorders is a disability with inadequacy in many areas. ASD is defined as a neuro-psychiatric disorders that start early in life and life-long, delay and deviation in social relationships, communication, behavioral and cognitive development. Şenol (2007:778-800), any child with ASD is not identical in terms of the specifications of ASD. Parents are faced with a series of behavior which are quite difficult to define (Darıca, Abidoğlu and Gümüşcü, 2011:145-149)

Families of children with ASD carry the concern of how they will act upon their children or in which direction their children will affect their life.

In this study, firstly ASD's definition will be made. In the following section, the definition of duty of care, dyadic adjustment, multidimensional perceived social support, expressed emotion, life satisfaction and posttraumatic growth that are thought as important in this issue will be explained and the relationship between children with Autism Spectrum Disorders and these variables will be given.

## 2. LITERATURE REVIEW

### 2.1. ASD

The first years of life of a newborn baby are a period where the fastest changes and developments are happened, and also the most intense period for the parents' relationship with their child. Sometimes, due to the inexperience of the parents, delays in child's development and changes are not recognized by parents and it may be the most important issue. Development takes place in four areas as cognitive, physical, emotional and social progress. Any positive or negative effects in these development areas also affect other areas. Stages of development as having crawled in ninth month, putting a few cubes in a row in the fifteenth month and learning to speak a few words in the eighteenth month is the sign of maturation of brain sections associated with these functions. Seeing these signs relax parents and specialists (Kayaalp, 2000: 3-4).

When something goes wrong, the suspect of difference occurs. These differences that direct families to specialists can be faced them with the reality of having a baby with ASD. ASD is a disability that occurs within the first 3 years of life and ongoing lifelong (Korkmaz, 2005:1).

There are some skills expected from every child during certain months and years. If the child is fall behind them, growth deficiency or development delay is concerned. Growth deficiency may be in various sections.

Even though the causes and forms of developmental delay are various, this delay in ASD is recognized firstly by not seeing communication (language) and relationship building skills (social) timely and appropriately. Today, many diagnostic systems are used for the diagnosis of ASD. The common feature of these systems emphasizes that there must be a lack of ability in three field to put ASD diagnosis.

These fields;

1. Disorders in communication and social development areas,
2. Repetitive, limited interests and behaviors,
3. Seeing these disorders before 30 months.

### **2.1.1. History of autism spectrum disorder**

Autism word was firstly used by Eugen Bleuler to explain the thought disorder as the clinical symptoms of schizophrenia with an aim to define isolating one self from outside (Cited: Bekiroğullari, Gülşen and Soytürk, 2011:638-653).

Autism is defined as a disease in 1943 by psychiatrist Leo Kanner and he has taken this term from Bleuler (Korkmaz, 2005:1). As a result of Leo Kanner's clinical evaluations made in 11 children, the symptoms of autism have been identified as showing no interest to other people, resisting the unusual order and impairment of language function. Kanner has used the autism word to identify these children as living off communication and the symptoms of autism has been associated with schizophrenia disease and defined as childhood schizophrenia.

According to Kanner, the characteristics of children with autism,

Repeating self-directed verbal expression often and in the same way, using personal pronouns reverse as "you" instead of "I" and delay in expressive language,

- Having a very good memory
- Limited self-initiated behaviors,
- Stereotyped movements (likewise repeated rapid movement sequence) or demonstrating extreme devotion to movements,
- Protection request for identity,
- Having difficulty in the communication with people,
- Having interest for inanimate objects (Darica et al., 2011:17-20).

Viennese pediatrician Hans Asperger also defined the diagnosis of autism independently and simultaneously from Kanner in 1944. Asperger's definition is based on abnormal behavior seen in adults. These,

- Odd in social relations,
- Not capable of empathy,
- Less verbal communication,
- Speaking compatible with grammar but with unusual intonations,
- Repeating the same activities,

- Suffering from getting out of the routine,
- Having special interest area,
- Having the memorization ability but having difficulties in understanding abstract ideas,
- Awkward people.

Asperger gave the name of autistic personality disorder to these people's behavior (Turan, 2000).

Bernard Rimland (1964) was indicated for the first time that Autism is a different disease about brain (Korkmaz, 2005:1). In 1977, Susan Folstein and Michael Rutter have made studies about twins to uncover the genetic basis of autism and provided new information about the causes of autism (Kırcaali-İftar, 2007, Cited: Aygen, 2011).

It was not noticed for a long time that autism was different from other psychotic disorders of schizophrenia and adult psychiatry. Diagnosis limits was clear first in 1980 and it took place under the Pervasive Developmental Disorders (PDD) title in Diagnostic and Statistical Manual of Mental Disorders (DSM-III) of American Psychiatric Association classification (Öztürk and Uluşahin, 2011: 744-744). The term of infantile autism was used first time for the behavior appeared before 30<sup>th</sup> month during this period (Cited: Tan, 2007)

In DSM-IV-TR published in 2000 Siff Exkorn (2005), autism has been usually placed under PDD with the heading of disorders diagnosed in firstly infancy, childhood and adolescence; it took place as Autism Spectrum Disorder (ASD) in DSM-5 (2013) under the heading of neurodevelopmental disorders. While PDD diagnosis was firstly being used as diagnosis in the clinical evaluation in 1980, the diagnosis of autism is being used today (Cited: Özkaya 2013:127-139). Autism spectrum disorder (ASD) term is also used in academic literature. DSM-5 criteria for ASD was extensively evaluated in a study made by Huerta et al. (2012, 1056-64) and recognized as the latest and largest study until now. As a result, according to DSM-IV-TR, it is seen that 91% of children with clinical diagnosis of PDD continue to receive diagnosis according to DSM-5 criteria.

### **2.1.2. Symptoms and diagnostics**

ASD is defined as neurodevelopmental disorders which is inborn and showing itself in the first three years of life with disparate clinical symptoms, having delays and inadequacies in social, cognitive, communicative development area and chronic (Öztürk and Uluşahin, 2011:747-749). Problems in ASD are common and in different areas. Firstly, it is recognized with the lack of social and communicative development. It begins early and affects every stages of life (Volkmar, Lord, Kin and Cook, 2002: 587-587).

According to DSM-5 criteria of American Psychiatric Association (2013), autism has been involved in ASD under the neurodevelopmental disorders. According to DSM-5, ASD shows itself by restricted and repetitive behaviors, interests and activities with deficiencies in social interaction. It is a disorder that cannot be explained by general developmental delay whose symptoms are shown in early childhood and caused problems in daily life (DSM-5, 2013).

While children with ASD have different properties and behaviors from children with normal development, it is also noted that all of the children with ASD are not showing the same characteristics and same behaviors (Darica et al., 2011:33-35).

It is known that children with ASD show lack of social interaction have delays in language development, limitations in cognitive development, differences and delays in motor development, unusual behaviors and difficulty in properly play (Bernad-Ripoll, 2007:100-106; Charlop-Christy and Daneshvar; 2003:12-21; Landa, 2007:16-25; Simpson and Myles, 1998: 149-153 Cited: Öncül, 2015).

Children with normal development are born with many skills. It is seen that some deficiencies and delays have seen in children with ASD. Lord and Ward, (1993), Researchers and clinicians are agreed on the belief of some symptoms of ASD-specific abnormal development begin 30 months ago. It is also seen that the research carried out in recent years are focused on whether there is a potential to determine the ASD in earlier periods (Cited: Bodur and Soysal, 2004:395-398).

It is observed that ASD infants are in two types of behavior. The first one is constantly crying and being in bad temper, the other is calm and spending all day in bed unresponsively (Darica et al, 2011:34). The most obvious other symptoms are severe disorders in communication and social interaction skills. One of the earliest symptoms draws attention in mimicking and development of gesture (Korkmaz, 2005:5).

While a child with normal development (ND) can mimicking even the simplest behavior, the ability to mimic is not developed in a baby with ASD. There are also problems in the use of gestures. They cannot play mimicking games played in infancy and even the very simple gestures as “bye-bye” are not seen on them. Parents understand that there are some differences in their child with the disconnection experienced in communication, not doing the simple mimics they want to teach, not giving a crying response to meet their needs, uncertainty in eye contact, not reacting to objects that are in their interest and giving different responses to sensual contact.

Although it is claimed that results will be issued by watching the video recording of very small babies with ASD according to the characteristics of movements, studies on this issue are not reliable (Korkmaz, 2005:5).

Some problems may be in the definitive diagnosis of children showing symptoms of ASD behavior. This may be caused by ASD's similarities with others in learning, communication and behavioral disabilities. ASD's being a disability that cannot observed frequently causes specialists not to meet with enough situations that reveal the differences between this syndrome and related deficiencies and this situation brings difficulties in diagnosing (Darica et al.,2011:24-25).

There is no standardized scientific method or biologic survey used for the definitive diagnosis of ASD, but there are some certain behavioral diagnostic criteria. The diagnosis is made based on the information of detailed developmental history received by family and observing the behavior of children with ASD systematically (Korkmaz, 2005:7).

There are also problems about early diagnosis. The reason for this is the emergence of ASD-specific symptoms in the later years of children. Therefore, it is necessary to wait for a definitive diagnosis (Korkmaz, 2005:14).



The diagnostic criteria used in ASD are the criteria adopted by DSM-5 (American Psychiatric Association, 2013), ICD (International Classification of Diseases) and WHO (World Health Organization). These criteria are accepted in research and studies made by specialists on ASD. The following table is giving the detailed ASD criteria according to DSM-5;

**Table 1.Diagnostic Criteria of DSM-5 for Autism Spectrum Disorders**

A. According to the information received from the story or at that moment, deficiencies show themselves with the following things and continue in social communication and social interaction with variants;

1. The lack of socio-emotional reciprocity for example, abnormal social approach and non-dual conversation, not sharing feelings and interests, not initiating social interaction and entering the social interaction.

2. The lack of nonverbal communicative behaviors used for social interaction for example, verbal and non-unified communications failure, informality in the ordinary eye contact and body language, lack of understanding and using the hand-arm motion, facial expressions and non-verbal communication.

3. The lack of building, maintaining and understanding relationships for example difficulties in adjusting the behavior according to different social environments, challenges to making friends and sharing imaginary game, having no interest to peers.

B. According to the information received from the story or at that moment, restricted, repetitive patterns of behavior, interests or activities characterized by at least two of the following;

1. Stereotyped actions or kinetic repetitive actions, object usage or speech (For example simple kinetic stereotyped patterns of behavior, sorting toys, resonance and unique sayings)

2. Resistance about being same, not showing flexibilityout of mediocrity, ritualized verbal or non-verbal behavior (For example, extreme distress against small

changes, experience difficulties in the transition, rigid thought patterns, ritualized greeting behavior, want to go the same way and eat the same meal every day)

3. Unusual intensity and focus, extremely limited and non-variable interests (For example, excessive attachment to unusual things or struggle with them, severely limited or obsessive interests)

4. Reacting at very high or low level against the sensory input or showing an unusual interest in the sensory side of environment (For example indifference against pain / heat, adverse response against some specific sounds or tissues, excessive sniffing to objects or excessive touching to the objects, fascination from light or motion)

C. Symptoms should be started in the early development stages (social requirements may not exactly represent itself until it exits on the limited competence)

D. Symptoms cause clinically significant deterioration on social fields or other functional areas.

E. These disorders cannot be explained better with intellectual disability or general development delays. Intellectual disability and disorder under the expansion of autism often occur together. For diagnosing disorder under the expansion of autism and intellectual disability, social communication should be less than expected compared to the general level of development (DSM -5, 2013).

It is stated that the level of needed support may differ according to the level of individuals diagnosed with ASD disease and ratings will be based on the needed support (Cited: Özkaya, 2013:127-139, DSM-5, 2013). The severity levels according to the needed support of individuals with ASD are seen in the following table.

**Table 2. Severity Levels for Autism Spectrum Disorders**

Severity Levels	Social Communication	Limited, Repetitive Behaviors
Third Level “It requires substantial support.”	Severe deficits in verbal and nonverbal social communication skills cause severe impairment in functioning, initiate social interaction in a very limited way and show very little response to the social relationship-building approach. For example, people who use only a few words that can be understood, start interaction very rarely and only responsive for direct social approach.	Not showing flexibility in behavior, extreme difficulty in the face of change or other limited/ repetitive behaviors significantly impairs functioning in all areas. They have a great difficulty in changing the focus and actions.
Second Level “Significantly requires support.”	Severe deficits in verbal and nonverbal social communication skills, social disturbances can be seen even support. They show very little reaction or unusual reactions to the social relationship-building approach. For example, a person who speak with the simple sentence and have limited interaction with special interest.	Not showing flexibility in behavior, extreme difficulty in the face of change or other limited/ repetitive behaviors occur frequently that can be seen by casual observer.
First level “Requires Support.”	Lack of social interaction cause visible defects if there is no support. There is difficulty to initiate social interactions. Their interest against social interaction seems very little. For example, a person who is incapable of conversation and unsuccessful attempts to make friends.	Not showing flexibility in behavior, causes considerable deterioration in functionality. They face with difficulties between events. Editing and design problems prevent independence.

(DSM-5, 2013)

### **2.1.3. Clinical presentation in ASD**

When we look at the literature about ASD, it is stated that characteristics of children with ASD are different from each other and they do not show same characteristics and behavior. There are several behavioral characteristics used to identify ASD, but usually all these features are not available in people with a diagnosis of ASD and usually not seen at the same time (Korkmaz, 2005:1-2)

The symptoms of ASD are located in three main groups:

1. Disorders in the development of social relations,
2. Disorders in verbal and nonverbal communication,
3. Obsessive, repetitive behaviors, restricted interests (Korkmaz, 2005:1-2).

Rutter and his friends summarize four main points for children with autism as a result of the evaluation by taking into account all aspects related to autism. Rutter and Lockyer (1969). These;

1. Frequency of occurrence of autism observed before 30 months.
2. A significant delay in children's speech and language development is in question.
3. A deficiency not associated with mental development but related to social development is in question.

Insistence on sameness and reaction to changes are among the prominent behaviors with stereotyped game skills (Darica et al., 2011:19).

#### **2.1.3.1. Sensorial properties**

In terms of sensorial properties, children with ASD react differently to be touched and aural, visual, painful, hot and cold stimulants compared to children with ND. Children with ASD have different reactions to sounds. Their reactions to sounds change between no reaction and overreaction (Darica et al., 2011:36). Kanner (1943) explained that many of his cases overreact against specific sounds such as lift, vacuum cleaner and wind. In early childhood, children's unresponsiveness to sounds makes the parents suspicious and it directs them to the implementation of a hearing

test. When something is said, children with ASD create the impression like they don't hear it (Bodur and Soysal, 2004:394-398).

They don't look at human faces and the objects around them; however, they look to the moving or rotating objects for a long time, such as washing machine. Some of them are bothered by the light (Darica et al., 2011:36).

They react to pain and hot-cold stimulants at two end points. These reactions might be not realizing this kind of stimulants or hypersensitivity. Babies with NGG start the social relationship with their mothers by smiling and they are willing to tactile contact with their mother for the first three months, however, children with ASD react negatively to being held and they generally refuse physical contact. According to Kanner (1943), behaviors such as unresponsiveness and not hugging can be seen in early childhood, when a mother tries to hold the baby. A baby with ASD doesn't make any claim and preparation to be held (Borozanci-Persson, 2003). However, as the exact opposite response, they touch or smell it when they encounter a new object. Children with ASD have nutrition and sleep problems. Food selection and refusing to eat solid food are seen. 6% of children's with ND have nutrition problems, however, this rate can reach to 21% in children with ASD. According to the research children with ASD's sleep problems are two times more compared to the children with ND (Darica et al., 2011:36-38).

### **2.1.3.2. Motor development properties**

Although, Kanner, in 1944, specify that children with ASD have normal motor development and this opinion is supported by other researchers (Rutter, 1972); motor skills of children with ASD, whose physical appearance are indistinguishable from the children with ND, may differ according to age. Motor impairments can be seen in children with ASD. These can be clumsy walking, shaking the arm senselessly while walking (flapping the arms), walking on the toes, rigid body posture (Ghaziuddin, 2005:13-41 Cited: İncekaş, 2009).

Children with ASD's posture looks different than normal when they don't use their hands and arms and behaviors like walking on the toes, repeating certain movements, swaying back and forth on one foot and one foot in front on the other, rotating for a long time can be seen. At the same time, hyperactivity (unusually

active) or hypo-activity (unusually inactive) is considered as the other motor skills (Darica et al., 2011:39).

Children with ASD have difficulties in activities which are necessary to use large muscle motor skills, such as dancing, swimming and jumping rope. The reason for this is that they are slow in learning because their mimicry skills very low or absence. Their small muscle motor skills are undeveloped, too. Although their small muscle skills are insufficient, they can rotate some small objects. The reason for children with ASD's motor skills are deficient is explained as incuriousness to their environment, too (Darica et al., 2011:39).

### **2.1.3.3. Social developmental properties**

Social skills are the necessary skills to build mutual and healthy relationships with other individuals (Bacanlı, 1999:25). Social skills of children with disabilities can cause problems in communicating with adults, compared to their peers without disabilities (Sabornie and Beard, 1990:35-38).

Studies that explain the social development of children with ASD are very few. In a study of Wing (1971), which is done for parents of children with ASD, the behavior of children with ASD in a year is determined. As a result of this, it was seen that mothers are suspicious of their children's differences, children are away from physical contact, they react very little to the sound of their mother, they don't use sign language to indicate their requirements. Wing (1989) has defined that the most obvious deficiencies for the children with ASD in three categories, which are communication, to be able to communicate socially and daydreaming (Wing, 1989:5-22). The observed behaviors have been continued in later years (Darica et al., 2011:41-45).

Children with ASD have difficulties in communicating and comprehension social relationships because; there are serious defects and deviations in verbal and non-verbal communication and interaction. These are the lack of verbal communication (aphasia) and the lack of efforts to communicate (Öztürk and Uluşahin, 2011:747).

The social characteristics of children with ASD are disliking physical contact, absence of the smile that is required for the mutual relationship, incuriousness for other people and not being aware of their existence (not communicate with parents and other people), inability in comprehension and application of social norms and the lack of playing skills (playing alone).

Children with ND's playing skills develop in the first years of life. First, they get to know the objects by touching and then they use them in accordance with their purpose. The playing skills of children with ASD do not develop in parallel with sensorimotor stage of symbolic thinking is acquired. According to the result of Black, Freeman and Montgomery's study (1975), as the game of children with ASD, the objects are not used for their purpose and only rotating (Darica et al., 2011:41-45). Children with ASD are interested with toys (dolls, cars, etc.) or inanimate objects, however, they do not play with them in accordance with their function, such as playing house (Korkmaz, 2005:15-16).

In addition, Clark and Rutter (1981) specify that children with ASD can be able to give the responses that are expected to be used in some social situations. When children with ASD were left alone in their groups, there is no reaction of social communication among them selves; however, when they are with their educators, their social communication and interaction increases (Darica et al., 2011:44-45).

#### **2.1.3.4. Language and communication properties**

The inability to communicate is one of the most obvious features of ASD, because their speech and language skills are not gained. The communication is divided into two, as verbal and non-verbal. Non-verbal communication is some movements and gestures such as smiling, waving hand, lifting arms when being hugged, which are observed in early infancy. These are accepted as the beginning of speaking. Children with ASD do not use these movements and gestures often (Darica et al., 2011:47).

There are two basic components of verbal communication. These are speaking and listening. Individuals with ASD have problems with speaking and comprehension which provides verbal communication. Speech delay in early childhood is the most important symptom of ASD (Rubin and Lennon, 2004: 271-285).

In half of the children with ASD speech does not develop as a communication tool (Korkmaz, 2005:42). In some of the children with ASD, when there is the ability of speaking, it may disappear suddenly. Speech delay is the most obvious feature that concerns the family and directs them to take expert help. A child with ND, right to the age of three, will have 200-300 words, can make a sentence with three words and in this way they can enter into the mutual relationships. Children with ASD generally can say their first words around the age of 5. Being limited of language development with a few words shows the difficulty in speech and language skills (Darıca et al., 2011:47).

In about half of the individuals with ASD, speaking is not observed for a lifetime. An important part of who can speak has a speech of their own. Some of the children with ASD can start to speak; however, their purpose is not get in a contact. Some researchers state that the speech of the children with ASD is not social-oriented; it is in a repetitive form (Akçakın, 2000:189-197).

Children with ASD, who can speak, cannot start conservation, tell an event or make a dual conservation. Wrong usage of pronouns, early and late echolalia, making up some words, repetitive usage of language is the most common problems for the individuals with ASD (Korkmaz, 2005:43). Comprehension of children with ASD is much better than their speech (Ghaziuddin, 2005:13-41). However, there are still comprehension problems this is why they do not understand complex orders (Korkmaz, 2005:42).

Speaking is one of the functions of the mind's highest level. Most of the children with ASD who cannot speak have mental retardation. Children with ASD who can speak at the right time are the clever ones (Korkmaz, 2005:43).

#### **2.1.3.5. Mental development properties**

The first years of ASD was defined, the opinion that individuals with ASD do not have the mental deficiencies was accepted. This opinion's reason was that the individuals with ASD have extraordinary skills in the areas of music and mind and these features are evaluated as a level of superior intelligence. However, recent research shows that %90 of the individuals with ASD has mental deficiency and more than the half of them have an intelligence level under 50 (Darıca et al., 2011:59).



ASD cases are a combination of mental deficiency, hearing loss and many medical disorders (Öztürk and Uluşahin, 2011:745). According to recent research, the main problem of ASD is the mental development. This deficiency causes to the first degree of language and communication problems and the second degree of behavioral and sensory difficulties (Darıca et al., 2011:61).

Different results were found in the studies about individuals with ASD, their gender and intelligence levels. Mostly, the level of intelligence of girls with ASD was lower than the boys'.

In Lotter's (1966) study of epidemiology, the 13 boys of 23 and the all 9 girls' intelligence quotient (IQ) were found fewer than 55. Lotter (1966:163-173) Tsai, Stewart and August (1981:165-173) drew attention to the differences in gender and intelligence and reported that girls have lower IQ. When this IQ rate is under 50 or over 70, gender difference became more apparent. Researchers stated that neurological disorders are more in girls and the speech or cognitive inefficiency of immediate family members were seen more.

Also, Wing (1981) has stated that the level of intelligence of girls is lower than boys' Wing (1981:129-137). In his study of gender differences, Volkmar (1993) has compared the children with pervasive developmental disorder (PDD) not otherwise specified (NOS), with pervasive developmental disorder (PDD) and non-ASD children with developmental disorder (DD) with regard to the degree of weight of intelligence, adaptation, behavior and symptoms of ASD. PDD and NOS-PDD groups were not different from each other in terms of gender ratios (PDD=3. 63:1, NOS-PDD=3. 62:1) in this study, gender difference has remained limited with IQ (Volkmar, Szatmari and Sparrow, 1993: 579-591).

In a study done by Akçakın (2002), the male-female difference has not been found in children with ASD according to the assessments of Ankara Developmental Screening Inventory (ADSI) and Stanford-Binet Test (Akçakın, 2002: 189-197).

#### **2.1.3.6. Behavioral properties**

When we look at the studies, we can see that children with ASD have behavior properties different from each other. Children with ASD have restricted skills and

problematic behaviors compared to children with ND. The reason for this is the inadequacies and deficiencies in communication.

Being uninterested with the people around, not recognizing their relatives, not to show separation anxiety, not playing games with their peers and retreat in establishing a relationship are in the behavioral priorities (Darica et al.,2011:62).

Children with ASD might have extraordinary fears. This sometimes can be seen about an experience that happened in the past (Korkmaz, 2005:65). Because the water at normal temperature hurts, the children might refuse to take a bath and this behavior may continue for a long time (Darica et al., 2011: 62-63).

Parents of children with ASD live in constant anxiety because they know that their children are not aware of the danger and they cannot protect themselves. They can play naked in the extreme cold for a long time (Korkmaz, 2005:60-61). They might move in traffic without knowing that cars could cause damage to him/her and they are not aware of the height (Darica et al., 2011: 64). They carry the risk of injuries and accidents. However, as they learn the rules in social environment over time, this risk is reduced. They laugh or cry for no reason and this is because they are not able to assess the environment in which they are located. Most of the children with ASD may show inappropriate responses to the situation, like laughing when they are damaged (Korkmaz, 2005:65).

Children with ASD are overly insistent about the preservation of sameness. It is known that preservation of sameness affects the language skills (Bodur and Soysal, 2004: 394-398). They might have some habits such as wearing certain clothes, eating certain foods or asking for going to groceries by using the same route (Bodur and Soysal, 2004:394-398). Children with ASD are used to the routines; any changes can cause different reactions for them.

Sometimes their reactions to these changes might be screams of joy or tantrums. This is because protecting the sameness is a relaxing function for them and they feel insecure because of the changes. They might have an addiction for some objects. They expect everyone to follow their wishes and elections.

Problem behaviors of children with ASD become apparent with the end of the infancy. These are tantrums (such as yelling, crying, throwing themselves on the ground), behaviors damaging to the environment (such as screaming suddenly, throwing products in the market), behaviors damaging to themselves (such as scratching their own face, kneeing), a single type-body movements (rotation, swaying front-to-back, draw some shapes in the air with their fingers, hitting to other parts of the body by the rhythmic movements of the hand, humming the same melody over and over) (Darica et al., 2011:65-68).

#### **2.1.3.7. Special skills in autism spectrum disorder**

There are research findings show that some of the children with ASD have superior skills in math, music and mechanical (Bodur and Soysal, 2004: 394-398). Children with ASD may show backwardness in a skill when they can improve themselves in another skill. For example, when a child with ASD is successful in music skills, they might be unsuccessful in riding a bicycle (Korkmaz, 2005: 73). They are usually successful in the skills that do not contain speaking ability and abstract meaning. These skills may not be seen in every child with ASD and generally they may not attract people's attention (Darica et al., 2011: 69-70).

In about the one-tenth of ASD cases, savant syndrome may be seen (Treffert, 2009:1351-1357). The savant term is firstly used by Down (1887) for describing the people with superior characteristics besides mental retardation. Savant syndrome describes the situation that is the person's general level of intelligence is below mean, however, they have excessive information in one or more areas or it describes the people with unusual mental skills which are not available in most people besides at a gross level developmental or mental deficiencies. It is certain with memory and math skills which are at a remarkable level of strongest extraordinary skills in the field of art or music.

#### **2.1.4. Incidence of autism spectrum disorder**

It is stated that ASD is one of the most common developmental disorders at the present time (Kılıç Ekici, 2011:70-75). In the first years that ASD is defined, it was thought that it is a less common case without mental disorders. As a result of many research the rate of cases is 5/10. 000 (Darica et al., 2011:23).

Wing (1986) has reported that this rate is 15/10. 000 in the report of “*National Autistic Children and Adults Association*”. The reason for this increase is that expansion of Kanner’s diagnostic criteria for ASD and new developments make ASD understandable (Darica et al., 2011: 23).

In another research made in California, diagnosis changes were discussed, it was found that the reason of one-fourth increase in 1992-2005 is associated with changes in diagnostic criteria (King and Bearman, 2009:1224-1234). In community studies made towards the end of the 2000s, it was stated that the incidence of ASD is 2%, the incidence of Asperger’s syndrome which is in PDD and NOS-PDD is 0. 6% (Levy, Mandell and Schultz, 2009:1627-1638).

The incidence of ASD was increased 78% in the last five years. In today’s research, the cases in America and Europe were increased and it was seen that this rate became 1/88 according to the data of Centre for Disease Prevention and Control (CDC) (MEB Kadıköy RAM, 2015).

There are different opinions about the reasons for this increase of ASD, such as environmental pollution, radiation, change of dietary habits (Korkmaz, 2005:23). It is not sufficient to explain the prevalence in the ratio of 1/100, although the reason for the increase depends on the recognition of ASD, increasing of the awareness of parents and the implementation of clinicians’ scanning scales. As a result of this, the importance of environmental factors as the cause of the prevalence of ASD has emerged (Dietert, Dietert and Dewitt, 2011:7111; Yamashita, Fujimoto, Nakajima, Isagai and Matsuishi , 2003:455-9).

There is no current and enough scientific information about the prevalence of ASD in our country. However, when the rate of 1/150 according to the data of Autism Platform (a roof formation which consists of 24 civil society organizations working with ASD in Turkey) is considering, individuals with ASD in the population of the whole country is estimated to be approximately 450, 000. On the basis of the same ratio, one might argue that children with ASD in the age group 0-14 were around 125. 000 (Tohum Autism Foundation, 2012).

### **2.1.5. Age and gender factors in autism spectrum disorder**

In previous years, researchers stated that beginning of ASD might be seen in the period between the child's birth and after approximately 30 months. However, in the recent research it is suggested that beginning of ASD is limited with early childhood. When the child is 36 months old or at a later age, ASD behavioral properties might be seen (Darıca et al., 2011: 23).

Although there are few studies about the relationship between gender and ASD, they have been made. According to the results of this research, boy/girl rate was stated 5/1 (Doğukan, 2008: 157-174). These results confirm that there is a difference in the gender ratio (Darıca et al., 2011: 23). Although ASD is less common in girls, it is more severe (Korkmaz, 2005:23).

### **2.1.6. The etiology of ASD**

Despite the passage of three quarters of a century after the definition of ASD which is based on Austrian child psychiatrist Leo Kanner's pediatric patients which are unable to establish social and emotional connections with others and interested with things rather than with people, many questions about the nature of this complex syndrome is not clarified yet (Siff Exkorn, 2005 Cited: Özkaya 2013:127-139).

Accompaniment of medical disorders to ASD reveals the presence of the biological etiology (Özusta, 1999:259-69). It is considered that ASD has many reason, however, recent research suggested that ASD occurs because many genes interact with one another (Pehlivan Türk, Bakkaloğlu and Ünal, 2003:88-96). Possible factors are included as genetic, biochemical, neuroanatomical, familial and environmental factors. These factors will be discussed briefly in the following section.

#### **2.1.6.1. Genetic factors**

In the 5-10% of individuals with ASD medical cause of the etiology of the disease can be detected. Genetic diseases such as Fragile X syndrome in 2-5% of them, Tuberous Sclerosis in 1-3% of them can cause to ASD (Korkmaz, 2005:24). In ASD cases, mental retardation and epilepsy, weak neurological symptoms, primitive reflexes and non-specific findings in electroencephalography (EEG) suggest that there

is biological basis about the reasons (Özusta, 1999:259-69, Cited: Özbaran, 2014:170-3)

Research shows that the incidence of ASD in twins is 50% more (Darica et al., 2011: 29). The percentage of incidence is significantly higher in identical twins than fraternal twins. ASD may be seen more in men. It is believed that this originated from a genetic basis (Korkmaz, 2005:33).

Some families which have multiple children with ASD or have members with mental retardation, speech problems, learning disabilities have provided the evidences for common genetic basis of ASD. In the genetic studies, findings different than normal are found in the blood of children and families with ASD. High serotonin has been identified in blood samples from the parents. It is unclear whether this assessment causes behavioral abnormalities. Although ASD is associated with some metabolic disorders, it is found in less than 5% of the cases (Lord, Cook, Leventhal and Amaral 2000:63-355) According to recent developments in genetic research, genes that are thought to be associated with ASD are located on the 15<sup>th</sup>, 13<sup>th</sup>, 6<sup>th</sup> and 7<sup>th</sup> chromosome. However, ASD is thought to occur as a result of the association of these genes and the environmental factors that are not effective alone (Korkmaz, 2005:26-28).

#### **2.1.6.2. Neuroanatomical and biochemical factors**

Recently, it is accepted that some structural abnormalities in the brain also cause ASD. Recent studies on this topic accentuate that ASD is a disorder related to the development of the cerebellum. Depending on the advancement of technology, this theory which posits that ASD is appeared in the result of the brain's failure to fulfil certain functions is being adopted today. This theory includes deficiency about learning, attention, and perception processes of the child with ASD. This opinion also confirms the data that accentuates the specific physical and biochemical diversity of the child with ASD (Darica et al., 2011: 28-29).

Distortions in various brain regions in ASD are shown in research. It has been mentioned that cellular changes are in amygdala and hippocampus and increased cell packing is in amygdala (Bachevalier, 1996: 217-20). In a study that investigates the post-mortem cortical mini-column structure of individuals with ASD, which has been

damaged to their medial temporal lobe and amygdala regions in their infancy, disorders in the mini-column structure which is treated as basic functional unit, and allows the organization of the brain have been found in the temporal lobe and the prefrontal cortex of individuals with ASD (Otsuka et al.,1999:517-9; Casanova, Buxhoeveden, Switala and Roy, 2002:428-32, Cited: Öztürk, 2010).

Reduction in volumes of neo-cerebellar in the cerebellum, reduction of purkinje cells in the cerebellar hemispheres are the findings seen in ASD. It is stated that this might be associated with the abnormalities in the attention, alertness and sensory processes in ASD. Riva and Giorgi, 2000:27-31).

The studies, which determine that individuals with ASD have gray matter loss in double-sided plenum temporal, state that this finding might be associated with the neurodevelopmental disorders that impair early language development in ASD (Rojas, Bawn, Benkers, Reite and Rogers, 2002:237-40).

### **2.1.6.3. Familial and environmental factors**

The studies that compare the parents of children with ASD and the parents of children with NGG, suggest that these two groups show mental and behavioral differences. The parents of children with ASD mostly carry obsessive features, have an introverted structure, have difficulty in communication, have problems in social areas, they mostly come from upper socio-economic level and especially fathers have schizoid personality disorders (Wolff, Narayan and Moyes, 1998:143-153; Volkmar and Klin, 2005:5-41, Gousse, Plumet and Fringe, 2002: 120-128, Cited:Öztürk, 2010).

Non-development of pre-natal and post biological aspects and some situations that have a negative impact especially in the first three months of pregnancy might become a factor at the risk of ASD. Usage of thalidomide (the medicine that used for morning sickness in pregnancy) and valproic acid, presence of some viral infections and various birth complications are related with the development of ASD in the womb (Nelson, 1991:761-766; Cited: Öztürk, 2010).

It is accentuated that psychological stress factors that mother faced in the prenatal period are also related with the development of ASD. Dietert (2011) and Yamashita (2003) have said that external factors, such as remaining under the general

stress and emotional load of the mother, can affect the brain development of the unborn child. They have also mentioned the important risks during pregnancy and important timeframes in late pregnancy and in the newborn period (Kinney, Munir, Crowley and Miller, 2008:1519-1532). Cited: Türkoğlu, Bilgiç and Uslu, 2012:167-172)

#### **2.1.7. Method of treatment for ASD**

When the literature is reviewed, it is observed that ASD does not have a definite treatment, studies are being carried out to improve the quality of life of individuals with ASD and the people who take care of them by relieving some of the symptoms. Although some of the results of these studies are positive, they can't reach to the criteria that have a value of evidence (Eldevik et al., 2009: 439-450).

From 1960 to the present, in the studies about the treatment of ASD, the opinion that education is the best treatment was adopted. In the education of children with ASD, education programs based on The Behavioral Modification Model are usually used (Darica et al., 2011: 73). Also, in the study of Eldevik, it was stated that getting early intensive behavioral therapy has a high positive impact on IQ and decorum.

The purposes of treatment in ASD are reducing destructive behaviors, improve the learning, ensure the acquisition of language skills and increase the communication and self-care skills. Lord and Bailey (2003). If the symptoms of ASD are heavy enough to not allow the implementation of the planned treatment options, it must be supported with psychopharmacologic treatment (Cited: İncekaş, 2009:28).

The most common methods of education, therapy and treatment in ASD are special education and behavioral methods as education methods; sensory integration therapy, aural integration therapy, music therapy as therapy methods; psychiatric treatment methods as treatment methods and the gluten-casein diet, extraction of heavy metals as alternative and supportive methods of treatment (Tohum Autism Foundation, 2012:34).



### **2.1.7.1. Education methods**

#### **2.1.7.1.1. Special education and behavioral methods**

Special education is the education which is necessary to enable the children with ASD to become less dependent and is provided to give age-appropriate self-care, mental, social, and communication skills (Korkmaz, 2005:87). The most common method in special education is behavior therapy. This method includes directly behavioral intervention which is made by trained persons at home or school for 20-40 hours per week. The method relies on objectively analyze the behaviors of the individual and the environmental characteristics that are associated with these behaviors. Therefore, appropriate behaviors (imitation skills, play skills, social skills, communication skills and self-care) are tried to be increased and inappropriate behaviors (tantrums, self-stimulating behaviors) are tried to be reduced by using the various reward mechanisms and some deterrent mechanisms when they are needed ( Tohum Autism Foundation, 2012:7-10; Weber and Newmark, 2007:983-1006).

When we look at the studies that compared applied behavior analysis and other methods, in the experimental studies managed by Lovaas, very important development of intelligence and social gains have been seen in about 90% of the children who take education based on applied behavior analysis for a period of 2 years. Lovaas (1987:3-9) In a study, it was stated that behavior therapy does not fix exactly all the symptoms of ASD, it is useful and the level of evidence is weak. (Tohum Autism Foundation, 2012) (Osborn, et al., 2008: 3755)

### **2.1.7.2. Therapy methods**

#### **2.1.7.2.1. Sensory integration therapy**

Sensory integration therapy assumes that there are some problems in the ability of perception, processing and interpretation of information that is provided by sensory organs of children with ASD. Therefore, it attempts to reduce behavior problems and increase the mental functions by solving these problems and developing the ability of sensory integration. Application activities are body brushing, compression knees and elbows, swinging in a hammock and so on. Sensory integration is being used prevalently in ASD since the 1970s. However, it does not

have sufficient scientific basis yet. A research compilation shows that there is a deficiency of convincing experimental research findings (Tohum Autism Foundation, 2012).

#### **2.1.7.2.2. Aural Integration therapy**

Aural integration therapy was developed by Berard in 1960's. It was started to be implemented with different names such as Tomatis, Earobics, Fast for Words. Sinha, Silove, Hayen and Williams (2006. 1018-1022, Cited: Özeren, 2013:57-63) At the beginning of the therapy, the frequencies of the sounds which the child is sensitive are detected and in the therapy they make the child listen to the music which is free from these frequencies. In a compilation study of Sinha, a variety of procedural problems are found in six experimental research and they decided that the effects of aural integration therapy on the children with ASD are not based on a scientific basis yet (Tohum Autism Foundation, 2012).

#### **2.1.7.2.3. Music therapy**

Music therapy includes singing, playing instruments and dancing with the music and it is applied by trained therapists. It provides a sense of accomplishment by reducing behavior problems, it increases the usage of physical and verbal language and it makes the children with ASD establish an emotional bond. In Whipple's meta-analysis research, the positive effects of music therapy have been shown. Whipple (2004:90-105) (Tohum Autism Foundation, 2012:25).

#### **2.1.7.3. Medical treatment methods**

##### **2.1.7.3.1. Psychiatric treatment methods**

Pharmacotherapy does not cause to a change or disappear the symptoms of ASD. It is applied to fixing the disease-related behavior problems such as hyperactivity, repetitive (stereotypical) movements, distress (anxiety), depression, sleep disorders, eating problems, self-destructive behavior or aggression which is only seen in the children with ASD and it provides benefit (Korkmaz, 2005:75-76).

#### **2.1.7.4. Alternative and supportive treatment methods**

##### **2.1.7.4.1. The gluten-casein diet**

Peptides that smaller than protein are biologically active and they might cause damage over chemical intermediate substances in the brain. These substances are found in some foods. Researches recommend a gluten and casein-free diet and assert that the severity of some symptoms of ASD (such as improvement in social skills, increase in the activities for communication and the problem-solving ability, improvement in toilet manners, improvement in the movements) decreases with this diet. Although this assumption is scientifically unconfirmed, gluten-casein diet is prevalently used for children with ASD. In this diet foods that include milk and dairy products, wheat, barley, rye and oats should not be given (Tohum Autism Foundation, 2012:32).

##### **2.1.7.4.2. Extraction of heavy metals**

It is believed that heavy metals that carry toxic property such as lead, mercury, aluminum, arsenic cause ASD. Mercury is found in vaccines of measles-mumps-rubella (MMR). According to the results of research done by 19 scientists from 13 different universities, which investigate the relationship between these vaccines and ASD, there is no relationship between the vaccine and the symptoms of ASD (Richler et al., 2006:299-316) (Tohum Autism Foundation, 2012:34).

Until this part of the study were given information about ASD. In the next section, it will be given information about other variables of the study such as burden of care, dyadic adjustment, multidimensional perceived social support, expressed emotion, life satisfaction and posttraumatic progress.

## **2.2. Burden Of Care**

The notion of the burden of care was defined for the difficulties that lived by home care givers to individuals with mental illness, by Grad and Sainburg in the early 1960's (Cited: Chou, Chu and Tseng, 2003. 73-82).

According to Turkish Language Association (TDK, 2015), the word of care is defined as taking care, the labor that is given for a good development, staying in a

good condition, labor format, supporting and providing someone's food, clothing, etc. requirements. Taking care is an experience perceived multi-dimensional by care givers (Akbayrak, 2002:160-161). Becoming a care giver is a condition that cannot be chosen. Adaptation to this situation happens after the situation has occurred (Eicher and Batshaw 1993:537-551). The process of the care giving role is determined by the disease process and it might change (Atagün, Balaban, Atagün, Elagöz and Özpolat, 2011:513-552). The burden of care represents that negative subjective and objective results caused by the care, such as psycho-social problems, physical health problems, economic problems, the deterioration of family relationships and the sense that they are not in control (Cited: Kızıllırmak, 2014).

There are two kinds of burden of care, as objective and subjective. Objective burden of care includes the changes and restrictions of the care givers and parents's life. These are the patient's disturbing behaviors, economic challenges that are caused by the disease, loss of income, influence to the events in daily and social life, tension in the home, negative effects on physical and mental health of family members. It states the side of family's burden that is observable and verifiable. Subjective burden of care is defined as the level of subjective distress related with the patient and feelings and attitudes that are associated with the role of the individual who is taking care. Objective burden can be identified more easily because of its concreteness; however, the determination of subjective perceptions is more difficult (İnci, 2006).

Getting a diagnosis of chronic illness, mental or physical disability for their children is a hard situation for the parents. There are special difficulties of the disabled child. Any illness or uncertainty in the family affects all family members. Chronic childhood diseases' symptoms, treatments, process and restriction of daily activities place the moral and financial burdens to families in the long term (Fazlıoğlu, Hocaoglu and Sönmez, 2010:190-205).

Family is one of the unchangeable factors of the life of a patient (Kuşçu, 2000:30-34). In our country, studies in relation to the people who care for individuals with chronic disease show that primary care providers are often selected from the family (Gülseren, 2002:143-151; Karahan and Güven, 2002: 155-159: Cited: Kızıllırmak, 2014). Because the primary care provider is in the focus of patient, they are usually in a relationship with the social environment of patient. When the

responsibilities of giving care increase, the relationship of giving and receiving care can turn into a dependent, one-way necessity with an intensive and a lengthy process that puts the life of caregiver into trouble.

When the chronic and intensive structure of care combines with the disputes that originate from other requests of the care givers such as work, family and social life, it usually can cause burden of care (Atagün et al., 2011: 513-552).

According to the studies, the people who are responsible at a basic level of care of patients are usually the female members in the family and to be a woman who taking care is related with more burdens. Men usually helping to care when in emergency situations or his wife have a job (Arslantaş and Adana 2011:251-277).

The elementary family structure increases the responsibility of the family members in providing the needs for care (Sales, 2003: 33-41). Mothers are more involved in the child's care in the disease process; working mothers are forced to leave their jobs. Care giver mothers cannot take time for them, are disrupting the care of other members of the family, and cannot implement social activities. This situation causes the increase of mother's burden of care (Yavaş, 1994:96-103; Hoekstra-Weebers, 2001:225-35; Last, 1998:169-79). The burden of care can increase when the severity of the disease and disability is much more (Schulze and Angermeyer 2003:299-312). Bahar, Bahar, Savaş and Parlar (2009:97-112) In a study of Bahar, it is stated that mothers, who are more responsible for the care of children with disabilities, are estranged themselves from the other members of family and their social life, because their spare time activities are restricted and they devote themselves completely to their children.

There are studies that examine the care burden of the parents of children with ASD. When the parents of children with ND are compared with the parents of children with ASD, it is seen that parents of children with ASD have more care burden and their physical and psychological stress are higher. The study of Aydoğdu shows that there is no difference between the care burden of parents of children with ASD and the care burden of parents of children with attention-deficit/ hyperactivity. It was commented that having a child developing different causes to similar needs for any mother (Bouma and Schweitzer, 1990:722-730; Fombonne, Simmons, Ford,

Meltzer and Goodman 2001:820-827; Klassen, Miller and Fine, 2004:541-547; Seltzer, Shattuck, Abbeduto and Greenberg, 2004:234-247).

According to a qualitative research done for determining the problems of parents of children with ASD, half of the parents stated that they isolate themselves from the social life for taking care of their children, they give up on their personal purposes, as children grow they have difficulties in giving them care and they worry about their children's future (Üstüner and Top, 2009:34-42).

They try to maintain a relationship compatible by establishing a balance between the couples themselves. The burden of the care of a child with disabilities participating in the family can upset this equilibrium. Couples might have to try to get back the balance and harmony between them and undertake unexpected and challenging responsibilities. In the next section, it will be talking about dyadic adjustment by considering that having a child with disabilities and the harmony between the parents are interrelated situations.

### **2.3. Dyadic Adjustment**

The notion of dyadic adjustment is associated with the notions such as marital satisfaction, marital happiness and marital success (Fışıloğlu, 2001:215-222; Fışıloğlu and Lorenzetti, 1994:539-552). Rhoden (2003:248-256) states that marriage is a multi-dimensional notion, happiness are conceptualized as marital satisfaction and adaptation of couples in marriage. Spanier (1976:15-28) defined the dyadic adjustment as the adaptation to changing circumstances in the lives of the spouses and changing as appropriate to each other within a certain period of time. According to Fışıloğlu (1992:16-23), in the investigation of the factors that lead to the family problems, one of the most emphasized factors is marital adjustment. Marital adjustment is a notion that includes the notions of marital satisfaction and happiness. Harmony is thought to be more important in assessing the quality of marriage. In the research about marriage, examination of the factors that affects the adjustment and development of approaches to improve the adjustment are found at the forefront (Kalkan, 2002).

Marriage of the couples that being in communication with each other, are capable of making the unity of thought on marriage and family matters, can solve

problems positively, can be defined as a good marriage (Açık, 2008). Marital adjustment is divided into various adjustment areas. These include various dimensions such as deciding, role flexibility, solving problems, communication, the resolution of the conflict, autonomy, marital satisfaction, the unity of the thought of spouses, problems related with marriage, intimacy, commitment, and expression of love (Sarısoy, 2000).

Sokolski and Hendrick (1999) had defined the marital adjustment as provide psychological satisfaction mutually at the equality in the decisions, in gain, dominance, the study, sharing problems, in the style of love, in the attitude, sexual satisfaction, in the format of communication, in expressing themselves to each other (Cited: Çelik, 2006).

The child that joined the family is a beginning of a new period and changing of the roles for a married couple. Also being parents of a child with disabilities lays more difficult burdens on their role of parenting. Usually in cases like this, the mother may have to care for the disabled child instead of working and the father may have to work harder due to economic difficulties.

The presence of a disabled child can cause unrest and tensions in the family. This may reflect on the relationship between the spouses and their marital adjustments. In some cases, disabled child might cause a negative effect on dyadic adjustment or there might be no effect. In some cases, the child causes to divorce. Sometimes, on the contrary, it was observed that the disabled child strengthened the marriage (Sarısoy, 2000).

Bolman (2006) stated that the rate of divorce in families who have children with ASD is 80%. Longo and Bond (1984:57-65) reported that the divorce rate in families of children with ASD is nine times than in the normal population. A lot of research shows that in families with children with disabilities, marriage or dyadic adjustment is low and the divorce rate is high (Breslau and Davis, 1986:309-314; Bristol, Gallagher and Schopler, 1988:441-451; Floyd and Zmich, 1991:1434-1448; Friedrich and Friedrich, 1981; Kazak and Clark 1987:220-228, Cited: Karpat, 2011).

Trute (1990:292-297), stated that parents with disabled child have a consensus on the lower level than the parents of the child with ND. Fisman, Wolf, Noh and

Speechley (1989:157-166) said that the intimacy of the parents of children with ASD is weaker than the intimacy of the parents of the children with ND (Cited: Karpat, 2011) Kazak and Marvin (1984:67-77) observed that having a disabled child makes the family closer and strengthens the marriage relationship (Cited: Sarisoy, 2000).

The burdens of care and the responsibilities of having a disabled child have overburdened on the parents and highlight the importance of social support. Considering that the social support is a condition that affects the burden of care, in the next section “multidimensional perceived social support” will be elucidated.

#### **2.4. Perceived Social Support**

Social support is defined as all kinds of material and spiritual help that is providing by the people around the person (spouse, family members, friends, neighbors, public institutions, etc.) in the stressful or difficult situations (Eker et al.1995:45-55). It is also, the presence of people that can help and that are reliable, when the person felt the need of support (Yıldırım, 1997:81-87). It was thought that staying healthy after the trauma is due to some reasons. Studies show that interpersonal support has a positive and useful effect in coping with stressful life events (Çakır and Palabıykoğlu, 1997:15-24). Social support includes all the interpersonal relations that provide financial, emotional, and cognitive assistance and protect the mental health of person (Hogue, 1985; Cited: Ardahan, 2006:68-75).

Social support provides the need to be loved to be understood, to be a part of a group and to receive help. Therefore, social support is divided as “received and perceived”. Received social support is “actualized” support and perceived social support is a support “with the possibility of actualization” (Cited: Kurt, 2010). Perceived social support is the presence of support resources that might provide help when the person needs. Because this support is subjective and qualitative, it can be defined and measured. It is reported that perceived social support is more determinant on the psychological health than received social support (Kaner, 2004:7-68, Cited: Kurt, 2010).

According to Caplan (1974) other important people are guiding the way for the person to overcome this situation by helping to activate the psychological power



of the person, preventing the emotional exhaustion, sharing the duties and providing the material, instrumental, experience, cognitive, social support (Cited:Kurt, 2010)

According to House (1981:1-12) social support system helps to reduce the impact of some factors that affect the life of the person, to increase the strength of the person in the face of negative life events, to improve the health. It acts as a buffer against the effects of environmental stressors partially or completely. When the family or the person has a problem, they try to overcome the problem with the help of many source of support (Cited: Akmanış, 2010). Kanner (2004:7-68) gathered these sources of support under two main headings as instrumental support and emotional-social support.

Instrumental support includes information, cognitive guidance and financial support. There is a positive theoretical relationship between a person's width of social support environment and having instrumental support. The burden of parents with disabled child which have a wide social support network can reduce due to the support they received. Information support includes the medical care and treatment possibilities for the disabled person, education and consulting services and institutions or organizations that provide them (Allen, Ciambrone and Welch, 2000:318-341; Cited: Kurt, 2010).

Emotional support means the presence of someone to share the person's private or personal problems. These people's reliability and giving the opportunity of sharing provide strength to the person with problems. In terms of mental health, it is useful to know that the person is valuable, important and not alone. Social support facilitates the compliance to chronic disease in the family, encourages the health-enhancing activity and healthy living and it has a positive impact on people's moral and coping skills (Kaner, 2004:7-68).

There are many studies on the importance of social support in families with disabled children. For families who have children with ASD, social support is very important in struggling with the challenges of ASD. In a study related to social support networks, it was found that the support network of mothers of children with ND is wider than the support network of mothers of children with ASD or mentally

retarded. 25% of the father of children with ASD or mentally retarded do not see any support from anyone (Yurdakul and Girli, 1999:1-5).

In the research that Coşkun and Akkaş (2009:213-227) did on the relationship between trait anxiety and social support perceptions about mothers who have children with disabilities, it was found that perceived social support level of mothers increases in inverse proportion with trait anxiety level and mothers feel less trait anxiety when they surrounded by other people and feel supported. It was determined that the level of social support is not related to the child's sex . Also the increasing age of the mother decreases the level of perceived social support and there's a direct proportional relationship between mother's education, level of income and social support.

In the research that Görgü conducted (2005) with mothers who have children with ASD, he predicted some factors affect multidimensional perceived social support and depression in mothers such as the mother's level of education, the presence of working life, monthly income level, the number of children, being the first person who realize that her child has ASD and taking care of him/her since birth, caregiver status and the degree of detection of ASD.

Kariman and Bayat (2008:1175-1194) specified that 26.7 % of mothers and fathers has received support for the care of disabled children and mothers perceive less social support than fathers according to a research that Kariman and Bayat did to identify the difficulties faced by the parents of disabled children and perceived levels of social support by using Multi-dimensional Perceived Social Support Scale.

The life of parents who have disabled children may be affected negatively by physical and psychosocial aspects and this may reflect family environment. Expressed emotion is considered as an indicator of the emotional aspects of family life and it is stated that individuals who experienced uncontrolled and intense emotion by others will have problems (Dattilio and Epstein, 2003:155-6).

It is accepted that having a disabled children may effect on parents' level of expression of emotion. The topic of expressed emotion will be discussed in the next section.

## 2.5. Expressed Emotion

Emotions are one of the experiences of human life. It is important for individuals to express and overcome their feelings in communication, mental health and relationships with other humans. Emotion expression is a method for individuals to transmit their desires, expectations and requirements to the other individuals.

Expression of emotions points some of the keys between individual relationships. It described as the number of other people's comments which containing criticism about patient, whether they have hostile attitude about the patient, overly intrusive level of attitude and the determinant of overall family attitudes and behaviors (Ölçer, Fiş, Berkem and Karadağ, 2010:144-149; Cited:Tutarel-Kışlak and Göztepe 2012:27-46).

Expressed emotion includes subtitles like being critical, getting hostile, excessive interest, being intrusive, becoming close and positive reviews (Wearden, Tarrier, Barrowclough, Zastowny and Rahill, 2000:633-666). It includes statements like being critical, blaming others in a judgmental way, breaking or resentment, dislike and disapproval (Cited:Tutarel-Kışlak et al., 2012:27-46).

Being hostile is often defined as a negatively expressed emotion (Wuerker, 1994:389-407). Excessive interest and being intrusive contains overprotection and behaviors like being restrictive, controlling and intrusive (Berkun, 1992:104-7; Deniz, İlnem and Yener, 1998:5-15; Cited: Tutarel-Kışlak et al., 2012:27-46). Expressed emotion is a measurement of family members' attitudes and behaviors towards the patient. At the same time, it considered as a measurement of emotional atmosphere and quality in the life of the family and home environment (Berkun, 1992:104-7; Cited: Tutarel-Kışlak et al.2012:27-46).

When the literature is examined, it is seen that concept of expressed emotion based on a study which made with schizophrenic patients and lasted for years in Medical Research Center, the UK . Brown, Carstairs and Topping (1958) discovered that schizophrenic patients' success is associated with the behavior of people in the place they returned when they're discharged (Norman and Malla, 1993:161-174; Hoste and Grange, 2008:395-400; Karancı and İnandılar, 2002:80-88; Cited: Hayta, 2009).

High levels of expressed emotion indicate that the individual has hostility, criticism of high intensity or overprotecting/caring attitude towards the patient. Studies which made with relatives of people with schizophrenia shows that families which has less expressed emotions can manage problems easier than the others. When expressed emotion is high, individuals have some problems to manage problems about patient so it shows that expressed emotion is not stable (Tüzer et al., 2003:198-203 Cited: Hayta, 2009).

It is understood that individuals show less expressed emotion when they feel strong and adequate, however, they show more expressed emotion if they feel weak and inadequate. The strength of the family members may affect by the variables of the patient (the severity, duration and individual differences of the disease) and other variables related to members themselves (information about the disease, experience, personality). It is stated that expressed emotion reflects the shape of the interaction between the patients and their relatives but it is not clear that how patient's relatives' personalities affect on the communication or until what level they are affected by the patient (Erol and Yazıcı, 2000:7-15 Cited: Hayta, 2009). Cultural and social structure of the individual, income level and the gender of the parents were reported to be associated with expressed emotion (Erol and Yazıcı, 2000:7-15, Cited: Hayta, 2009).

It is seen that expressed emotion was investigated in clinical diseases and families when research that made at home and abroad were analyzed (Örn.,Berkun, 1992:104-107; Cosci Londi, Patussi and Sirigatti, 2011:17; Cruise, Sheeber and Tampson, 2011:781-784; Ebrinç et al.,2001:5-14; Gavazzi et al.,2000; Guerro, La Valley and Farinelli, 2008: 699-724; İlnem, Çete, Deniz and Yener, 1998:12-20; Ingoldsby, Horlacher, Schvaneveldt and Matthews, 2005:25-44; Mc Farlane and Cook, 2007:185-97; Subandi, 2011. 331-346; Tüzer et al.,2003:198-203; Cited: Tutarel-Kışlak et al., 2012:27-46).

Gartland and Day (1999) found that perceived level of expressed emotion in children with clinically more severe asthma is higher than the others in a study they made with 32 asthmatic children and their parents ranging from ages 5 to 12 years (Gartland and Day, 1999: 573-584 Cited: Hayta, 2009)

It was mentioned earlier that expressed emotion concept is based on the studies made patients with schizophrenia. Also ASD is a compelling case like schizophrenia that affects the relatives of patients. Clark (1989) indicates that ASD may increase the risk of schizophrenia in the future (Clarke et al., 1989:692-699; Cited Bora, 2008:39-46). The prevalence of schizophrenia has been reported to be high in ASD according to the Volkmar and Cohen's (1991:1705-1707 Cited Bora, 2008:39-46), research. Stahlberg, Soderstrom, Rastam and Gillberg, (2004:891-902 Cited Bora, 2008:39-46) reported that 15% of schizophrenia or psychotic bipolar disorder seen in ASD. It is a neurodevelopmental disease with the prevalence of rapid acceleration. ASD is also a disability from a social aspect. It involves a lifelong process that affects and forces family.

The relationship between ASD and expressed emotion that reflects interaction with the patient relatives was observed that is not discussed enough in the literature.

Various inhibitions, strains, conflicts, sudden and adverse changes that may occur in life and they can affect the life satisfaction of individuals. Researches show that having a disabled child increases parents' stress, anxiety and fear and adversely affects their future expectations (Cin and Kılıç, 2005:1-24). This situation will be able to affect the life satisfaction of the parents. The parents to have a child with disabilities are a condition that affects the life satisfaction. It will be described in the next section.

## **2.6. Life Satisfaction**

The concept of life satisfaction was introduced by Neugarten, Havinghurt and Tobin (1961:134-143) for the first time. He described the concept of satisfaction as fulfilling requests, expectations and wishes. Budak (2000) determined it as re-establishment of equilibrium after fulfilling biological needs like hunger in organism, thirst, sex, etc. and psychological needs such as love, intimacy, success and curiosity (Cited: Akandere , Acar and Baştuğ, 2009:24-32)

According to Dimmer, Emmons, Larsen and Griffin (1985:71-75), life satisfaction is individuals' emotional reactions to their free times, work etc (Cited:Sarıkaya, 2011) Likeable and unlikeable emotions are expressed as positive-negative sensation. Life satisfaction is referred as cognitive assessment within the life

of the individual. The comparisons that individuals make about life standards create values on their life (Diener et al., 1985:71-75; Cited : Sarıkaya, 2011). These standards might be their own criteria for a good life or general judgments that they care (Şahin, 2008; Cited: Aydemir, 2013). However, it is emphasized that the overall judgment is more important than satisfaction in the life (Pavot and Diener, 1993:164-172; Cited :Toprak, 2014).

There's a positive correlation between positive mood, life satisfaction and subjective well-being (Diener and Suh, 1997:189-216 Cited: Toprak, 2014) Veenhoven (1996:11-48) identified life satisfaction as quality of life as a whole and the degree of positive development. Determining factor in life satisfaction were divided into three groups. These are changes in life, being experienced against life events and internal progress of development (Veenhoven, 1996:11-48: Cited: Güler and Emeç 2009:129-149). Life satisfaction also expresses how much the individual likes his/her own life. Having a meaningful life, enjoying the life, having more responsibilities and busyness were found to be associated with life satisfaction for individuals (Peterson, Park and Seligman, 2005:25-41, Cited: Güler and Emeç 2009:129-149).

The level of life satisfaction is an indicator that gives information about individual's mental health. People who have reached their wishes and goals have higher life satisfaction. They are happy and healthy (Gümüşbaş, 2008).

Challenging situations that individuals experience in their lives might cause decrease in their satisfaction of life. There are many variables that affect the life satisfaction levels. These variables are age, retirement, gender, education, income level, marriage, family and social life, stress level, physical health status, lifestyle and personalities etc. erdir (Chow, 2005:139-150, Cited: Güler and Emeç 2009:129-149). Also, social relations, sex life, success, physical activity, obsession with nature, reading or listening music, eating and drinking have positive effects on life satisfaction (Dockery, 2003:1-20 Cited: Güler and Emeç 2009:129-149).

Having a disabled child is one of the challenging experiences in life for the family. The presence of disabled individual is harder for mother (Eracar and Onur, 1999; Eracar, 2003). To having a disabled child increases parents' stress, anxiety and

the level of concern. It also decreases their future expectations (Cin and Kılıç, 2005:1-24). Negatively affected expectations can affect parents' life satisfaction. But individuals who use proper ways to handle the stress of having a disabled child have higher life satisfaction (Deniz, 2006:1161-1170: Cited: Deniz et al., 2009:953-968).

When Kanner's (2001:33-48) research about the stress, social support and life satisfaction of parents who have children with disability was examined, Rating Scale for Family Stress, Family Support Scale and Satisfaction With Life Scale were applied to 104 mothers and 102 fathers who have children with mental disabilities, 101 mothers and 109 fathers who have hearing-impaired children, a total of 416 people. It was found that the parents who have children with mental disability have higher life satisfaction level than the parents who have hearing-impaired children.

Arslan, Hamarta and Deniz (2002:161-170) investigated that being parents of disabled child and life satisfaction level of parents according to the child's gender and the type of disable. The results showed that there are no significant difference between the life satisfaction of the parents according to the gender of disabled child and the state of being parents of children with disabilities. However, parents who have children with orthopedic disabilities have less life satisfaction than the parents who have children with mental disabilities, hearing and speech impaired children.

Dilmaç and Arıcak (2009: 954-968) investigated the instant-constant anxiety impact on life satisfaction of parents who have children with disabilities. As a result of research, it has been seen that instant-constant anxiety affects life satisfaction in a significant way. Parents' instant-constant anxiety and life satisfaction differ significantly according to the type of children's disability.

The next section will focus on the concept of posttraumatic growth with the thought of having a child with disabilities is one of the major traumatic events in the life of human.

## **2.7. Posttraumatic Growth**

Trauma is all short of events that hurts, horrifies and wounds individual's mental and physical presence in many ways (Öztürk and Uluşahin 2011:496-496). Experienced life event is severe so it makes individuals desperate and prevents the use

of their existing coping mechanism (Türksoy, 2003:165-178). It includes events which is a major threat to the physical or mental integrity of the person himself or relatives. These events are severe and traumatic and they come suddenly. Affecting by the acute event is closely related to the severity of the event (Öztürk and Uluşahin 2011, 496-497).

Mental health problems and signs of stress occurring in individuals, some developments called posttraumatic growth may also occur. The concept of posttraumatic growth expresses observed positive psychological changes after trauma (Tedeschi and Colhoun, 2004:1-18) Many different expressions are used for these positive changes that occur after trauma such as stress-related development, posttraumatic growth, transformational coping, benefit, durability.

Research in posttraumatic growth in trauma has started in the middle of the 1980s on groups who have experienced trauma and they have increased in recent years. These studies were performed on cancer patients, people with HIV, people who have been abused and raped, people who have heart attack. In short, these studies were conducted in populations living in various types of trauma and the relationship between various variables was investigated. The event that led to the formation of posttraumatic growth is psychologically traumatic (Tedeschi, Park and Calhoun, 1998:1-23).

Experienced traumatic events give individuals a deep shock about the structures formed by them with experience gained throughout their life. Individuals confronted with the negative effects of trauma even if they want to restructure themselves and this causes brief reactions. Some individual try getting out of this negative situation and building them selves a better life. So they see their situation as a new beginning, not a loss (Tedeschi et al., 1998:1-23). This conditions cause them to create more successful coping mechanisms and being more powerful against new traumas. A person separates his/her life into two parts as before and after the trauma. There is an improvement if individuals have positive changes in their lives (Tedeschi et al., 1998:1-23).

Posttraumatic growth is a process that associated with posttraumatic stress according to Tedeschi and Calhoun (1998). In recent years, the concept of



Posttraumatic Growth is gaining importance and taking its place in research. In this study, the use of the concept of posttraumatic growth is preferred.

Posttraumatic growth is divided into three groups including ‘changes in the self-perception, interpersonal relations and philosophy of life’ (Tedeschi et al.,1998:1-23, Cited: Güven, 2010).

### **2.7.1. Changes in the self-perception**

Traumatized people often know their power. They have a confidence based on previous experience against the new traumas that can be experienced. The change in self-perception takes place in three areas.

#### **2.7.1.1. Victim statement against survivors**

It means that the person sees himself/herself as a survivor, not a victim of trauma. A person also perceives himself/herself as an important and strong person.

#### **2.7.1.2. Self-confidence**

When literature studies are examined, it is stated that surviving from a traumatic experience makes individuals feel stronger. They can improve the ability of finding better coping strategies for the possibility of living another traumatic experience in the later stages of their life.

#### **2.7.1.3. Getting hurt easily-sensitivity**

Some of the people that can develop after trauma understand their power and know that life is precious. They are individuals who aware of being mortal and vulnerable. But it does not mean that they feel less need for social support. A feeling of strength leads to expect more social support and it causes them not to choose social support groups which are less useful ones (Tedeschi et al.,1998:1-23).

### **2.7.2. Changes in interpersonal relations**

Changes in interpersonal relations are divided into two groups. These are self-disclosure and emotional expression with pity-compassion and transferring these feelings to other individuals.

### **2.7.2.1. Self-disclosure and emotional expression**

The need for sharing the results of their traumatic experiences can cause individuals to open themselves more to others. Although self-disclosure allows people to exhibit different behaviors, it also directs them to the most appropriate person to seek support.

To being aware of their sensitivity, more expressed emotion and being open to all help can cause the use of social support that have not been evaluated previously. As a result of traumatic experiences, some people tend to share their feelings about the negative aspects of the event (Tedeschi et al., 1998:1-23). In a study of prostate cancer survivors and their spouses showed that use of the emotional support helps patients to express their feelings. Therefore, it is concluded that it helps them get through this negative process easier (Thornton and Perez, 2006:285-296; Cited: Çolakoğlu, 2013)

### **2.7.2.2. Pity/compassion and transferring these feelings to other individuals**

In posttraumatic growth, it requires more intensely expressed emotion because a person knows he/she can get hurt. So, these people have a more sympathetic approach to others. After a traumatic experience in interpersonal relationships empathy, compassion, and sensitivity is enhanced. They may feel the need to help people who have similar trauma also they can establish empathy and develop compassion and kindness towards them. Need to transfer the downsides that they lived before, knowledge and experiences about how to stay alive after a trauma are another development which observed in individuals who have experienced trauma. However, this type of development is seen through a certain time has passed after trauma, when they realize that they endure hardship and understand that they survive. At the same time, the point to consider is, helping other individuals who are in difficult situations allows more healing. More awareness about the struggles of the individual may be provided by using the way of social comparison (Tedeschi et al., 1998:1-23).

### **2.7.3. The change in the philosophy of life**

This change is third positive development in posttraumatic growth. Accepting the trauma and its effects leads to a new perspective to life with the reasons may be turned into the meaning of life and it is a relief to a person's emotional life. New changes taking place in this perspective understand the importance of life and what priorities should be first, searching for the meaning of existence, spiritual growth and wisdom (Tedeschi and Calhoun, 1996:455-471).

#### **2.7.3.1. The value of life and priorities**

People who experienced trauma state that they see surviving from a trauma as a chance, they know the importance of every moment of life and they are happy for little things in life. Creation of awareness, which is a significant improvement after trauma, allows people to change their priorities and perspective of life. Having a major stressor might cause a realization to a person that he/she should give more priority to their relations (Tedeschi et al., 1998. 1-23).

#### **2.7.3.2. Existence-related theme and search for meaning**

People who experienced trauma question the meaning of life more intensely than the others. People understand the importance of life and existence if they have experienced trauma in their lives. However, this does not mean that they can't find successful solutions to their problems (Tedeschi et al., 1998:1-23).

#### **2.7.3.3. Mental / spiritual development**

Shaw, Joseph and Linley (2005:1-11), have suggested that there are many consistent evidence about the idea that religion and spirituality is effective in the development process after the trauma in the review of the literature that examines the relationship between religion and spirituality with posttraumatic growth. This evidences show that religion and spirituality reduce the effects of trauma and they help people to see trauma as a religious challenge, not a problem. Also, religion and spirituality allows people to create a cognitive framework which provides personal/spiritual development (Cited: Çolakoğlu, 2013)

#### 2.7.3.4. Wisdom

In posttraumatic growth, wisdom is defined as a result of compliance. There are three patterns of wisdom that play a role in compliance. These are recognizing and managing uncertainty, combine information with emotion and recognize and accept the limits as an individual. It is demonstrated that these patterns are taken into account in the process of adaptation after trauma (Linley and Josep, 2004:11-21). The individual's understanding of the value of his/her own life, regulation of life priorities, knowing the coping strategies when they are needed and the processes like these are associated with wisdom (Cited: Çolakoğlu, 2013) There are many studies abroad related to posttraumatic growth. In the research that Windows, Jacobsen, Booth-Jones and Fields (2005:266-273) did, predictors of posttraumatic growth were investigated on individuals who had a bone marrow transplant. Being young, low education level, use of coping mechanisms of solving problems with the use of positive reinterpretation and alternative reward quest are associated with posttraumatic growth after transplantation (Cited: Çolakoğlu, 2013)

Schroevers, Helgeson, Sandermen and Ranchor (2010:16-53) investigated posttraumatic growth longitudinally on cancer survivors. In this study, Posttraumatic Growth Inventory was applied the patients twice after three months and eight years of receiving a diagnosis of cancer. As a result of regression analyses, it was revealed that getting more emotional social support after three months of receiving a diagnosis of cancer significantly to experience positive results after illness (Cited: Çolakoğlu, 2013)

A study on posttraumatic growth in recent years in our country is gaining importance. One of these studies shows development after a trauma which experienced by couples who lost their child. In this study, it was found that having another child and age factor affects the development significantly (Yıldırım, 2003, Cited: Çolakoğlu, 2013). In another study, posttraumatic growth and related factors were investigated on the caregivers of patients with schizophrenia. As a result, it was found that being a young caregiver, give care to young patients, the presence of social support and problem-focused coping are variables that associated with posttraumatic

growth (Özlü, Yıldız and Aker, 2010:89-94). In our country, it is seen that the work done on posttraumatic growth is more about earthquakes and diseases (Cited: Çolakoğlu, 2013)

When the literature about the families who have children with ASD is investigated; during a quantitative study, Phelps, McCammon, Wuensch and Golden (2009:133-141) stated that the main sense is stress in the families who have a child with ASD. But families can emphasize the richness of the inner world and the feeling of growth, too.

Even if many quantitative studies mention serious emotional disturbance in families who have children with ASD, some of them contains some positive results. These positive results are posttraumatic growth. A person's environment and social support after trauma and the accessibility of this support are development-enhancing factors (Başoğlu, 2002:9-25).

Research shows that social support is an important predictor of posttraumatic growth. There is a positive correlation between perceived social support and posttraumatic growth. For example, Dirik's study (2006) which is about the level of posttraumatic growth that examined of 117 patients with rheumatoid arthritis, Güven's study (2010) which is about the relationship between perceived social support and the level of depression on people who experienced the Marmara earthquake, Bayraktar's study (2008) which is about the level of posttraumatic growth on 78 cancer patients.

## **2.8. Purpose And The Importance Of The Study, Research Hypotheses**

### **2.8.1. Purpose of the study**

The overall purposes of the search are examined the life satisfaction and posttraumatic growth of mothers who have children with ASD and investigate the relationship with some variables about them.

Predictor variables are the mother's socio-demographic characteristics (age, education) and characteristics of children with ASD (age, gender, percentage of disability, level of qualification in self-care, the duration of the disease, ASD behavior symptom level). Also mothers who have children with ND were included in the study

as a comparison group. Care burden, dyadic adjustment, multidimensional perceived social support, expressed emotion, life satisfaction and posttraumatic growth were also investigated in this group. For this purpose, mothers who have children with ASD have higher levels of expressed emotion, posttraumatic growth and burden of care, however, they have less dyadic adjustment, multidimensional perceived social support and life satisfaction compared to the mothers who have children with ND is the main hypothesis of the research.

### **2.8.2. The research hypothesis**

The following hypothesis will be tested in research:

1. The level of burden of care is higher for the mothers who have children with ASD compared to the mothers who have children with ND.
2. The burden of the care of mothers who have children with ASD is associated with mothers' socio-demographic characteristics, symptom level, the duration of the disease, percentage of disability, the degree of dependency and dyadic adjustment.
3. Mothers' (who have children with ASD) life satisfaction is lower than the mothers who have children with NG.
4. The level of behavioral signs of ASD affects mother's burden care, dyadic adjustment, expressed emotion and posttraumatic growth.
5. Posttraumatic growth levels of mothers who have children with ASD affect from socio-demographic factors such as age and education.

### **2.8.3. Limitations of the study**

1. The high education level of the majority of mothers of children with ND affects the homogenous of sample.
2. Determination of MR diagnosis of children with ASD as report, achieving this information based on the mother's statement and not applying the intelligence test for children are another limitations of the study.
3. Sample's not having the competence to represent the universe of the subject that is researched as number of participants is another limitation.

#### **2.8.4. The Importance of the study**

Having a disabled child brings very difficult problems in terms of social cohesion. This is a common problem for people with disabilities and their families. Mothers are more involved with the care, health and education of disabled children. Mothers put more effort in this situation.

Having a child with ASD is an unexpected thing for a mother. Also, it is a complex and incomprehensible condition in terms of the behavioral symptoms of ASD.

The cause of ASD is unknown and there is no proven treatment for it so these reasons make mothers feel desperate, hopeless and exhausted. Mothers have difficulties about what to do with their ASD children and this may affect their lives, too.

For this reason, research's results are important to understand the feelings and struggles of mothers who have children with ASD also it is important to determine the difference of mothers who have children with normal development.

In the research which was made with the families who have children with ASD, different dimensions were examined such as stress, anxiety, depression, hopelessness, social support and marital satisfaction.

It increases the importance of the study that examining the mother's own dimension in life with influencers and other individuals in many ways. Mother accepts this as a tragic event after receiving the diagnosis of child.

Another important point of research is, make mothers who have children with ASD feel that they are not alone and provide awareness to other individuals in society about them.

### **3. METHOD**

This study was made for searching the burden care, dyadic adjustment, multidimensional perceived social support, perception of expressed emotion, life satisfaction and posttraumatic growth of the mother who have children with ASD. This chapter includes the details about attendees, socio-demographic characteristics, measuring tools, the process of data collection and the statistical processes that are used.

#### **3.1. Research Model**

This study investigates whether there is a significant difference between mothers who have children with ASD and mothers who have children with ND about dyadic adjustment, multidimensional perceived social support, the level of life satisfaction, posttraumatic growth and expressed emotion. It also targets to find out the effects on mother if the child's level of behavioral signs of ASD has any effects on mother's independent variables. Rational screening model was used in this research.

#### **3.2. Universe**

Universe in this study is, mothers of children with ASD, children who attended special education institutions in the 2015-2016 academic year, and the mothers of children with ND who residing in the province of Bursa.

#### **3.3. Sample**

Sample is consisted of 122 mothers, 62(50. 8%) of them are mothers who have children with ASD and 60 (49. 2%) of them are mothers who have children with ND. The study has been reached to mother of children with ASD by visiting Education Center for Children with ASD and rehabilitation centers affiliate to the Ministry of Education. Mothers who have children with ND were included in the study by visiting various businesses and homes in the province of Bursa.

Age range of mothers of children with ND is 23-60 and the mean 37. 83 (SD = 7. 54). Age range of mothers of children with ASD is 23-59 and the mean is 38. 11 (SD =6. 51) Age of mothers is the normally distributed in all groups. Education year range of the mothers of children with ND is 5-16 and mean is 12. 77 years (SD= 3.



24). Education year range of mothers of children with ASD is 5-27 and mean is 8.13 years (SD= 3.47). Mothers' education is normally distributed. However, education years of the mothers of children with ASD are less than mothers of children with ND. Those who have seen more than 5 years of education between the mothers of children with ASD are in the first order with 27.9% rate.

When the marital statuses of mothers of children with ND are considered, 91.7% were married and this rate is 95.2% when we look at the mothers of children with ASD. When the children number of mothers of children with ND are examined, the rate of mothers with one child is 48.3% (n = 29) and the rate of children number of mothers of children with ASD, the rate of two child is 59.7% (n = 37). While 57 mothers of children with ND (95%) are working, only 4 mothers of children with ASD (6.5%) are employed. 3 of mothers with ND children (5%) are not working, 58 mothers with ASD children (93.5%) do not work. According to the working conditions of all groups, there is no statistically significant difference ( $\chi^2= 95.63$   $p<0,000$ ) 42.6% of mothers of children with ASD (n = 52) is a housewife and this is followed by teachers with a rate of 11.5% (n = 14).

Socio-demographic characteristics of mothers who constitute the study sample is shown in Table 3.

**Table 3. Socio-Demographic Characteristics of the Mothers of ND and ASD**

Variable	ND				ASD				Chi-Square	
	(N=60)				(N=62)				X <sup>2</sup>	p
	N	%	X±SD	Range	N	%	X±SD	Range		
<b>Age of Mothers</b>			37.83±7.54	23-60			38.11±6.51	23-59		
<b>Education Level of Mothers (Years)</b>			12.77±3.24	5- 17			8.13±3.47	5-16		
<b>Marital Status</b>	Married	55	91.7		59	95.2				
	Divorced	4	6.7		3	4.8				
	Widow	1	1.7		0	0				
<b>Divorce Duration (Years)</b>			2.5 ± 1.73	1-5			3.67 ±3.06	1-7		
<b>Number of Children</b>	One Child	29	48.3		14	22.6			10.34	0.016*
	Two Children	27	45		37	59.7				
	Three Children	4	6.7		10	16.1				
	Four Children	0	0		1	1.6				
<b>Working Status</b>	No	3	5		58	93.5			95.63	0.000*
	Yes	57	95		4	6.5				
<b>Residence</b>	Village	1	1.7		3	4.8			16.38	0.000*
	District	2	3.3		18	29				
	Province	57	95		41	66.1				
<b>Who lives with?</b>	My husband and child or children	54	90		56	90.3				
	Me and my child or children	3	5		2	3.2				
	Other	3	5		4	6.5				
<b>Does mother have physical ailments?</b>	No	60	100		58	93.5			4	0.045*
	Yes	0	0		4	6.5				
<b>Does mother have a psychiatric disorder?</b>	No	60	100		53	85.5			9.4	0.002*
	Yes	0	0		9	14.5				
<b>Is there a usage of psychiatric drugs?</b>	No	60	100		55	88.7			7.19	0.007*
	Yes	0	0		7	11.3				
<b>Is there any disabled person between other family members?</b>	No	60	100		60	96.8			1.97	0.161
	Yes	0	0		2	3.2				
<b>Is there somebody with chronic illness between other family members?</b>	No	56	93.3		48	77.4			4.94	0.026*
	Yes	4	6.7		14	22.6				
<b>Who else is responsible from the care of the child?</b>	Only My Husband	38	65.5		16	25.8			20.02	0.000*
	Only Me	10	17.2		24	38.7				
	My husband and Children	4	6.9		13	21				
	My husband, Children and Relatives	3	5.2		4	6.5				
	Other	3	5.2		5	8.1				

\* P &lt;0, 05

After that, socio-demographic information will be given about children of mothers of sampling.

There are 62 children with ASD and 60 children with ND in the sample of study. When gender distribution of ND children is examined, 37 (% 61. 7) are girls and 23 (% 38. 3) are boys. When the gender distribution of ASD children is examined, 23 (% 38. 3) are girls and 52 (% 38. 3) are boys ( $\chi^2=26. 69$   $p<0. 000$ ). Groups in terms of sex are not showing a normal distribution. In all groups, the number of boys is greater than the number of girls. At the same time, number of boys in ASD children is greater than number of girls.

When the education level of ASD children is examined, 58. 1% ( $n = 36$ ) had been training in Special Education and Rehabilitation Center and it is followed by Autistic Children Education Center with a rate of 43. 3% ( $n = 26$ ). The question asked for the mothers about the disability percentage of children with ASD, disability percentage point range declared by the mother is between 40 and 99 ( $78.53 \pm 17:28$ ) according to Health Board Report. When the diagnosed years of ASD children examined, the first diagnoses range is between 1-18 years ( $8.02 \pm 4.82$ ). Education year of ASD children is between 1-17 years. The first diagnosed year and education year is correlated with each other.

Mothers of children with ASD in the study has answered the question about their children have any other disease or not as 57. 9% ( $n = 22$ ) obsession and 31. 6% ( $n = 12$ ) mental retardation. The question of how much their children are depended to fulfill their self-care as walking, eating and dressing asked to the mothers participating in the study. It is reported that 80. 6% ( $n = 50$ ) is independent while walking, 40. 3% ( $n = 25$ ) is half-dependent while eating, 48. 4% ( $n = 30$ ) is half-dependent while dressing/undressing, 41. 9% ( $n = 26$ ) is half-dependent while going to toilet and 46. 8% ( $n = 29$ ) is dependent while cleaning.

Socio-demographic characteristics of the mothers' children form the study sample is shown in Table 4.a,4.b.

**Table 4.a Socio-Demographic Characteristics of the Children with ASD and ND**

Variable		ND				ASD					
		(n=60)				(n=62)					
		n	%	X±SD	Range	n	%	X±SD	Range	X <sup>2</sup>	P
Age				10.58±6.5	1-26			11.53±5.14	4-21		
Sex	Girl	37	61.7			10	16.1			26.698	0.000*
	Boy	23	38.3			52	83.9				
Order Number of Children	Only one	30	50			14	22.6			10.17	0.017*
	First Child	15	25			25	40.3				
	Second Child	13	21.7			21	33.9				
	Third Child	2	3.3			2	3.2			122	0.000*
	Fourth Child	16	26.7			0	0				
	Fifth Child	0	0			3	4.8				
	Education Level	Not going to school	16	26.7			0	0			122
Primary School		0	0			3	4.8				
Special Subclass		0	0			12	19.04				
Special Education		0	0								
Rehabilitation Center											
Ocem		0	0			11	17.7				
Ocem +Rehabilitation		0	0			0	0				
Primary School		26	43.3			8	13.3				
High School		10	16.7			0	0				
University		8	13.3			0	0				
Disability Percentage								78.53±17.28	40-99		
First Diagnosis Year of ASD Children								8.02±4.82	1-18		
Another Problem of the Child with ASD		No				24	38.7				
		Yes				38	61.3				
Accompanying Problems		Epilepsy				2	5.3				
		Sleep				0	0				
		Obsession				22	57.9				
		Fear				0	0				
		Solid Food Refusal				1	2.6				
		Allergy				0	0				
		Constipation				1	2.6				
		Hearing Loss				0	0				
		Superior Intelligence				0	0				
		Mr				12	31.6				
		Asperger's Syndrome				0	0				
		Other				0	0				

\* P &lt;0, 05

**Table 4.b Socio-Demographic Characteristics of the Children with ASD and ND**

Variable	ND				ASD						
	(n=60)				(n=62)						
	n	%	X±SD	Range	n	%	X±SD	Range	X <sub>2</sub>	P	
Dependency on Mother While Walking	Independent				50	80.6					
	Half-Dependent				8	12.9					
	Dependent				4	6.5					
Dependency on Mother While Eating	Independent				20	32.3					
	Half-Dependent				25	40.3					
	Dependent				17	27.4					
Dependency on Mother While Dressing/Undressing	Independent				11	17.7					
	Half-Dependent				30	48.4					
	Dependent				21	33.9					
Dependency on Mother While Cleaning	Independent				6	9.7					
	Half-Dependent				27	43.5					
	Dependent				29	46.8					
Dependency on Mother While Going to Toilet	Independent				14	22.6					
	Half-Dependent				26	41.9					
	Dependent				22	35.5					
Do mothers find special education enough for their children?	No				38	63.3					
	Yes				22	36.7					
Education Duration of Special Child (in Years)					7.34±4.54					1-17	
Is there a usage of drugs?	No				26	41.9					
	Yes				36	58.1					
Do they exercise?	No				58	93.5					
	Yes				4	6.5					

\* P &lt;0, 05

### **3.4. Data Collection Tools**

‘Autism Behavior Checklist’ was used to measure the ASD behavior symptom level, ‘Zarit Caregiver Burden Scale’ was used to investigate the burden of care for mothers who have children with ASD, ‘Dyadic Adjustment Scale’ was used to measure the dyadic adjustment between the parents who have children with ASD, ‘Multidimensional Perceived Social Support Scale’ was used to investigate the social support from outside, ‘Expressed Emotion Scale’ was used to measure expressed emotion of mothers for the children, ‘Satisfaction with Life Scale’ was used to measure life satisfaction of mothers who have children with ASD and ‘Posttraumatic Growth Scale’ was used to determine the level of posttraumatic growth because of the trauma that mothers can experience depending on the having children with ASD. ‘Socio-demographic Data Form’, which was held by the researcher, was used for the collection of personal information of mothers.

#### **3.4.1. Socio-demographic data form**

Socio-demographic data form consists of questions about the mother and the child. In the first part, they are with their mother, while the second section contains questions about the child. In the first part, following questions were asked to mother; age, education status, job, place of residence (village, district, province), marital status, duration of divorce (if she divorced), number of children, whom she is living within the family, whether there is another individual who has a chronic illness or disability in the family, who is dealing with the care of children with ASD, whether the mother has physical or psychiatric disorder and for this reason, the question of taking any medication.

In the second part of socio-demographic, data form has questions relating to children. Following questions were asked to children: age, gender, education status, the percentage of disability according to the health report and diagnosis, the first diagnosis time, other disorders associated with ASD symptoms, the level of dependence on parent in the self-care, since when the child has received a private school education, mother’s satisfaction level from the education and her suggestions, whether the disability that accompanies another disease, child’s level of dependency

to mother about walking, nutrition, dressing and sanitation, child's medicine use and the exercises that he/she should do regularly.

### **3.4.2. Autism behavior checklist (ABC)**

Autism Behavior Checklist was improved by Krug, Alrick and Almond (1978) and it was revised at 1993 and 2008. The scale is called 'ABC' and it is used for screening and evaluation of training in our country. ABC is one of the five subscales of the Autism Screening Instrument for Educational Planning tool (ASIEP-2) (Bildt et al., 2005:672-681; Eaves, Campbell and Chambers, 2000:311-321; Sevin, Matson and Coe 1991:417-432; Cited: Yılmaz-Irmak, Tekinsav-Sütçü, Aydın, Sorias, 2007:13-23). ABC's 1993 version maintains; 9 questions in sensory sub-scale (6-10-21-26-34-39-44-52-57), 12 questions in relationship building sub-scale (3-7-13-17-24-25-27-28-33-38-43-47), 12 questions in use of body and object sub-scale (1-5-9-12-16-22-30-35-40-51-53-54), 13 questions in language skills sub-scale (4-8-11-15-18-20-29-32-37-42-46-48-56) and 11 questions in social and self-care subscale (2-14-19-23-31-36-41-45-49-50-55). It is an assessment tool that consists of five subscales. 57 articles that define ASD symptoms in ABC have been obtained as a review results of previously developed tool. Items in the scale were corrected again by the 26 ASD experts. Scale was sent to 3,000 people working in the field of special education in order to determine the validity of the content and was asked to fill in for someone they knew. Experts participating in the study were collected data from 1049 people. These people are 172 people with ASD, 423 idiot people, 254 people who have emotional problems, 100 people with hearing and vision disabilities and 100 people who do not have any disorder. 2x2 square table is used to find the frequency of behavior definition in sub-groups which is included in sample. It was found that 55 of the 57 behavior definition can significantly predict ( $p < .000$ ) the diagnosis of ASD. Square analysis proved that behavior definitions in ABC are associated with ASD (Krug et al., 1993; Cited: Yılmaz-Irmak, Tekinsav-Sütçü, Aydın, Sorias, 2007:13-23).

Statistical analysis of proportional reduction in error (PRE) was used to determine the power in the relationship between emotional behaviors and ASD (Krug et al., 1993; Cited: Yılmaz-Irmak, Tekinsav-Sütçü, Aydın, Sorias, 2007:13-23). Weight scores ranging from 1-4 for each statement are given according to gram and Phi scores which were determined in this analysis.

ABC is an easy scale because it provides information about the children from parents and teachers (Krug, 1993). The scale has a score between 1 and 4 that associated with the relationship with ASD against each item in scale. The participants decide whether the item is appropriate for their child and they mark the score if it's appropriate. A total score is obtained by adding up all the scores that are marked. Cut-off point was identified as 68 in the original test. So a score of 68 and above is considered as areas of suspected child with ASD. The total points that obtained are change between 0 and 159 in the version of 1993. Validity and reliability study of the scale in Turkey were made by Yılmaz Irmak, Tekinsav-Sütçü, Aydın and Sorias (Yılmaz-Irmak, Tekinsav-Sütçü, Aydın, Sorias, 2007:13-23). Scale is found to be reliable and valid for Turkey according to all the findings from the study. This scale's cutoff point is identified as 39. The children who scored 39 are considered as ASD patient. The results in the original scale can be grouped as mental retardation, learning disabilities, blindness or deafness. However, the Turkish validity and reliability study found autism was only cut-off point.

### **3.4.3. Zarit caregiver burden scale (ZCBS)**

This scale was developed by Zarit, Reever and Bach-Peterson (1980. 449-655) Inci and Erdem (2008:4) did scale's Turkish study. This is a scale that used to evaluate the problems of caregivers. It consists of 19 statements about the effects of being caregiver on the lives of individuals. It has Likert-type evaluation that includes 5 statements such as never, rarely, sometimes, usually and always. The scale scores are high, suggests that the burden of the care giving of living is high (Özlü, Yıldız and Aker 2009:38-42). Scale questions are divided into five groups. The first group are the questions covering the deterioration of mental tension and private life (2, 3, 10, 11, 12, 17 and 19). The second group is the questions which measure nervousness and restriction (5 and 9). The third group are the questions that measures the distortion of social relations (6, 13 and 18). Our fourth group is the questions 7 and 15 that examine the economic burden. The dependency is measured in the last group (8 and 14). In our study, Zarit Caregiver Burden Scale was applied. Zarit Caregiver Scale was applied in this study which consist of 19 items of 'Zarit Caregiver Burder Scale's validity and reliability study on relatives of patients with schizophrenia' (Özlü et al., 2009: 38-42).



#### **3.4.4. Dyadic adjustment scale (DAS)**

It was prepared by Spanier (1976:15-28) to evaluate the quality of relationship as the perspective of married couples or couples who live together. The scale consists of 32 items and yes-no questions and it was edited by Likert-type. There are four subscales in the scale.

- 1) Peer consensus subscale: It consist of 13 items related to the level of agreement on key issues in the marriage (Substances that are numbered as 1, 2, 3, 5, 7, 8, 9, 10, 11, 12, 13, 14 and 15).
- 2) Peer to Peer Satisfaction Subscale: Evaluates the positive and negative characteristics related to emotion and communication that consists of ten items (Substances that are numbered as 16, 17, 18, 19, 20, 21, 22, 23, 31 and 32)
- 3) Peer-to-peer Cohesion Subscale: It consist of 5 items related to the behaviors do with the time spent together, exchange of ideas and debating calmly(Substances that are numbered as 24, 25, 26, 27 and 28).
- 4) Subscale of Emotional Expression :It consist of 4 items about agreements on ways to show love and showing affection behavior (Substances that are numbered as 4, 6, 29 and 30)

Received highest score is 151 and lowest score is 0 in the scale. The rise in the total score shows the total harmony of the couple in marriage. It indicates the mismatch in marriage if the scores are lower than 98. DAS is a scale that is used in many different cultures. The Turkish adaptation of the scale was made by Özkan (1995) and validity and reliability studies were made by Yavuz (1995). Turkish validity of dyadic adjustment scale was made by Fışıloğlu and Demir (2001:215-222). In the Turkish sample of the study of validity and reliability which was made by Fışıloğlu and Demir; it was found that the mean score for male is 103, 7 (S. D. =18, 8), for female is 105, 2 (S. D. =18, 4) including an mean 104, 5 (S. D. =18. 6). The internal consistency reliability of the scale results in a Turkish sample, the result was 0. 92 in a way that is close to the original result. In addition, the reliability of the results is sub-scale shows little difference from the original and it is between 0. 75 and 0. 83.

### **3.4.5. Multi-dimensional scale of perceived social support (MPSSS)**

This scale was developed by Zimet and Dahlem in United States of America (Zimet, Dahlem, ZimetandFarley, (1988:30-41)). In Turkey, the validity, application and reliability studies were made by Eker and Arkar (1995:45-55), Çakır and Palabıyık (1997:15-24), Eker, Arkar and Yıldız (2001:17-25) MPSSS is a scale that evaluates subjectively the adequacy of social support received from three different sources (family, friend and a special person). It consists of 12 items and is easy to use. This scale contains three groups about the source of social support, each consist of four items. The proposed sub-scale structure also includes the support received from a special friend. Factor analysis supports the three-factor structure (Kazarian and McCabe, 1991:150-160; Zimet et al., 1988: 30-41; Eker and Arkar, 1995:45-55). Each item rated between absolutely no=1 and absolutely yes=7 by using Likert scale which consist of 7 parts. 3, 4, 8 and 11<sup>th</sup> substances evaluate family support. 6, 7, 9 and 12<sup>th</sup> substances evaluate the friend support while 1, 2, 5 and 10<sup>th</sup> substances evaluate the support of a special person. The lowest score that can be taken is 4 and the highest score is 28 from the subscale. The highest score is 84 and lowest score is 12 which can be taken from the total scale score obtained by summing up the scores from the subscales. The scale has no cut-off point. The higher scores obtained from the scale implies that high received social support. The Turkish form of MPSSS's factor structure, validity and reliability has been found generally satisfying. Eker and ark., 2001: 17-25).

### **3.4.6. Expressed emotion scale (EES)**

This scale based on the patient perception and self-perception of the relatives of patient. It has been prepared based on the concept of “expressed emotion” to quantify and qualify the emotional tone that accompanies the interactions in relationships by Berksun (1992). In total, it contains 41 substances. It is replied in the form of true/false and is rated between 0-1. As scores rise, the level of expression of emotion increases. Theoretically, the two sub-scales consist of criticism/hostility and excessive interest, protectiveness, simplistic, interventionism. Although there are substances depicting the positive attitudes and the feeling on the scale, these substances have entered into groups of criticism/hostility when the answers are taken under review as wrong. While preparing the substances, Turkish society and cultural

features have been taken into account. This is one of the strengths of the scale. The substances that are in the Criticism/Hostility sub-scale of the Expressed Emotion Scale (EES) are the substances that are numbered as 1, 2, 3, 6, 7, 8, 10, 11, 13, 14, 17, 18, 19, 20, 24, 25, 26, 27, 28, 29, 30, 32, 33, 34, 35, 38, 39, 40 and 41. The substances that are in the Emotional over Involvement sub-scale are the substances that are numbered as 4, 5, 9, 12, 15, 16, 21, 22, 23, 31, 36 and 37 (Berkson, 1992).

#### **3.4.7. Satisfaction with life scale (SWLS)**

Satisfaction with life scale is a scale prepared by Diener and his friends (1985:71-75) in order to determine an individual's life satisfaction. The test-retest reliability of the scale is found as .71. The scale consists a total of 5 items. Options are available from 1 to 7 in the Likert-type scales. When this 7 scale convert to scale, 1 is "Not really appropriate", 2 is "Not appropriate", 3 is "Not a bit appropriate", 4 is "Neither appropriate nor appropriate", 5 is "Little appropriate", 6 is "Appropriate", 7 is "very appropriate". The highest score that can be taken from SWLS is 35 and the lowest score is 5. High score from the scale represents the height of life satisfaction. Scoring of SWLS is as; 5-9 (too dissatisfied), 10 -14 (little dissatisfied), 15 – 20 (little satisfied) and 21 – 30 (satisfied). Although the number of scale items is little, Diener who developed the original has calculated the correlations of this scale with many other multi-point satisfaction scales and observed that this is at least .85. Turkish adaptation was made by Köker (1991).

#### **3.4.8. Posttraumatic growth inventory (PTGI)**

The scale developed by Tedeschi and Calhoun (1996:455-471) in order to evaluate the positive transformation of individuals consists of 21 items. Scale items include 5 subscales as "New possibilities", "Relations with others", "Personal empowerment", "Spiritual transformation" and "Knowing the value of life". The score is between 0 and 6 (0 = "I have never experienced such a change." 5 = "I have experienced extreme change. "). As a result of the reliability study made by Tedeschi and Calhoun (1996:455-471) conducted on the original form of the scale performed on college students, internal consistency coefficient is 0.90, the test-retest reliability is 0.71, internal consistency of the subtests is differing between 0.67 and 0.85. Turkish translation of Posttraumatic Growth Inventory and evaluation of

psychometric properties s performed by Dirik (2006) with rheumatoid arthritis patients. In the factor analysis conducted under the reliability-validity studies, 3 dimensions were determined as “Changes in self-perception”, “Changes in relationships with others” and “Changes in the philosophy of life”. It has seen that 0.92 for the changes in the dimensions of self-perception, 0.87 for the subscales relationships with others, 0.81 for the changes in the dimension of life philosophy and 0.95 for the total ingredients of reliability coefficient in a result of reliability analysis that is made to determine the psychometric properties of the scale.

### **3.5. Operation**

Research applications have started after receiving an approval from the Near East University Faculty of Medicine Ethics Committee. The mothers of 62 children who were diagnosed with ASD and studying in Bursa Autistic Children Education Center (OÇEM) and Special Bilgiç Special Education and Rehabilitation Center are taken as the workgroup. The mothers in the studying group have been reached in education center waiting room. Meeting all the mothers in the waiting room, the aim to being there and the importance of the study has been mentioned. Being the mother of the child with ASD (not being a sitter or relative) and being literate were searched as criteria to participate in the study by performing the individual first interview by contacting with mothers. Application has been launched with eligible mothers. A volunteer participant mother was informed about the scope of the investigation, who conducts the research and they can give up participating in this research when they want to by taking a quiet and comfortable room with the disclosure form and it is stated that the study is based on the voluntary participation. Firstly, questions were asked by researchers while filling of socio-demographic information form and communication with participants was established. Later, scales are given and asked to fill out. The order of the scale is arranged to include different combinations, so each scale was presented to the participants in random order. The application of the scale took about 30-60 minutes. Workplace and home visits has been made to reach the control group study. They were informed about the scope of the investigation, who conducts the research and they can give up participating in this research when they want to by taking a quiet and comfortable room with the disclosure form and it is stated that the study is based on the voluntary participation after the meeting. They are

asked to fill scales. Having a disabled person in family and being literate were searched as criteria to participate in the control group. Autism Behavior Checklist Scale which is in the research group has not been applied in the control group.

### **3.6. Statistical Analysis**

Statistical analysis of the scale of application in the study was performed with SPSS version 22 for windows which is Statistical Program for Social Sciences. Zarit Caregiver Burden Scale (ZCBS), Dyadic Adjustment Scale (DAS), Multi-dimensional Scale of Perceived Social Support (MPSSS), Expressed Emotion Scale (EES), Satisfaction with Life Scale (SWLS), Posttraumatic Growth Inventory (PTGI) and the Autism Behavior Checklist (ABC) for participants of children with ASD as an edition to them have been applied to investigate the hypothesis of the study for a total of 122 participants.

All data were examined and data cleaning was made, missing values were determined and put into their places. Chi-square was used for some socio-demographic characteristics that are categorical discontinuous variable. T test statistical analysis method was used for the comparison of intergroup scale. Groups were compared with the Mann-Whitney U for the subscales of Dyadic Adjustment Scale without normal distribution. Regression analysis was performed to identify the variables that can affect the Zarit Caregiver Burden Scale.

## 4. RESULTS

Analyzes related to answers the questions in the research is included in this part of study. Levels of caregiver burden, dyadic adjustment, multidimensional perceived social support, expressed emotion, life satisfaction and posttraumatic growth of mothers of children with ASD and ND are examined and the relationship between these variables and their impacts on the care burden are tried to be examined.

### 4.1. The Mean of Scores Received From All Scale And Standard Deviations

The mean and standard deviation values of the clinical scores obtained from 122 people are given in Table 5.a.,5.b.

**Table 5.a The Mean and Standard Deviations of Scores Obtained From the Scales**

Scales	Mother of Children with ND n (60)	Mother of Children with ASD n (62)
<b>Autism Behavior Checklist</b>		60. 69 ± 25. 32
<b>Sensorial subscale</b>		8. 79 ± 5. 58
<b>Relationship building subscale</b>		14. 68 ± 9. 21
<b>Body and object use subscale</b>		13. 05 ± 7. 96
<b>Language skills subscale</b>		10. 65 ± 6. 72
<b>Social and self-care skills subscale</b>		13. 05±7. 96
<b>Multidimensional Perceived Social Support Scale</b>	67. 60 ± 11. 58	49. 55 ±20. 17
<b>Special Human Dimension</b>	20. 50 ± 6. 73	13. 00 ± 8. 36
<b>Family support dimension</b>	23. 32 ± 5. 23	19. 11 ± 7. 81
<b>Friends support dimension</b>	23. 78 ± 4. 04	17. 44 ± 8. 26
<b>Expressed Emotion Scale</b>	13. 33 ± 3. 23	18. 55 ± 3. 78
<b>Being critical/Hostile</b>	6. 40 ± 2. 31	8. 82 ± 3. 15
<b>Being overprotective</b>	6. 93 ± 2. 35	9. 73 ± 1. 53

*ABC = Autism Behavior Checklist, MPSSS = Multidimensional Perceived Social Support Scale, EES = Expressed Emotion Scale, PGI = Posttraumatic Growth Inventory, SWLS = Satisfaction with Life Scale, ZCBS = Zarit Caregiver Burden Scale, DAS = Dyadic Adjustment Scale.*

**Table 5.b The Mean and Standard Deviations of Scores Obtained From the Scales**

<b>Scales</b>	<b>Mother of Children with ND n (60)</b>	<b>Mother of Children with ASD n (62)</b>
<b>Posttraumatic Growth Inventory</b>	76.02 ± 19.18	77.13 ± 18.35
<b>Changes in Relations with Others</b>	25.20 ± 6.66	23.34 ± 7.33
<b>Change of Life Philosophy</b>	16.45 ± 5.04	17.26 ± 5.19
<b>Changes in Self-Perception</b>	34.37 ± 8.73	36.53 ± 8.56
<b>Satisfaction with Life Scale</b>	23.15 ± 6.39	19.71 ± 6.86
<b>Zarit Caregiver Burden Scale</b>	37.15 ± 8.80	56.02 ± 15.75
<b>Dyadic Adjustment Scale</b>	106.10 ± 25.84	105.05 ± 24.82
<b>Satisfaction Subscale</b>	36.07 ± 9.53	34.92 ± 8.46
<b>Cohesion subscale</b>	13.28 ± 5.43	12.19 ± 5.63
<b>Consensus subscale</b>	47.83 ± 10.75	46.66 ± 11.92
<b>Emotion subscale</b>	8.92 ± 2.63	8.27 ± 3.19

*ABC = Autism Behavior Checklist, MPSSS = Multidimensional Perceived Social Support Scale, EES = Expressed Emotion Scale, PGI = Posttraumatic Growth Inventory, SWLS = Satisfaction with Life Scale, ZCBS = Zarit Caregiver Burden Scale, DAS = Dyadic Adjustment Scale.*

#### 4.2. Comparison the Mothers of Children with ASD and ND According to the Points Received From the Scales

The two groups of mothers were compared in terms of scores obtained from the scale by using t-test. Table 6. shows a comparison of mothers of children with ASD and ND according to the score obtained from the scales. Mann Whitney U method was used while two groups of mothers are comparing in terms of the scores from this scale because the satisfaction subscale of Dyadic Adjustment Scale is not showing a normal distribution.

**Table 6. Comparison the Mothers of Children with ASD and ND According to the Scores Received From the Scales**

	ND	ASD	t	df	p
<b>MPSSS</b>	67.60±11.58	49.55±20.17	6.04	120	.000*
• <b>Special Human Dimension</b>	20.50±6.73	13.00±8.36	5.44	120	.025*
• <b>Family Support Dimension</b>	23.32±5.23	19.11±7.81	3.48	120	.000*
• <b>Friends support dimension</b>	23.78±4.04	17.44±8.26	5.37	120	.000*
<b>Expressed Emotion Scale</b>	13.33±3.23	18.55±3.78	-8.18	120	.000*
• <b>Being critical/Hostile</b>	6.40±2.31	8.82±3.15	-4.83	120	.039*
• <b>Being overprotective</b>	6.93±2.35	9.73±1.53	-7.8	120	.000*
<b>Posttraumatic Growth Inventory</b>	76.02±19.18	77.13±18.35	-0.33	120	0.83
• <b>Changes in Relations with Others</b>	25.20±6.66	23.34±7.33	1.47	120	0.205
• <b>Change of Life Philosophy</b>	16.45±5.04	17.26±5.19	-0.87	120	0.68
• <b>Changes in Self-Perception</b>	34.37±8.73	36.53±8.56	-1.38	120	0.87
<b>Zarit Caregiver Burden Scale</b>	37.15±8.80	56.02±15.75	-8.13	120	.000*
<b>Dyadic Adjustment Scale</b>	106.10 ± 25.84	105.05 ± 24.82	0.23	120	0.82
• <b>Cohesion subscale</b>	13.28±5.43	12.19±5.63	1.09	120	0.28
• <b>Consensus subscale</b>	47.83±10.75	49.66±11.92	-0.89	120	0.38
• <b>Emotion subscale</b>	8.92±2.63	8.27±3.19	1.21	120	0.23

*ABC = Autism Behavior Checklist, MPSSS = Multidimensional Perceived Social Support Scale, EES = Expressed Emotion Scale, PGI = Posttraumatic Growth Inventory, SWLS = Satisfaction with Life Scale, ZCBS = Zarit Caregiver Burden Scale, DAS = Dyadic Adjustment Scale.*



There is a statistically significant difference between the mothers who have children with ASD and ND in terms of MPSSS total meanscores. The total mean score the mothers who have children with ND receive from the scale is 67.60, while those who have children with ASD is 49.55. According to this, mothers who have children with ND have more multidimensional perceived social support. When the MPSSS' sub-scales examined, there is a statistically significant difference between the mothers who have children with ASD and ND in terms of MPSSS (specific human dimension) mean scores. The total mean score that mothers who have children with ND receive from the scale is 20.50, while the mothers who have children with ASD is 13.00. The mothers with ND children have higher scores of MPSSS (Specific Human Dimension) compared to the mother who have children with ASD. Similarly, there is a statistically significant difference between the mothers who have children with ASD and ND in terms of MPSSS (Family Support Dimension) mean scores. The total mean score the mothers who have children with ND receive from the scale is 23.32, while those who have children with ASD is 19.11. According to this, the mothers who have children with ND have higher scores of MPSSS (family support dimension). There is a statistically significant difference between the mothers who have children with ASD and ND in terms of MPSSS (Friend Support Dimension) total mean scores. The total mean score the mothers who have children with ND receive from the scale is 23.78, while the mothers who have children with ASD is 17.44. So, the mothers who have children with ND have higher scores of MPSSS (Friend Support Dimension) than those who have children with ASD.

There is also statistically significant difference between the mothers who have children with ASD and ND in terms of EES (Expressed Emotion Scale) total mean scores. The total mean score the mothers who have children with ND received from the scale is 13.33, while the mothers who have children with ASD received 18.55. According to the results, the mothers who have children with ASD have higher levels of expressedemotion. When the EES' sub-scales examined, there is a significant difference between the groups with ASD and ND in terms of Critical/Hostile sub-scale mean scores. The total mean score the mothers who have children with ND received from this sub-scale is 6.40, while the mothers who have children with ASD received 8.82. So, the mothers who have children with ASD have higher levels of Expressed Emotion (Critical/Hostile Dimension). There is a statistically significant

difference between the mothers who have children with ASD and ND in terms of Protective/Caring sub-scale mean scores. The total mean score the mothers who have children with ND received from the scale is 6.93, while the mothers who have children with ASD received 9.73. It has been found that the mothers who have children with ASD are extremely over-protective/caring.

There is also statistically significant difference between the mothers who have children with ASD and ND in terms of SWLS (Satisfaction With Life Scale) total mean scores. The total mean score the mothers who have children with ND received from the scale is 23.15, while the mothers who have children with ASD received 19.71. According to the results, the mothers who have children with ND have higher scores of SWLS than those who have children with ASD.

There is a significant difference between the mothers who have children with ASD and ND in terms of ZCBS (Zarit Caregiver Burden Scale). The total mean score the mothers who have children with ND received from the scale is 37.15, while the mothers who have children with ASD received 56.02. As a result, the mothers who have children with ASD have higher scores of ZCBS.

When all of the scales examined, DAS (Satisfaction sub-scale) did not show a normal distribution. So, the difference between the two groups was investigated with Man Whitney U test but it was found that there was no significant difference between them.

#### **4.3. Comparison of the Mothers Who Have Children with ASD and ND In Terms of Educational Status**

T-test was made between two group of mothers in order to understand whether there are differences in terms of educational level and it was found that there was a significant difference between the two groups. The mothers with ND children have higher levels of education ( $M = 12.77 \pm 3.47$ ) than the mothers who have children with ASD ( $M = 8.13 \pm 3.24$ ).

#### **4.4. Comparison of the Mothers Who Have Children with ASD and ND In Terms of Working Status**

Fisher's Exact Test was made between two group of mothers in order to understand whether there are differences in terms of working status and it was found that there was a significant difference between the two groups ( $p < 0.000$ ). 58 of the mothers who have children with ASD don't work while 4 of them work. Conversely, 57 of the mothers who have children with ND work while 3 of them don't work.

#### **4.5. Findings related to comparison of ZCBS in terms of Mother's Educational Status, Work, Number of Children, MPSSS and Group**

Univariate Variance Analysis was made by controlling the levels of certain variables that can be effective on the mothers' burden of care levels.

When the number of children, mother's educational status, working status and the points of multidimensional perceived social support checked, it was found that there is no difference between the groups in terms of ZCBS points ( $F = 17.39$ ,  $p < .001$ )

#### **4.6. Relations Between Variables**

The mothers' relationship between maternal age, education level, number of children, the duration of children's education, percentage of disability, the year of first diagnosis and all scores obtained from the clinical scales that have been applied were examined and the results are summarized in Table 7.a,7.b

**Table 7.a Correlations of the Scores and Variables Obtained From All Scales That the Mothers of Children With ASD.**

	ZCBS	Mother's Education Year	Mother's Age	Number of Children	ASD's Disability Percentage	MPSSS	MPSSS (Special People Dimension)	MPSSS(Family Support Dimension)	MPSSS(Friends Support Dimension)	EES	EES (Hostility Dimension)	ESC (Protective Dimension)	PTGI	PTGI (Dimension of Change in Relations with Others)	PTGI (Dimension of Change in LifePhilosophy)	PTGI (Dimension of Self-Perception)	SWLS	ABC	ABC (Relation Building)	ABC (Sensory)	ABC (Using the Body Language)	ABC (Language Skills)	ABC (Social Skills)	DAS	DAS Cohesion	DAS Consensus	DAS (Emotional Expression Scale)	Children Training Time	The First Year of Diagnosis
ZCBS	1	.130	.094	.172	.35*	.038	.086	.043	.046	.278*	.293*	.081	.033	.146	.011	.047	.507*	.312*	.213	.188	.278*	.144	.316*	.379*	.177	.228*	.337*	.177	.142
Mother's Education Year		1	.030	.200	.222*	.113	.112	.069	.069	.252*	.139	.336*	.178	.254*	.146	.077	.061	.077	.030	.220	.036	.001	.081	.008	.074	.041	.102	.054	.082
Mother's Age			1	.112	.181	.088	.066	.189	.189	.183	.189	.064	.030	.102	.083	.094	.006	.066	.065	.000	.004	.005	.007	.002	.118	.113	.148	.582*	.534*
Number of Children				1	.185	.020	.066	.017	.017	.276*	.304*	.055	.118	.111	.105	.094	.040	.299	.166	.233	.344*	.088	.219	.004	.005	.034	.164	.191	
ASD's Disability Percentage					1	.050	.073	.084	.084	.168	.099	.212	.291	.124	.149	.426*	.036	.410*	.328*	.278*	.377*	.156	.332*	.007	.003	.033	.147	.371*	.315*
MPSSS						1	.841*	.834**	.834**	.257*	.277*	.064	.043	.139	.076	.073	.316*	.022	.134	.117	.065	.302*	.027	.122	.055	.115	.169	.151	
MPSSS (Special People Dimension)							1	.507*	.521**	.318*	.357*	.049	.130	.243	.097	.011	.276*	.049	.135	.102	.141	.280*	.033	.076	.061	.116	.089	.112	.056
MPSSS(Family Support Dimension)								1	.540**	.174	.204	.008	.118	.011	.000	.251*	.069	.069	.093	.111	.211	.011	.011	.149	.118	.149	.119	.111	
MPSSS (Friends Support Dimension)									1	.141	.122	.098	.085	.083	.089	.255*	.066	.031	.004	.009	.005	.255*	.012	.065	.049	.049	.049	.180	.208
EES										1	.919*	.577*	.023	.033	.044	.338*	.284*	.173	.229	.430*	.014	.011	.121	.219	.118	.177	.063	.068	.075
EES (Hostility Dimension)											1	.207	.005	.082	.051	.399*	.244	.146	.176	.365*	.050	.050	.098	.172	.099	.005	.135	.142	
ESC (Protective Dimension)												1	.067	.087	.073	.012	.208	.125	.370*	.309*	.139	.039	.098	.133	.222	.146	.109	.106	
PTGI													1	.868**	.853**	.205	.189	.158	.107	.075	.175	.158	.020	.209	.226	.132	.302*	.273*	
PTGI (Dimension of Change in Relations with Others)														1	.682*	.591*	.298*	.061	.045	.007	.052	.009	.008	.377*	.177	.268*	.178	.159	
PTGI (Dimension of Change in LifePhilosophy)															1	.637*	.141	.070	.017	.009	.003	.007	.108	.190	.216	.087	.214	.206	
PTGI (Dimension of Self-Perception)																1	.098	.291*	.149	.281*	.216	.104	.103	.072	.140	.001	.365*	.325*	
SWLS																	1	.222	.223	.223	.176	.204	.103	.461*	.299	.396*	.050	.057	

**Table 7.b Correlations of the Scores and Variables Obtained From All Scales That the Mothers of Children With ASD.**

	ZCBS	Mother's Education Year	Mother's Age	Number of Children	ASD's Disability Percentage	MPSSS	MPSSS (Special People Dimension)	MPSSS(Family Support Dimension)	MPSSS (Friends Support Dimension)	EES	EES (Hostility Dimension)	ESC (Protective Dimension)	PTGI	PTGI (Dimension of Change in Relations with Others)	PTGI (Dimension of Change in LifePhilosophy)	PTGI (Dimension of Self-Perception)	SWLS	ABC	ABC (Relation Building)	ABC (Sensory)	ABC (Using the Body Language)	ABC (Language Skills)	ABC (Social Skills)	DAS	DAS Cohesion	DAS Consensus	DAS (Emotional Expression Scale)	Children Training Time	The First Year of Diagnosis
ABC																	1	.81 8**	.74 0**	.83 0**	.51 4**	.69 3**	.15 9	.07 2	.10 2	.24 5	.09 9	.06 4	
ABC (Relation Building)																		1	.64 2**	.55 4**	.12 8	.51 1**	.19 0	.10 6	.10 7	.26 2*	.10 2	.03 0	
ABC (Sensory)																			1	.49 7**	.17 5	.40 4**	.11 4	.02 5	.07 2	.17 9	.11 0	.09 8	
ABC (Using the Body Language)																			1	.38 3**	.50 0**	.16 2	.08 9	.12 8	.17 0	.04 6	.03 8		
ABC (Language Skills)																					1	.20 8	.07 4	.02 6	.08 3	.04 3	.20 7	.21 2	
ABC (Social Skills)																						1	.16 4	.03 2	.13 9	.22 1	.08 2	.02 8	
DAS																							1	.69 6**	.90 9**	.83 3**	.09 7	.15 0	
DAS (Cohesion)																								1	.47 5**	.44 9**	.12 3	.14 9	
DAS ( consensus)																									1	.73 5**	.11 0	.15 2	
DAS (Emotional Expression Scale)																										1	.09 7	.17 6	
Children Training Time																											1	.94 0**	
The First Year of Diagnosis																												1	

*ABC = Autism Behavior Checklist, MPSSS = Multidimensional Perceived Social Support Scale, EES = Expressed Emotion Scale, PGI = Posttraumatic Growth Inventory, SWLS = Satisfaction with Life Scale, ZCBS = Zarit Caregiver Burden Scale, DAS = Dyadic Adjustment Scale.*

*According to analysis of ZCBS' relationship with other variables in mothers of children with ASD,* there is a positive relationship between ZCBS and disability percentage of children with ASD, ABC total score, ABC (Social and Self-care Skills) ABC Body and Object Use subscale and EES Critical/hostile sub-scale. There is a negative relationship between ZCBS and total SWLS, total DAS, DAS emotional expression sub-scale and DAS consensus sub-scale.

*According to the analysis of age status' relationship with other variables in mothers of children with ASD,* there is a positive relationship between maternal age and the duration of mother's education and the first year of the child at diagnosis.

*According to analysis of number of children's relationship with other variables in mothers of children with ASD,* there is a positive relationship between the number of children and EES Critical/hostile sub-scale, total score of ABC, ABC Body and Object Use sub-scale and total score of EES.

*According to analysis of Disability Percentage of Children who have ASD's relationship with other variables,* there is a positive relationship between disability percentage and the duration of mother's education, the first year of the child at diagnosis, total score of PGI, PGI Change in Self-Perception sub-scale, total score of ABC, ABC Relationship Building sub-scale, ABC Body and Object Use sub-scale and ABC Emotional sub-scale.

*According to analysis of MPSSS' relationship with other variables in the mothers of children with ASD,* there is a negative relationship between MPSSS and Special People, Family et al.end Support – which are subscales of MPSSS-, total score of SWLS and ABC Language Skills subscale. There is a negative relationship between MPSSS and total score of ESS and EES Critical/hostile sub-scale.

*According to analysis of MPSSS Special People sub-scale's relationship with other variables in the mothers of children with ASD,* there is a positive relationship between MPSSS Special People sub-scale and total score of SWLS and ABC Language Skills sub-scale. There is a negative relationship between MPSSS Special People sub-scale and total score of EES and EES Critical/hostile sub-scale.

*According to analysis of MPSSS Family Support sub-scale's relationship with other variables in the mothers of children with ASD, there is a positive relationship between MPSSS Family Support sub-scale and total score of SWLS; negative relationship between PGI Change in Self-Perception sub-scale.*

*According to analysis of MPSSS Friend Support sub-scale's relationship with other variables in the mothers of children with ASD, there is a positive relationship between MPSSS Friend Support sub-scale and total score of SWLS and ABC Language Skills sub-scale.*

*According to analysis of the total score of EES's relationship with other variables in the mothers of children with ASD, there is a positive relationship between the total score of EES and EES Critical/hostile sub-scale, EES Overprotecting/Caring sub-scale, total score of ABC, ABC Body and Object Use subscale and ABC Emotional sub-scale. There is a negative relationship between EES and total score of SWLS.*

*According to analysis of EES Critical/hostile sub-scale's relationship with other variables in the mothers of children with ASD, there's a positive relationship between EES Critical/hostile sub-scale and ABC Body and Object Use sub-scale. There is a negative relationship between EES Critical/hostile sub-scale and total score of SWLS.*

*According to analysis of EES Overprotecting/Caring sub-scale's relationship with other variables in the mothers of children with ASD, there's a positive relationship between EES Overprotecting/Caring sub-scale and ABC Body and Object Use subscale and ABC Emotional sub-scale.*

*According to analysis of PGI's relationship with other variables in the mothers of children with ASD, there is a positive relationship between PGI and Changes in Relations with Others, Change In Philosophy Of Life and Change In Perception Of Self which are the sub-scales of PGI. Similarly, there is a positive relationship between PGI and the duration of mother's education, the first year of diagnosis and DAS Consensus sub-scale.*

*According to analysis of PGI Changes in Relations with Others sub-scale's relationship with other variables in the mothers of children with ASD, there is a positive relationship between PGI Changes in Relations with Others sub-scale and total score of SWLS, total score of DAS and DAS Consensus sub-scale.*

*According to analysis of PGI Change in Self-Perception sub-scale's relationship with other variables in the mothers of children with ASD, there is a positive relationship between PGI Change in Self-Perception sub-scale and the duration of mother's education, the first year of diagnosis and ABC.*

*According to analysis of SWLS' relationship with other variables in the mothers of children with ASD, there is a positive relationship between total score of SWLS and total score of DAS, DAS Consensus sub-scale and DAS Cohesion sub-scale.*

*According to analysis of ABC and its sub-scales' (Relationship Building , Emotional, Body and Object Use, Social and Self-care Skills) relationship with other variables in the mothers of children with ASD, there is a positive relationship between ABC and its sub-scales including Relationship Building , Emotional, Body and Object Use, Social and Self-care Skills.*

*According to analysis of DAS' relationship with other variables in the mothers of children with ASD, there is a positive relationship between total score of DAS and its sub-scales including Cohesion, Consensus and Emotional Expression.*

*According to analysis of Duration Of The Education Of Children who have ASD's relationship with other variables, there is a positive relationship between Duration Of The Education Of Children and the first year of diagnosis.*

There is a positive relationship between disability percentage of children with ASD and total score of PGI and PGI Change in Self-Perception sub-scale.



#### **4.7. Comparison of the Mothers Who Have Children with ASD In Terms of Factors That Affect ZCBS**

Stepwise regression analysis was performed to identify factors that are associated with ZCBS. Regression analysis was performed to the percentage of the child's disability, total score of DAS and EES. However, EES were removed from the model. In this case, variables associated with ZCBS are the percentage of the obstacle and DAS. The percentage of the child's disability and total score of DAS predict ZCBS significantly  $R^2=.20$   $F(2, 61)=7.42$ ,  $p < .001$ . The percentage of the child's disability and total score of DAS explain 45% of the variance in the total scores of ZCBS.

#### **4.8. Comparison of the Mothers Who Have Children with ASD In Terms of Factors That Affect Life Satisfaction**

Some variables were subjected to regression analysis which are believed to be effective in levels of mothers' life satisfaction. Some scales were entered into a Stepwise regression analysis including ZCBS, total MPSSS, MPSSS Special People, MPSSS Family Support, MPSSS Friend Support, DAS Cohesion, DAS Consensus, DAS Emotion sub-scale, EES-C/H sub-scale.

Emotional sub-scales. Only the DAS-Consensus and ESS-C/H sub-scale scores predict the modal significantly.  $R^2=.234$ ,  $F(2, 61)=14.93$ ,  $p < .001$ . The percentage of the DAS Consensus and EES-C/H scores explain 58% of the variance in Life Satisfaction scores.

## 5. DISCUSSION

Mother is the person who carries most of the load in the family with disabled children (Eracar and Onur, 1999; Eracar, 2003). We can explain that with the attitude and behavior of mothers about accepting disabled children in the family. Having a disabled child is a very difficult situation that affects the family in many ways. A mother's burden of care is increasing because generally mothers are dealing with child's care, health and education. There is a risk of decrease in the level of life satisfaction, multidimensional perceived social support and dyadic adjustment in mothers. Giving birth to a disabled child is a traumatic situation for mother while she was waiting for a healthy child. However, the condition that is not expected of mothers could have positive reflections to their lives.

The general aim of our research is findings related to ZCBS, MPSSS, DAS, EES, SWLS and PGI in mothers. Our aim in the first phase of our research is examine whether there are differences between the mothers who have children with ASD and ND in terms of identifying information, burden of care, dyadic adjustment, multidimensional perceived social support, expressed emotions, life satisfaction and posttraumatic growth and discuss the reasons for this difference.

Our aim in the second phase of our research is discuss the mothers who have children with ASD's burden of care, dyadic adjustment, multidimensional perceived social support, expressed emotions, life satisfaction, posttraumatic growth and their relationship with other variables that affect them.

The most important result expected in research is finding a significant difference between mothers who have children with ASD and ND in terms of burden of care, multidimensional perceived social support, expressed emotion and life satisfaction also finding a significant relationship between the variables we investigate and the percentage of disability of children with ASD and sociodemographic characteristics of the mother.

In this chapter, the main findings obtained from analysis carried out in accordance with these purposes discussed in light of the current literature.

### **5.1. Discussing the Sociodemographic Findings Related to Mothers Who Have Children with ASD and ND**

In the research, significant differences were detected in findings related to educational status in mothers who have children with ASD. When comparison about educational status between two groups was made, it is seen that mothers of children with ASD have low levels of education.

Kızılırmak (2014) found that 2. 9% (n=7) of the caregivers are illiterate while 3. 7% (n=9) of them are literate; 23% (n=56) of them are primary school graduates while 18. 9% (n=46) of them are secondary school graduates, 27. 2% (n=66) of them are high school graduates and 24. 3% (n=59) of them are college graduates and above in his study about the burden of care and family status in families of individuals with mental disorders. Cangür (2013) found that 21.6 % of those who are caring for the individuals are illiterate, 49 % of them are primary school graduates, 22.5 % of them are secondary-high school graduates and 6.9 % of them are college graduates and above in his study about families with people with mental and physical disabilities.

It is seen in Ar's study (2014) about marital adjustment and the level of anxiety in parents of children with ASD that 56.0 % (n=103) of the mothers who have children with ASD are primary school graduates, 13.0 % (n=24) of them are secondary school graduates and 20.7 % (n=38) of them are high school graduates. 84. 2 % (n=155) of the mothers don't work while 89.7 % (n=165) of the fathers work at various jobs. It is observed that a significant proportion of mothers have low levels of education in Ar's study, similar to our findings.

Similarly, when the defining characteristics of the mothers examined in Kırbaş and Özkan' s study with families who have children with Down syndrome, it was determined that 69.8 % of the mothers who have children with Down syndrome are primary school graduates. Most of the mothers (75.5 %) who have disabled children are primary school graduates in Yamaç's (2011) study and 85.7 % of them are primary school graduates in Uyaroğlu and Bodur's (2009) study. Similarly, it was found that most of the mothers who have disabled children are primary school graduates in other studies performed in our country (Sarı Yıldırım 2007; Karadağ

2009, Öztürk, 2011; Verep, 2005; Yıldırım and Conk 2005; Danış, 2006). These research findings about the mother's level of education coincide with our work.

The presence of an individual with a chronic illness in the family increases the responsibilities of the family members. Family members may be faced unwanted situations like leaving their jobs or educations due to maintenance responsibilities (Ruh Sağlığı Modülleri 2008).

In the study, significant differences were detected in findings related to the working status of the mothers who have children with ASD and ND. 93.5 % of the mothers who have children with ASD and 5% of the mothers who have children with ND do not work. Most of the mothers who have children with ASD are housewife.

It is seen that there is a significant difference between the mothers who have children with ASD, chronic disease and ND in terms of the educational level and working status (Özdemir et al., 2009; İnci and Erdem, 2008; Bıçak, 2009). Haveman (1997) stated that mothers with low levels of education separate less time for themselves and they live responsibility for the maintenance of their children more intensely in his research.

Mothers who have children with ASD give less importance to their careers, believe that they shouldn't be doing another job outside the home and give importance to being a good mother and father. These families are trying to spend more time with family members, closely involved with children's behavior problems and they give more importance to peer support roles in marriage and parenting (Tunali and Power, 1993).

It was determined that 85.7 % of the mothers who have children with Down syndrome don't work and all of them have social supporting a study which Kırbaş and Özkan (2013) did on families who have children with Down syndrome, 35.5 % of the mothers who have children with mental disabilitiesworking a study which Yamaç (2011) did and all of the mothers who have children with mental disabilities are housewife's in a study which Uyaroğlu and Bodur (2009) did. It was found that most of the mothers who have children with mental disability are housewife's and only a few of them work in another study which conducted in our country (Sarı Yıldırım

2007; Karadağ 2009, Öztürk, 2011; Verap, 2005; Yıldırım and Conk 2005; Danış, 2006).

Findings in research are similar to findings about educational and working status of the mother in this study. They stay at home due to the care of the child, they prefer to be at home and their inability for profession because of the low level of education can be interpreted as the reasons why mothers who have children with ASD don't work.

A child with ASD is incapable of self-care and the mother can't afford time to education because of the care burden. Also, the mother has low levels of education and no time for working life because she pays more attention to her child's education and development than her own education, working life and development. There is a significant difference between the mother who have children with ASD and ND because of the reasons stated in the previous sentences.

It is seen that the majority of caregivers are the mothers or sisters when the literature related to people who care for disabled children is examined (Lowyck et al., 2004, Nasr and Kausar 2009, Çetin 2011, Çınar 2011, Günaydın et al., 2012).

It was found that all of the caregivers are the mothers in Karahan and İslam's (2013) study. Also, 89.7 % of them are the mothers in Raina's (2005) study. Mothers stated that they take more responsibility for child care than fathers in Meral's (2006) study.

Verap (2005) stated that more than half of the mothers (62%) take care of the children alone. Danış specified that about half of the mothers (44.5 %) have fulfilled the responsibility for the care of children. However, Uyaroğlu and Bodur (2009) reported that 40% of the mothers get their husband's help in child care.

Heller (1997) made a research about the wishes of children and adults with mental disabilities who live in the institution and with their family, supply support and maintenance responsibility. In the research, it is stated that having a disabled child affects mother's life more than father's. Fathers are not able to affect emotionally as much as mothers because they don't take care of the children enough and they have less expectations regarding the child's care. Fathers spend more time at work for

economic reasons so they support their children in this way. As a result, mothers have more responsibility in child care.

It is seen in Cangür's (2013) study that mothers have 75.6 %, fathers have 5.9% and the other people have 17.6 % of the percentage for disabled child care in family. In Daniş's (2006) study which is related to families with disabled children, mothers stated that they don't get enough support from their husbands. Kaner (2004) reported that fathers give more financial care support than mothers.

In the study, it was determined that there is a significant difference between the mothers who have children with ASD and ND in terms of the findings which show the help they get from the other family members for the child care. 38.7 % of the mothers who have children with ASD replied as 'just me', however, only 17.2 % of the mothers who have children with ND replied 'just me' to "Is there another person that deals with the care of the child?" question. Also, 65.5% of the mothers who have children with ND get spousal support and 25.8 % of the mothers who have children with ASD get spousal support.

According to this, it can be said that the mothers who have children with ASD receive less support from their husbands on child care than the mothers who have children with ND. Because parents who have disabled child share the responsibilities of the different aspects because of the burden care. The mothers take care of the disabled children while fathers fulfill their mission to provide financial support.

In the study, it was determined that there is a significant difference between the mothers who have children with ASD and ND in terms of the findings about the number of children. It was found that the mothers who have children with ASD have more children than the mothers who have children with ND. The number of mothers who have 3 children is higher in the ASD Group.

Parents of autistic children expressed that they decided to make a new child most of the time because of worries about the future in the study which Esenler (2001) did with the mothers of children who had been diagnosed ASD or attention-deficit/ hyperactivity disorder. They think having more children provides assurance to their disabled child when they die. The reason why the mothers who have children with

ASD have more children supports with this view. The mother worries for the ASD child's future and thinks 'What happens to my child if I die?'.

## **5.2. Discussion of the Introductory Findings Regarding Children with ASD**

There are 62 children with ASD and 60 children with ND in the research group. It is seen that 52 of them is male and 10 of them is female when the gender of children with ASD examined.

This rate is shown as 1 girl corresponds to 2 or 3 boys in the studies of the epidemiology of ASD (Burd et al., 1987; Lotter, 1966; Wing, 1981). It was determined that 78.9 % of the children with ASD is male and 21.2 % of them is female in the study which Meral (2006) did with the families who have children with ASD.

In the study, it was determined that the disability percentage of children with ASD is in the range of 40-99 ( $78.53 \pm 17.58$ ), 31.1 % of the children's disability percentage is 80 % and 19.4 % of the children's disability percentage is 90%. It is found that 70 % of children who diagnosed with ASD have mental disorder according to Pehlivanürk's (2004) research. In this study, it was determined that whether there is MR in children according to notifications of mothers who have children with ASD and the reports received from the hospital. Intelligence test could not be implemented because a large number of children can't speak and they can't Cooper the test. According to notifications of mothers who have children with ASD, 12 (19%) of the 62 children with ASD have MR which is considerably lower than the general percentage (80%). In the study, the first year of the diagnosis of ASD children and the year of beginning the special education are associated with each other, so families have started their children's special education just after diagnosis.

It was detected that 40.3% (n=25) of the children are semi-dependent in nutrition, 48.4% (n=30) of them are semi-dependent about dressing/undressing, 41.9 % (n=26) of them are semi-dependent in toilet, 46.8 % (n=29) of them are dependent about cleanliness; 57.9 % (n=22) of them have obsession and 31.6% (n=12) of them have MR in the study. Kırbaş and Özkan (2013) found that 33.3% of the children have other health problems, 68.3% of them need help for dressing and undressing,

52. 4% of them need help while eating in the study of children with Down syndrome. These findings are similar to research findings.

### **5.3. Discussing the MPSSS Findings Related to Mothers Who Have Children with ASD and ND**

According to the research, there is a statistically significant difference between the groups of ASD and ND in terms of MPSSS mean scores. The mothers who have children with ND have higher levels of multidimensional perceived social support than the mothers who have children with ASD.

Social support means the help that individual gets from other people. It can be defined as an information which provides faith for being loved, feeling precious, being accepted and being a part of interpersonal support network. The individuals may receive social support from free-time activities, fun activities, community programs, professional people and institutions as well as they receive from spouse, family et al. ends (Siklos and Kerns, 2006: 923). We can speak of the existence of a different structure between individuals with ASD and the family system compared to the parents of the child with ND (Warter, 2009). Of having a child with ASD has deeper effect on the family structure. (Anderson, 1998; Bayat, 2005; Hastings and Brown, 2002; Marcus, Kuncie and Schopler, 1997).

In a study that Yurdakul and Girli (1999) did to determine the social support network of families with a disabled child, they investigated the relationship between having social support and its effects on psychological health and they compared them with the parents who have children with ND at the same age in terms of the levels of social support and psychological health. 58 parents who have children with ASD, 83 parents who have children with mental disability and 78 parents who have children with ND participated to the study. As a result of the research, it was found that social support network of families who have a child with a disability is more narrow. It was determined that the parents who have children with disabilities receive support from their own families and they have less friend support as a result of the analysis. Also, there is a significant negative relationship between the degree of satisfaction with the perceived support and depression scores.



The difficulties arising from the child with ASD completely change the style of interaction between family members (Tunali and Power, 1993) and in an effort to struggling with ASD is felt by family, relatives, friends, neighbors and society (Taylor and Aspinwall, 1990).

Özkan (2002) investigated the relationship between the mothers who have children with ASD and ND in terms of multidimensional perceived social support and depression levels. Özkan (2002) concluded that there is a significant difference for perceived social support between the mothers who have children with mental disability and ND.

In a study that Şentürk and Saraçoğlu (2013) did to compare the perceived social support levels which received from the family of the mothers who have children with ASD and ND, they detected that there is a significant difference between the mothers who have children with ASD and ND in terms of ASD. The mothers who have children with disabilities have fewer points of ASD than the mothers who have children with ND. The findings of this are similar to Senturk and Saraçoğlu's study's findings.

In a study that Gül (2015) did to investigate the symptoms of post-traumatic stress and social support levels of the families who have children with disabilities and ND, it was founded that there is no significant difference between the families who have children with disabilities and ND in terms of multidimensional perceived social support levels and the mean score of multidimensional perceived social support of families are close to each other.

Görgü (2005) investigated the perceived social support of the mothers who have children with ASD between the ages of 3-7 and found that the mean total score of MPSSS of the sample as low in his study.

Stagg and Katran (1986) compared the mothers who have children with disabilities and ND in terms of social support and they found that the mothers who have children with mental disability at young age get less satisfaction with social support which they provide compared to the mothers who have children with ND (Cited:Duygun, 2001). Also, it was observed that the mothers of children with ASD

who get more social support have less depression and worry (Gray and Holden, 1992).

We can speak of the existence of a different structure between individuals with ASD and the family system compared to the parents of the child with ND (Warter, 2009). Ofhaving a child with ASD has deeper effect on the family structure. (Anderson, 1998; Bayat, 2005; Hastings and Brown, 2002; Marcus, Kuncce and Schopler, 1997). In an effort to struggling with ASD is felt by family, relatives, friends, neighbors and society (Taylor and Aspinwall, 1990).

In a study conducted with caregivers of patients with schizophrenia, it was found that the mean scores for burden of care are low in caregivers who express general health perception good. However, their mean scores for perceived family and friend support are high (Çınar 2011).

So-kum Tang and Yuk-ki Chen (1997) identified that the mothers who constantly give care to child with disabilities adversely affected as psychologically and physically. However, received support from the social environment has an important role to deal with the problems problems which have created by obstacles and reduce the effects of stress (Cited:Özkan, 2002).

There are differences in the researches about the subject when the literature was examined. Some of the researches say that there is no difference between the families who have children with ASD and ND in terms of perceived social support (Doğan, 2001; Dyson, 1997); but some of the researches sat that the families who have children with disabilities have lower levels of perceived social support (Heiman and Berger, 2008; Tröster, 2001).

As a result, the mothers who have children with ASD have lower levels of ASD compared to the mothers who have children with ND.

According to the study findings, there is a statistically significant difference between the groups of ASD and ND in terms of MPSSS Special Human sub-scale mean scores. So, the mothers who have children with ND have higher scores of M PSSS Special Human sub-scale.

According to the results of the study that Akmanis (2010) did about the perceived social support of mothers who have children with ASD, the mean overall score of perceived social support of mothers who have children with ASD is 49,88; the mean score of perceived family support is 19,83; The mean score of perceived support from friends is 15.10 and the mean score of perceived support for private persons is 14,95. The mean score of perceived support for private persons were found to be lower than the family and friend support. Sheppard (1993) stated that mothers' depression is the result of low social support and the social support provided by peer is an important factor to predict the depression in mothers in a study that he did with the mothers of children with disabilities. In the literature, it was also stated that fathers are insufficient to fulfill the duty of care of disabled children, to support his wife, to show interest to child and to participate in social activities together. Despite that, social support is needed more in families with disabled children (Yurdakul and Girli 1999; Başer, 2006; Özbey, 2012).

It was determined that Special People Support is one of the lowest in the dimensions of perceived social support in findings of the study. The findings of the study are consistent with the findings of Akmanış.

In this research, there is a statistically significant difference between the groups of ASD and ND in terms of MPSSS Family Support sub-scale. So, the mothers who have children with ND have higher levels of Perceived Family Support sub-scale.

Dönmez (1998) stated that the mothers who have disabled child received good support from relatives and a result of this, they stated that support is useful in dealing with the problems in his study about the investigation of the mothers' problems which they face in the life cycle. In a study conducted with caregivers of patients with schizophrenia, it was found that the mean scores for burden of care are low in caregivers who express general health perception good (Çınar, 2011).

In a study that Akmanis (2010) did to examine the levels of despair of the mothers who have children with disabilities according to the perceived social support, it was found that the family support sub-scale is the dimension cause the most significant difference from the PSSS sub-scales. Karadağ (2009) determined that the

mothers who have children with disabilities have higher mean scores from the perceived family support scale than the family and friend support scale in the research which was made to investigate the difficulties faced by mothers of disabled children, social support perceived from the family and hopelessness levels of mothers. In this study, it was found again that the family support is higher than the friend and private individual support. Ell (1996) found that the social support has an important role in coping with disability and the family support which is one of the social support systems is the most important source of support as a result of his research (Cited: Duygun, 2001:46-47).

Different from the study findings, there are studies that indicate that family support may be lower. In the study which was made by Görgü (2005) to investigate the perceived social support of mothers who have children with ASD between the ages of 3-7 and the levels of depression, it was found that the family support of the mothers who have children with ASD is lower than the friend and special individual support.

In this research, there is a statistically significant difference between the groups of ASD and ND in terms of MPSSS Friend Support sub-scale. So, the mothers who have children with ND have higher levels of Perceived Friend Support sub-scale.

It was found that the Friend Support of the mothers who have children with ASD were low in the study that Görgü (2005) did. The findings of the research are similar with Görgü's findings. In a study that Yurdakul and Girli (1999) did to determine the social support network of families with a disabled child, it was determined that the parents who have children with disabilities receive support from their own families and they have less friend support.

There was no significant relationship between the total scores of MPSSS and age, educational level and number of the children of mothers who have children with ASD and ASD child's disability percentage.

Özkan (2002) investigated the relationship between the mothers who have children with ASD and ND in terms of perceived social support and depression levels and he concluded that there is a significant difference between the mothers who have children with mentally disabled and ND in terms of perceived social support.

However, he determined that the child's age, gender, mother's education, income and work status have no significant contribution to predict perceptions of social support for mothers with disabled children. Kariman and Bayat (2008) found that age and education are not important for social support which is the dimension parents who have children with disability perceive.

There was no relationship between the child's ASD degree and social support perceived by the mother in Akmaniş's (2010) study. In our research, there was no significant difference between the level of the child's disability and the level of social support perceived by the mother (family support, friend support and special individual support).

Görgü (2005) found that the age and marital status of mothers, the order of birth, gender and the age of the child with autism and the time of the diagnosis do not predict the social support level perceived by the mothers of children with ASD. It has been seen that, the educational status of the mother, working at a job outside the home, the status of the husband's education, monthly income, the number of children that are owned, the person who is looking after the children after birth, and taking the help of caregiver now predict the social support level perceived by the mothers. According to the finding of Özkan (2002), the finding affirmed that the educational status of the mother, working status and the number of children that are owned predict the social support level perceived by the mothers supports our research findings.

The research findings (Özkan, 2002; Kahrman and Bayat, 2008; Akmaniş, 2010) shows that there is not a relationship between the age, the educational status of mothers, the number of children, the percentage of the obstacle of the child with ASD and the MPSSS point.

In the research of Görgü (2005), it has been seen that the number of children that are owned by the mother of children with ASD, the educational status and the degree of ASD detection of mothers predict the social support level perceived by the mothers. In this research, a significant relationship has not been found between the educational status of the mothers of children with ASD, the number of children and the social support perceived by the mothers.

When the literature reviewed, different from our findings, Kırbaş and Özkan (2013), Kahriman and Bayat (2008), Coşkun and Akkaş (2009) and Karadağ (2009) found in their research that the perceived social support level increases with the increase of the educational status and the age of mother. Duvdevany and Abboud (2003) found that the educated mothers are using the social support systems more.

In the research, it has been found that there is a negative relationship between the MPSSS and the EES. When the social support level perceived by the mothers of children with ASD increases, the level of expressed emotion (EE) decreases. Ebrinç et al.(2001) investigated that the family functionality, social support and the EE of the schizophrenia patients and their families, and reported that the patients with low-level of EE have more perceived level of familial and social support. In the research of Ebrinç et al.(2001) that investigates the family functioning, social support and expressed emotion in schizophrenic patients and their families, a significant negative relationship was found between the family's, special person's and the total PSSS scores and EE scores.

In the research, a negative relationship was found between the MPSSS Special Person sub-scale of the mothers who have children with ASD and the ESS. There is a negative relationship between the MPSSS Special Person sub-scale and the ESS Critical/Hostile sub-scale. We can make a conclusion that if the mothers of children with ASD getting support from a private person, they are less critical toward their children. As a result, increasing of the perceived social support from their husband and other family members causes the decreasing of the EE level of the mothers and more positive relationships within the family.

In the research, there is a positive relationship between the MPSSS and the LSS. In the research of Uludağ (2014) that investigates the relationship between the burden of care and life satisfaction in parents of children with congenital heart disease (CHD) and the perceived social support, in parents of children with CHD, the burden of care decreases and the life satisfaction increases with the increasing of SSFF (Social Support From Family) and SSFFR (Social Support From Friend) level. In the research, the positive relationship between the PSSS of the mothers of children with ASD and the life satisfaction is similar with the research of Uludağ (2014). Kaner (2004) reported that the life satisfaction decreases when the stress level of parents

increases and the social supports decreases. The research findings about the relationship between the stress of parents and the life satisfaction, the decrement of stress with the increment of social support, the social supports reduce the stress and raise the life satisfaction are supported by other studies in the literature (Adamakos et al., 1986; Banaz, 1992; Barrett, 1999; Beckman, 1991; Beckman and Pokorni, 1988; Botuck and Winsberg, 1991; Crnic et al., 1983; Diener and Diener 1995; Diener et al., 1985; Dunst and Trivette, 1986; Dyson, 1997; Krause, 1988; Milgram and Atzil, 1988; Olson et al., 1994; Pittman and Loyd, 1988; Sarason et al., 1983; Schilmoeller and Baranowski, 1991; Seltzer and Krauss, 1989; Sloper et al., 1991).

We can say that high perceived social support of mothers who have children with disabilities, reduces the stress associated with the care of children with disabilities and raises the life satisfaction.

There is a negative relationship between MPSSS Family Support sub-scale and PGI Change in Perception of Self sub-scale. When the literature reviewed, it is seen that there is a positive relationship between the perceived social support and the posttraumatic growth. The relationship between the social support and posttraumatic growth has been investigated in those who gave the care for patients with schizophrenia (Özlü, 2007) and in the families of autistic children (Elçi, 2004). In the research of Etişken (2013) that investigates the posttraumatic growth in infertile individuals, a significant positive relationship has been found between the level of perceived social support total score of respondents and the level of posttraumatic growth total score, and between the posttraumatic growth inventory total score and the perceived social support scale “Social Support from Family” sub-scale. As a result of research that Schexnaildre (2011) made with 94 children who survived Hurricane Katrina that occurred in 2005 in the United States of America, positive changes in the aftermath of trauma occur in children and social support from the environment is an important determinant of posttraumatic growth was recorded. In his study about the factors that affect the posttraumatic growth in infertile individuals, Etişken (2013) could not find a significant relationship between the dimension of support from a private person, which is one of the perceived social support sub-dimensions, and the posttraumatic growth. A positive relationship between the perceived social support

and the posttraumatic growth was found in the findings in literature, however, in the study, it has been found that there is a negative relationship.

This finding can be explained as mothers who have children with ASD mostly are forced to put in a personal effort related to the child care and responsibilities because of the absence of family support, and this increases the confidence in them selves.

In the study, a significant relationship between the burden of care of the mothers who have children with ASD and the multidimensional perceived social support and its sub-dimensions has not been found. In the studies that investigate the relationship between the burden of care and the MPSSS, it has been identified that the individuals, who have more burden of care, have less perceived social support (Sharpe et al., 2012; Milbury et al., 2013). It has been stated that existence of PSSS develops appropriate coping behaviors for parents and the more support that parents have, the more they can fight with the stress that is because of the disease (Tak and Mccubbin, 2002).

#### **5.4. Discussion of findings about the EES of the mothers of children with ND and the mothers of children with ASD**

Expressed emotion (EE) is defined as the criticism, hostility, or emotional excessive interest of the relatives toward the individual with the diagnosis of schizophrenia (Kavanagh, 1992). It has been identified that emotional aspect of the interaction between the family and patient influences the course of schizophrenia (Berksun, 1992: 104-7). The concept of EE includes to be critical, to take a hostile stance, excessive interest, being intrusive, intimacy and positive comments (Berksun, 1992: 104-7; Deniz et al., 1998; Wearden et al., 2000). Being critical includes blaming others in the nature of criticism, resentment, dislike and disapproval. Being hostile is generally defined as negative expressed emotion.

Expressed emotion is a concept generally studied in a clinical sample. Measurements of EE focus on patients and their relatives. It is known that high expressed emotion in the family is important for the relapse of the disease and the escalation of its violence (Berksun, 1992 :104-7; Cosc et al., 2011; Cruise et al., 2011; Ebrin et al., 2001; İlnem et al., 1998; Kocabıyık et al., 2005; McFarlane et



al.,2007; Subandı, 2011; Tüzer et al.,2003; Spiegel and Wissler, 1986; Vaughn and Leff 1976; Holey, 2007; Halford, 1991). The expressed emotion of the family predicts the results of the physical and mental diseases, however, in the expressed emotion cultural differences are also observed. Family, cultural differences, attitudes towards the disease and the patient, roles, structure of society determines the EE and hence affects the course of the disease (Bhugra and McKenzie, 2003). As a result, EE is a factor that determines the psychological health in a serious level, has an impact on the patient and family.

In a study of Arıkan et al. (1988), attitudes, of families with and without psychotic members, against the psychotic members and their diseases have been evaluated. It was determined that in the families had psychotic members, restrictive and protective/caring attitudes are significantly more.

In the study, there are significant differences in the EES score means of the groups with ND and ASD, the level of expressed emotion of the mothers who have children with ASD is higher. There is a difference between the groups with ND and ASD, in terms of the EES Critical/hostile sub-scale score means; the mothers who have children with ASD have a higher level of critical/hostile attitude toward their children. The reason for that can be explained as the educational level of mothers is low and their subjective burden due to the uncertainties related to the illness of the child is more.

Similarly, it has been found that the mothers of children with ASD are more Overly protective/caring. In the study of Ölçer et al. (2010), 65 children followed with the diagnosis of asthma were compared with 76 children who does not have a chronic disease, ESS has been applied to their mothers. The level of EE is higher in the group of mothers of children with asthma. It has seen that the high level of EE and the frequency of getting a psychiatric diagnosis for the child and behavior problems are related. The study of Ölçer et al. (2010), supports the research findings.

In the study, some additional diagnosis and problems such as MR obsession are seen besides the ASD in the children with ASD. This increases the incidence of behavior problems of the child with ASD and may cause the increase of mothers'

level of EE. Or conversely this may increase the incidence of additional diagnosis and problems in the children because the EE level of mothers increases.

The protective/caring attitudes, one of the EE sub-dimensions, for the mothers of children with ASD are more than the mothers of the children with ND. We can say that, the reason for that is, due to the level of the obstacle, children with ASD have a life that is dependent on their mothers and for the mothers, having a child that needs to be kept under control.

In the research of Adana and Arslantaş (2012), that investigates the factors which affect the perception of the burden of the people who care for schizophrenia patients and expressed emotion, it has seen that the care givers do not have a job and have a low-level of education and this causes more EE for the care givers. In the study of Ebrinç et al. (2001), a negative relationship is revealed between the educational status of parents of schizophrenic and EES Overly protective/caring sub-scale. Similarly in this study, a negative relationship has been found between the educational status of mothers of children with ASD and EES Overly protective/caring sub-scale. When the education level of mothers decreases, their EE overly protective/caring attitudes increase. This finding parallels the findings of Ebrinç et al. (2001) and of Adana and Arslantaş (2012).

In the same study, Adana and Arslantaş (2012) stated that if the patient is male, this causes more EE declaration in the family members. In this study, it has seen when the children with ASD were evaluated according to the gender 83. 9% of them are male. The argument of Adana and Arslantaş (2012) is parallel with the findings of the study.

In this study, a significant relationship were found between the educational status of mother, the number of children, the level of the signs of child's illness and the total EES score, EES sub-dimensions. In the study of Tüzer et al.. (2003) that analyzes the family environment of patients with schizophrenia and the expressed emotion, a significant relationship could not found between the sociodemographic characteristics of the patients and their relatives and EES total and sub-scales.

In this study, a negative relationship has been found between the educational status of mother and EES and Overly protective/caring sub-scale of EES. In the study

of Cohan et al. (2008), it has been found that psychosocial education reduces the EE level of caregivers of the patients with chronic disorder (Cited: Özkan, 2011). High education level of mothers who have children with ASD provides more healthy behavior and attitudes towards the child and overly protective/caring attitudes. In the research, we can see that low education level of mothers who have children with ASD causes a higher EE level of mothers and a higher overly protective/caring level of EE.

In this research, a positive relationship has been found between the number of children and Critical/hostile sub-scale of EES. Özdemir et al.. (2009) found in their research about the burden of the care giving of mothers with a child with cancer that the burden of care scores of mothers with three or more children are higher than others. In the study of Arslantaş and Adana (2012) that investigates the factors that affect the perception of the burden and the expressed emotion of care givers, there was a correlation with middle and high level between the perceived family burden and EES. Similarly, Bogren (1997) also found that when the EE level increases, the perceived family burden score increases.

Based on this finding, we can say that the EE level of mothers of the children with ASD increases because of the burden of care of the child with disabilities and the burden added with the existence of the other children. The different communication with the child with ASD and with other children and the stress of mother due to the burden of care can cause an increase on the EE critical/hostile level of mother.

### **5.5. Discussion of findings about the SWLS of the mothers of children with ND and the mothers of children with ASD**

The age, gender, work conditions, educational status, religion, race, income level, marriage and family life, social life, personality traits and biological factors are associated with the life satisfaction (Köker, 1991)

In this study, in terms of total SWLS scores, statistically significant differences have been found between the mothers of children with ND and mothers of children with ASD. The SWLS score of the mothers of children with ND is higher than the score of the mothers of children with ASD.

In the research that named “the investigation of variables about the quality of life of parents with disabled children” of Aysan and Özben (2007), it has been found that the life satisfaction of fathers who have children with disabilities is lower than the life satisfaction of fathers who have healthy children. In the research of İnce and Tüfekçi (2015) about the marital adjustment and life satisfaction of parents who have children with disabilities, they indicated that life satisfaction of parents who have children with disabilities is lower.

In the study of Strachan (2005), he aims to determine the effects of the stress on the life satisfaction of the fathers who have children, ranging from ages 5-12, with disabilities and their ways of coping with stress. In this study, he compared the life changes, stress and coping levels and life satisfaction of the fathers with and without children with disabilities. 127 fathers without children with disabilities and 85 fathers of children with disabilities are participated in the study. When these two groups are compared in terms of life satisfaction, parenting stress, physical and emotional health status, level of coping with problems, the intensity of daily life, life changes in the family, it has been found that there are significant differences and fathers with children with disabilities have more life changes, more daily family problems, the severity of the difficulty of their physical and emotional health situation is more and their life satisfaction is lower than the fathers without children with disabilities (Cited: Sarıkaya, 2011:17).

In the study of Vallerand et al.,(1989) about the life satisfaction, they found that the life satisfaction of parents who have members with disabilities is lower than the parents who have normal members. The findings of Vallerand et al. (1989) support the findings of this research.

In other researches about the life satisfaction of parents of children with disabilities or chronic disease, different findings have been found between these groups. For instance, it has been found that the life satisfaction of parents of children with chronic disease is lower (Baykan et al., 2010), and the life satisfaction of parents of children with disabilities is higher (Baykan et al., 2010; Deniz et al., 2009; Altay and Avcı, 2009; Erdem et al., 2004).

Based on the findings in the study of Strachan (2005), we can say that the presence of a disabled child in the family may disturb the balance in family life, they face more intense family problems than the families of children with ND, they experience more intense emotional or psychological difficulties due to the burnout brought on by the burden of child care. Therefore, their life satisfaction is lower than the families with children with ND.

In this research, there is a positive relationship between SWLS and DAS, between the SWLS and DAS Consensus sub-scale, between the SWLS and DAS Emotional expression sub-scale and between the LSS and DAS Commitment sub-scale. In the study of İnce and Tüfekçi (2015) about the marital adjustment and life satisfaction in parents who have children with disabilities and the factors affecting this, they said that the level of marital adjustment and life satisfaction of parents who have children with disabilities are low. It has been found that there is a strong and positive relationship between the marital adjustment and life satisfaction. The finding of İnce and Tüfekçi supports our findings. One of the results of the study of Özekes et al., (1998) about the role of having a disabled child in the marriage relationship was that the spouses perceive each other more reliable and more dependent after the child with disabilities. According to Özekes (1998), contrary to the popular belief, spouses are more connected to each other and are try to cope with the problems that brought the child disabled.

In the study, some variables, which might be effective in levels of life satisfaction, examined and it has been found that just the scores of the DAS cohesion and consensus sub-scales predict the scores of life satisfaction. The mothers who have children with ASD are in harmony with their spouse and this increases the life satisfaction of mothers.

Different from the research findings, Truth (1990) stated that the parents who have children with disabilities have a consensus on the lower level than the parents with normal children.

Cooke and the others (1986), Martin (1975) and Kazak and Marvin (1984) observed that in the family with disabled children, the presence of the child brings the family together and strengthens the marriage (Cited: Sarısoy, 2000).

As a result, we can state that the couple harmony, commitment and consensus of the parents of children with ASD makes their lives easier about the challenges of children with ASD, is effective to perceive their lives in a positive direction and allows them to receive satisfaction from life.

#### **5.6. Discussion of findings about the ZCBS of the mothers of children with ND and the mothers of children with ASD**

In the study, significant differences in terms of the level of the mother's burden of care have been found between the mothers of child with ND and ASD.

Parents, who have children with disabilities, undertake the responsibilities of the care for children, in addition to their role in parenting and housework. Giving care to a child with disabilities is different and more difficult than giving care to a child with ND (Duygun and Sezgin, 2003; Küçüker, 1997).

When the literature reviewed, it is seen that there are differences in terms of burden of care of mothers or caregivers in the disability groups. In his work with the people who care for schizophrenia patients, Çınar (2011) found that the care givers who say that their perception of general health is good have a low mean of burden of care score. In the research of Lee et al. (2007) and Uğuz et al. (2004), they found that responsibilities regarding the children's care of families who have a child with ASD are more than the other disabled groups. In the research of Erdem et al., (2013) about the burden of care of the mothers who have children with epilepsy, diabetes mellitus (DM), chronic kidney failure (CKF), it has been found that the burden of care of the mothers who have children with DM is more than the mothers of children with epilepsy and CKF.

Lee et al. (2007) found that the mothers of children with ASD have heavier burden of care than the healthy control group. The research shows that mothers of children with ASD are more stressful about the self-efficacy, behavior problems, and physical development of children than the fathers (Dabrowska and Pisula, 2010).

In several studies, it is stated that a family depends a child with ASD has much more responsibilities. Higher burden of care level of the mothers who have

children with ASD than the mothers who have children with ND may be about the lack of self-care skills of children with ASD.

Erikson and Upshur (1989) stated in their study with 202 mothers of the child with and without disabilities that there is a significant correlation between the burden and the increase of time spent on care and the difficulty of care, with the increasing of assistance and social support of the father, the burden decreases. In this study, according to the report of mothers who have children with ND, the ratio of the husbands interested in the child's care is 65. 5%. This ratio decreases to 25. 8% for the mothers who have children with ASD. The ratio of support from their husbands is higher for the mothers with ND children than the mothers with ASD children.

The results of the study of Erikson and Upshur (1989) are parallel with the results of this study. ASD is seen in the ratio of 0. 05-1. 1% and it lasts lifetime. Just the 5-17% of these cases is able to maintain their life full independently in the adult age (Çetin, 2008). The reason for that the perceived burden of care of the mothers with ASD child is higher than the mothers with ND child is that ASD lasts lifetime, a large majority of children with ASD is dependent on the care of mothers, and the children with ND is not dependent on the care of mothers.

According to the findings of this study, there is a positive relationship between the burden of care of the mother with ASD child and the disability percentage of the child. In the study, it has been seen that the disability percentage of the child with ASD predicts the burden of care.

Baronet (2003) and Haveman et al. (1997) found that the bad physical health and limited ability to adapt of child increase the burden of caregiver. When the time spent for the care of the child increases, the caregiver's burden increases. When the inability level of the child with ASD increases, the dependence on mother also increases. Because the mothers are the primer caregivers, their burden of care increases, too.

Hamarta, Uslu and Deniz (2002) stated that children with mental disabilities carry out their self-care skills with the help of their parents, they live a life dependent on their parents and these situations increase the burden on parents.

The most consistent results of the features of patients about the burden of care is concerned with the dependence. As the patient's level of dependence increases, the negative experiences of care givers increase and this contributes to the burden of caregiver (Nijboer et al., 1999; Given, 1997). In this study, it has been found that the children with ASD are dependent or semi-dependent in other self-care skills besides walking (nutrition, dressing, toilet, cleaning) and they have other illness or problems besides the ASD (obsession, MR). The high lack level of self-care of the children with ASD and their dependent life on the mother brings objective burden to the mother. The probability of lasting for a lifetime of that process and the thought of they could not get better brings subjective burden to the mother.

As a result, high percentage of the disability of the child with ASD, severe level of ASD symptoms and high level of dependency on mother for self-care skills of everyday life increase the burden of care of mothers.

According to our research findings, there is a positive relationship between the ZCBS and EES. As the burden of care of mother increases, the level of expressed emotion increases. Bove et al. (1999) think that as the perceived family burden increases, EE also increases. In the study of Sirivastava (2005), high DD is revealed in who have a high level of subjective burden of care and a high level of personal stress. Gutiérrez-Maldonado (2005) said that the high level of subjective and objective burden is related with the high expressed emotion. The finding of Boye et al. (1999) supports our finding that is about the positive relationship between the burden of care of the mothers who have children with ASD and the level of expressed emotion

As a result, the burden of care, makes the mothers of children with disabilities have difficulties and this burden causes stress and the high level of expressed emotion.

There is a negative relationship between the ZCBS and SWLS. As the burden of care of the mothers who have a child with ASD increases, the life satisfaction decreases. For the parents, dealing with the care of their children is one of the most essential tasks. Although, the care of children with ND and the care of children with ASD are same in terms of parenting, the times of care of children are different from each other. More objective and subjective burden of care due to the child with



disabilities, the psychological burden of the mother due to the lost sense, cannot allocate time for themselves due to the care of the child, staying away from the social life may cause the decrease of life satisfaction of the mothers who have a child with disabilities. In some cases, this care causes the fraying of the family both physically and emotionally, and decreases their life satisfaction (Raina et al., 2005).

In the study of Akarsu (2014) about the responsibility of families of children with mental disabilities, self-care skills and life satisfaction of mothers, it has been found that as the self-care skills of children increase, the burden of care of mothers decreases and their life satisfaction increases. In the same study, it has been found that as a result of the increase of mothers' burden of care, their life satisfaction decreases.

Similarly in the studies in the literature (Deniz et al., 2009; Aysan and Özben, 2007; Uyaroglu and Bodur 2009; Erhan, 2005), it has been found that as the dependency of the disabled child increases, the burden of mother and the stress they lived increase and their life satisfaction is adversely affected. The children with ASD are dependent partially or completely on the mother in terms of self-care. The responsibility of care of the mother decreases with the increase of self-care skills of children. Thus, the burden of mothers also decreases. This reduce the stress and concerns of mothers and affects their life satisfaction in a positive way (Sarı, 2007:33-40; Deniz et al., 2009; Aysan and Özben, 2007; Uyaroglu and Bodur 2009; Orhan, 2004). As a result, it can be said that the burden of care of the child with disabilities is one of the most important factors that affects the life satisfaction of mother.

In the research, a negative relationship has been found between the ZCBS and DAS. As the burden of care increases, the dyadic adjustment decreases. In our research, the dyadic adjustment predicts the burden of care significantly.

When the literature about the dyadic adjustment reviewed, it has been seen that there were studies that support and do not support the results of this research. Blacher et al., (1990), Donovan (1988), Byrne and Cuningham (1985), Truth (1990), Waisbren (1980) and Kazak (1987) observed that having a child with disabilities does not cause differentiation in the marriage relationship (Cited: Sarisoy, 2000). On the other hand according to Zucman (1982), mothers cannot see their husbands started to move away from the house and from themselves when they trying to cater the needs

and claims of children with disabilities and to take care of their children. From this perspective, having a disabled child in the family, beyond to influence the family status, especially has an effect to the test the couple's relationship (Cited: Duygun and Sezgin, 2003).

Özekes, Girli, Yurdakul and Sarısoy (2000) also reached a conclusion indicating that having a child with disabilities has a negative impact on the marital relationship of couples.

In the research, the reason for the negative relationship between the burden of care and the dyadic adjustment can be explained as the mother's allocation of the most of her time to the care of children with ASD and the failure to allocate time to her husband.

#### **5.7. Discussion of findings about the DAS of the mothers of children with ND and the mothers of children with ASD**

In the study, significant differences in terms of the mean score of the DAS have not been found between the groups of child with ND and ASD. It has been identified that DAS-Satisfaction sub-scale does not have a normal distribution, the differences between the two groups have been examined and significant differences have not been found.

The dyadic adjustment is defined as adaptation of the spouses to the daily life and changing conditions in life and changing as appropriate to each other within a certain period of time (Spanier, 1976). When the disabled child is not fully able to perform the role in the family, this may cause the compliance issues in the family. The temporary or continuous illness or disability of one member or more in the family affects the compliance of all the family members and may throw off the balance of families even in the most robust structure (Yörükoğlu, 1998).

In the study of İnce and Tüfekçi (2015) about the marital adjustment and life satisfaction in parents who have children with disabilities and the factors affecting this, they found that the level of marital adjustment of parents who have children with disabilities are low. Similarly, it has been found that the level of marital adjustment of

parents who have children with ASD and Down syndrome is low (Toros, 2002), the intimacy of mothers of autistic children with their husbands is weaker than the mothers of children with ND. In contrast, in the study of Gündoğdu (1995), it has been seen that the marital adjustment of parents who have children with ASD is more positive than the parents of normal children. Cooke et al. (1986) and Martin (1975) observed that the existence of the disabled child brings the family closer and makes the marriage stronger (Cited: Sarisoy, 2000). Kogel et al. (1983) stated that the marital adjustment of parents who have children with autism is very close to the marital adjustment of parents who have normal children.

Kazak and Marvin (1984) could not find a significant difference in the marital adjustment of all parents. It has been seen that the parents who have children with disability have a higher score from the “expression of love” and “consensus” subscales of DAS than the parents who have children with ND. Therefore, they came to a conclusion that the marriage is getting stronger because of the common response to the developmental needs of the disabled child, a joint effort and the division of responsibility.

In the study of Brobst (2009) named parenting on children, it has been investigated that the effect of the behavior problems of children with ASD on the stress of parent and the dyadic adjustment. 25 couples who have a child with ASD and 20 couples who have a child with ND have been compared and the stress and spouse satisfaction due to the behavior problems of child have been investigated. It has been found that the parents who have a child with ASD have more parenting stress due to the behavior problems of child and the satisfaction among couples are lower in the parents who have a child with ASD than the parents who have a child with ND. They stated that the behavior problems of child with ASD affect the adjustment between couples who have a child with ASD. They were able to identify that, there are differences between these two groups in terms of the measures related to the problems of the children, issues that couples shared and features of couples, the parents of children with ASD have more stress and their perceived social support and dyadic adjustment is low. In the same research, they were able to identify that there is not a difference between these two groups in terms of the perceived special person support, respect between the spouses and their commitment in relationships. Ainbinder et al.

(1998) and Pelchat et al., (2003) stated that the mothers of children with ASD have less support from their husbands.

Sometimes, the existence of a child with autism may bring the spouses closer (Wing, 2005), the perceptions of marital adjustment of the parents may be positive (Gündoğdu, 1995; Özekes et al., 1998).

According to the thought of Wing (2005), Özekes et al., (1998) and Gündoğdu (1995), the reason for not to be obvious of the difference in the DAS and sub-scale scores of the mothers who have a child with ND and the mothers who have a child with ASD may be having a child with disability contributes to the dyadic adjustment.

### **5.8. Discussion of findings about the PGI of the mothers of children with ND and the mothers of children with ASD**

In the research, there is not a significant difference in terms of total PGI score, PGI-Change In Other Relationships sub-scale, PGI-Change In Philosophy Of Life sub-scale and PGI-Change In Perception Of Self sub-scale, between the mothers of children with ND and the mothers of children with ASD.

Unlike the sources of everyday stress, having a child with disability is one of the traumatic experiences of families that is perceived as a threat for bodily integrity of their children and the continuity of healthy family life (Ardıç, 2013; McCubbin and Huang, 1989; Uğuz, Toros, Yazgan and Çolakkadıoğlu, 2004).

Having a child with disabilities is an important stressor for the families. As the level of stress of the families increases, the effort that the person spends to cope with the stressor also increases. This effort helps some families to increase their durability and to feel empowered olur (Zhang, Yan, Du and Liu, 2013). This positive change in the families is called post-traumatic growth (Hastings et al., 2005).

The researches that investigate the post-traumatic growth in the families with disabled child, show that having a child with disabilities causes positive changes in the life of families, it pushes them to find new and different solutions, leads to an increase in patience and compassion and strengthens them spiritually (Bayat, 2007; Ekas and Whitman, 2011; Phelps, McCammon, Wuensch and Golden, 2009).

In their researches, Mapp and Hudson (1997) mentioned that as the elapsed time increases after the diagnosis post-traumatic growth will occur and stress, depression and anxiety levels of families will decrease.

In this research, the reason for the lack of a difference between the mothers of children with ASD and the mothers of children with ND may be the durability of the mothers of children with ASD that occurs at the end of their struggle with stress and their learning from past experiences,

In the research, there is a negative relationship between the educational status of mother and the PGI-Relationship with the others sub-scale. In the review study of Linley and Joseph (2004) that investigates the effects of socio-demographic characteristics on the posttraumatic growth, they stated that the effects of educational status on the posttraumatic growth has not been fully clarified in the literature, just like the age, gender and income level.

Windows et al., (2005) found a significant relationship between the educational status and posttraumatic growth. It has been found that, the change in one's self sub-scale scores of secondary school and university graduates are higher than the scores of the primary school graduates and the only literate ones. In this study, it has not been found a relationship between the educational status of mother and the PGI- Self sub-scale. Windows et al.. (2005) stated that the change in one's self in other words the change in the perception of self is related with the evaluation of the person's own proficiency and the self-confidence of them. They expect people with higher educational status to evaluate themselves and choose an enterprising way in dealing with incidents, in the aftermath of trauma. In this study, the reason for the lack of this may be associated with low educational status of the mother of child with ASD.

In the research, it has been seen that the low educational status of mothers with an ASD child increases the PGI-Relationships with the others sub-scale. The low educational status of mothers who have a child with ASD might cause the increase of Relationships with the Others in their development after the trauma, to open themselves more against other people, to want to share more with others due to the need for psychological support in dealing with incidents, to be in search of trust and

psychological support and the high educational status of mothers who have a child with ASD might cause the power to put up their fight with the difficulties of trauma individually due to their cognitive competences.

In the research, there is a positive relationship between the percentage of disabilities and PGI-Change in Perception of Self sub-scale. The high percentage of disabilities of the child with ASD increases the score of PGI-Change in Perception of Self of mothers.

In the posttraumatic growth in the parents of children with ASD study of Kenneth et al.. (2009), a significant relationship has not been found between the ASD level of child and the posttraumatic growth of parents.

Aslantaş and Adana (2011) stated that disease-related symptoms and the burden of care are in a linear relationship. In the results of study of Özlü et al., (2010) that investigates whether there is a change in the perception of the burden with espousing the disease of the relatives of patient over time and acquiring coping strategies, they were able to identify that the posttraumatic growth is higher when the care giver is young, the patient is young, there is social support, they use the problem-focused coping strategy.

Yorulmaz et al., (2010:2313-2319) have concluded that the disease awareness is related with the high level of post-traumatic growth. Micheal et al., (2009:123-129) have concluded that in the parents of children with cancer, the perception of how the disease has affected them is significantly related with the post-traumatic growth, however, the diagnosis of the disease is not related with the post-traumatic growth of the parents.

As a result, we can say that the positive relationship between the disability percentage of the child with ASD and PGI/PGI-Self sub-scale of the mothers is related with the disease awareness of the mothers.

In the research, there is a positive relationship between the PGI-Change in Perception of Self sub-scale and the first diagnosis year. Mapp and Hudson (1997) mentioned in their research that as the elapsed time after diagnosis increases, the post-traumatic growth will occur and the stress, depression and lost level of parents will

decrease. The result of the research of Mapp and Hudson (1997) supports the relationship between the PGI and the first diagnosis, in this research.

Having a child with disabilities is an important stressor for the families. As the stress level of parents increases, the effort spent for coping with these stressors increases. This effort helps to increase the durability of the person and to feel empowered in some families (Zhang, Yan, Du and Liu, 2013). In the study of Zhang et al., (2013) that investigates the post-traumatic growth of the mothers with ASD child, they found that positive coping methods predict the post-traumatic growth.

Based on the thought of Zhang, Yan, Du and Liu, we can say that the struggle with the stress of children with ASD empowers the mother. Based on the thought of Mapp and Hudson, we can say that after the diagnosis, developing the ways of coping with the situation of the child decreases this stress and causes the development of the post-traumatic growth (in the Self sub-scale) of mother.

In the research, there is a positive relationship between the PGI and DAS/DAS-Consensus sub-scale.

In the study of Elçi (2004) that made with the parents of children with ASD, it has been found that different variables predict the post-traumatic growth of the parents. For the mothers, the social support, problem solving/optimistic coping strategy predicts the post-traumatic growth. In the study of Etişken (2013) that is about the factors that affect the post-traumatic growth in the infertile individuals, it has not been found a significant relationship between the Support from a Private Person sub-scale of perceived social support and the post-traumatic growth.

The finding of the study of Etişken (2013) that the perceived support of special person level in the post-traumatic growth is different from the finding of this study that the consensus of mothers of ASD children with their husbands increases the post-traumatic growth.

In our study, we found that the support received from private person predicts the positive relationship between the Dyadic Adjustment, Consensus and the post-traumatic growth. When the mother is in consensus with the husband, when they

move together about the decision-making and problem solving related to their children with ASD, the post-traumatic growth of mothers may be increase.

There is a positive relationship between the PGI-Relationship with the others sub-scale and SWLS. The researches that investigates the post-traumatic growth in the families with disabled child show that having a disabled child causes positive changes in the life of parents, them to find new and different solutions in their lives, an increase in their feel of patience and compassion and makes them spiritually stronger (Ekas and Whitman, 2011; Phelps, McCammon, Wuensch and Golden, 2009).

As a result, having a disabled child can cause troubles in mother's life; however, it also causes positive changes. To understand the value and the meaning of life, to approach patiently and more positive against the problems of life can affect their satisfaction in life positively.



## 6. CONCLUSION AND RECOMMENDATIONS

This study has been made in order to identify the burden of care, dyadic adjustment, perceived social support, expressed emotion, life satisfaction level and post-traumatic growth of the mothers of children with ASD and children with ND, and determine the differences between them. For this purpose, ZCBS, DAS, MPSSS, EES, SWLS and PGI have been applied to the mothers. In addition to these scales, ABC has been applied to the mothers of children with ASD, in order to determine the level of children's symptom.

According to the mean score of the main variables of the research which forms the basis, the significant differences have been revealed about the perceived social support, expressed emotion, life satisfaction and the burden of care between the mothers of children with ASD and the mothers of children with ND. The burden of care of the mothers who have a child with ASD is higher than the mothers of children with ND. The first hypothesis of the research was confirmed. The perceived social support of mothers of children with ASD is lower than the mothers of children with ND. The expressed emotion of mothers of children with ASD is higher than the mothers of children with ND. The life satisfaction level of mothers of children with ASD is lower than the mothers of children with ND. The life satisfaction hypothesis in the study was confirmed.

The post-traumatic growth and the dyadic adjustment were not significantly different for the both two groups of mothers.

There is a significant relationship between *the burden of care* of mother and expressed emotion level, EE (Critical/Hostile sub-scale), life satisfaction, dyadic adjustment, DA-Emotional sub-scale, DA-Consensus sub-scale, and the disability percentage of child, however, there is not a significant relationship between *the burden of care* and the educational status of mother, the age of mother, the number of children, multidimensional perceived social support level, and post-traumatic growth. In the research, the second hypothesis that says the burden of care is related with the disability percentage, dyadic adjustment and satisfaction with life scales has been confirmed with some findings. However, the thesis that says it is related with the socio-demographic characteristics of the mother could not be confirmed with the

findings. The fourth hypothesis of the research that says there is a relationship between the burden of care and the disability percentage of the child, has been confirmed with the findings.

There is a significant relationship between *the multidimensional perceived social support* of mother and expressed emotion level, EE (Critical/Hostile sub-scale), life satisfaction and between *the perceived family support* and post-traumatic growth-the perception of self. However, it has been found that there is not a significant relationship between *the multidimensional perceived social support level* and the educational status, age, burden of care, and post-traumatic growth of mother, and dyadic adjustment.

A significant relationship has been found between *the expressed emotion level, EE (Critical/Hostile sub-scale)* and the life satisfaction of mother. However, a significant relationship has not been found between *the expressed emotion* and the child and the mother's socio-demographic characteristics, and the other variables. The fourth hypothesis of the research that says there is a relationship between the expressed emotion level of mother and the ASD behavior symptom level has been confirmed.

A significant relationship has been found between *the post-traumatic growth level* of mother and the educational status of mother, the first diagnosis year of child, disability percentage, dyadic adjustment, DA-Consensus sub-scale; between *the post-traumatic growth-Change in the relationship with the others sub-scale* and the educational status of mother, the life satisfaction, the dyadic adjustment, DA-Consensus sub-scale; between *the post-traumatic growth-Change in the perception of self-sub-scale* and the educational time of mother, the disability percentage of child, the first diagnosis year of child, perceived family support. A significant relationship with other variables has not been determined. The fifth hypothesis of the research that says the educational status of mother affects the post-traumatic growth of mother, has been confirmed with the findings.

A significant relationship has been found between *the life satisfaction* of mother and the dyadic adjustment, the DA-Emotional/Consensus/Commitment subscales. The fourth hypothesis of the research that says there is a relationship between

the expressed emotion level of mother and the ASD behavior symptom level, has been confirmed with the findings. In the fourth hypothesis of the research, the relationship between ASD symptom level and life satisfaction has not been determined, however, the relationship between the life satisfaction and the disability percentage has been determined. The hypothesis has been confirmed with the findings, because the ASD symptom level and the disability percentage are related with each other.

A significant difference about the educational status, working and the number of children has been found between the mothers of children with ASD and children with ND. A significant relationship has been found between the educational status of mother with ASD child and the expressed emotion (protective/caring sub-scale). A significant relationship has been found between the first diagnosis year of the child with ASD and the education time of the child.

The disability percentage of the child and the dyadic adjustment predict the burden of care of the mother; the dyadic adjustment-consensus and the dyadic adjustment-the level of commitment predict the life satisfaction of mother.

In this research, the mothers of children with ASD were included in the study. In other studies, the study with other disability groups and comparisons can be made. In the study, mothers were selected as parents. In other studies that can be done in the future, the differences between the parents can be investigated.

The multidimensional perceived social support and the burden of care variables are the variables have the biggest relationship in other variables of the study. The effect of the dyadic adjustment-consensus on the burden of care and the post-traumatic growth in the families with disabled child and their significant relationship have been identified.

In the research, the burden of care of the mother is heavy, the multidimensional perceived support is low and the dyadic adjustment is not in a sufficient level. The mothers cannot take enough satisfaction from their lives. Therefore, based on the findings of this study, establishment of counseling units for the members of family with disabled child in official institutions is important and required for overcoming the traumatic situation that the parents experienced when they find out that they have a child with ASD and for preventing a disconnect among

couples because of the children with disabilities. In the study, the educational status and working status of the mother have a positive effect on the struggle with ASD child. Therefore, the working conditions of the mothers with ASD child should be limited for the duration of the child's education and the work employment needs to be done to ensure that keep the mother involved in the social life along with the responsibility of care. Having a high level of education status and a working life, increase the mother's contribution in the individual development of the child with ASD.

During the implementation phase of the scales in the study, it has been noticed the subjects that mothers of children with ASD have difficulty in coping of and their needs to acquire knowledge in these subjects. Detailed information about ASD should be given to the families. The community information studies should be made to make it easier for the families of the children with ASD to get involved in the community and to be adapted.

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## APPENDİCES

### APPENDİX 1. INFORMED CONSENT FORM

ARAŞTIRMA AMAÇLI ÇALIŞMA İÇİN AYDINLATILMIŞ ONAM FORMU  
(Hasta Grubu)  
(Araştırmacının Açıklaması)

Araştırmamızın adı “Otizmlı çocuğa sahip olan annelerin bakım yükü, çift uyumu, algılanan sosyal destek, duygu dışavurumu, yaşam doyumu, travma sonrası gelişimi açısından incelenmesi” dir.

Sizin de bu araştırmaya katılmanızı öneriyoruz. Bu araştırmaya katılıp katılmamakta serbestsiniz. Çalışmaya katılım gönüllülük esasına dayalıdır. Kararınızdan önce araştırma hakkında sizi bilgilendirmek istiyoruz. Bu bilgileri okuyup anladıktan sonra araştırmaya katılmak isterseniz formu imzalayınız.

Bu araştırmayı yapmak istememizin nedeni, otizmlı çocuğu olan ailelerde, çocuğun engel derecesine göre getirdiği bakım yükünün ağırlığıyla aile üyelerinin psikolojik sorunlar yaşaması ve bu yükün annelerde yoğunlaşması, yaşadıkları bu travma sonrasında yaşamlarında nelerin değiştiğine ve ne yaşadıklarına yönelik çalışmalara ihtiyaç duyulmasıdır. Yakın Doğu Üniversitesi Sosyal Bilimler Enstitüsü Uygulamalı (Klinik) Psikolojisi Anabilim Dalları’nın ortak katılımı ile gerçekleştirilecek bu çalışmaya katılımınız araştırmanın başarısı için önemlidir.

Eğer araştırmaya katılmayı kabul ederseniz doldurduğunuz formlar istatistiksel karşılaştırma amaçlı kullanılacaktır. Doldurduğunuz cevap formlarıyla, kişisel bilgileriniz ayrı zarflara konulacak ve gizlilik sağlanacaktır.

Bu çalışmaya katılmanız için sizden herhangi bir ücret istenmeyecektir. Çalışmaya katıldığınız için size ek bir ödeme de yapılmayacaktır.

Sizinle ilgili tıbbi bilgiler gizli tutulacak, ancak çalışmanın kalitesini denetleyen görevliler, etik kurullar ya da resmi makamlarca gereği halinde incelenebilecektir.

Bu çalışmaya katılmayı reddedebilirsiniz. Bu araştırmaya katılmak tamamen isteğe bağlıdır ve reddettiğiniz takdirde size uygulanan tedavide herhangi bir

değişiklik olmayacaktır.Yine çalışmanın herhangi bir aşamasında onayınızı çekmek hakkına da sahipsiniz.

*(Katılımcının/Hastanın Beyanı)*

Sayın Gülbahar Baştuğ ve Güliz Çetinbakış tarafından Psikoloji Anabilim Dalı'nda bir araştırma yapılacağı belirtilerek bu araştırma ile ilgili yukarıdaki bilgiler bana aktarıldı. Bu bilgilerden böyle bir araştırmaya “katılımcı” olarak davet edildim.

Eğer bu araştırmaya katılırsam araştırmacı ile kalması gereken bana ait bilgilerin gizliliğine bu araştırma sırasında da büyük özen ve saygı ile yaklaşılacağına inanıyorum. Araştırma sonuçlarının eğitim ve bilimsel amaçlarla kullanımı sırasında kişisel bilgilerimin ihtimamla korunacağı konusunda bana yeterli güven verildi.

Projenin yürütülmesi sırasında herhangi bir sebep göstermeden araştırmadan çekilebilirim. *(Ancak araştırmacıları zor durumda bırakmamak için araştırmadan çekileceğimi önceden bildirmemim uygun olacağının bilincindeyim)* Ayrıca tıbbi durumuma herhangi bir zarar verilmemesi koşuluyla araştırmacı tarafından araştırma dışı tutulabilirim.

Araştırma için yapılacak harcamalarla ilgili herhangi bir parasal sorumluluk altına girmiyorum.Bana da bir ödeme yapılmayacaktır.

İster doğrudan, ister dolaylı olsun araştırma uygulamasından kaynaklanan nedenlerle meydana gelebilecek herhangi bir sağlık sorununun ortaya çıkması halinde, her türlü tıbbi müdahalenin sağlanacağı konusunda gerekli güvence verildi.(Bu tıbbi müdahalelerle ilgili olarak da parasal bir yük altına girmeyeceğim).

Araştırma sırasında bir sağlık sorunu ile karşılaştığımda; herhangi bir saatte, araştırmacı Güliz Çetinbakış'ı +90 533 436 19 14 (cep) no'lu telefondan ve [gulizden@gmail.com](mailto:gulizden@gmail.com) internet adresinden arayabileceğimi biliyorum.

Bu araştırmaya katılmak zorunda değilim ve katılmayabilirim. Araştırmaya katılmam konusunda zorlayıcı bir davranışla karşılaşmış değilim. Eğer katılmayı reddedersem, bu durumun tıbbi bakıma ve hekim ile olan ilişkiye herhangi bir zarar getirmeyeceğini de biliyorum.

Bana yapılan tüm açıklamaları ayrıntılarıyla anlamış bulunmaktayım. Kendi başıma belli bir düşünme süresi sonunda adı geçen bu araştırma projesinde “katılımcı” olarak yer alma kararını aldım. Bu konuda yapılan daveti büyük bir memnuniyet ve gönüllülük içerisinde kabul ediyorum.

İmzalı bu form kâğıdının bir kopyası bana verilecektir.

Katılımcı

Adı, soyadı:

Adres:

Tel.

İmza

Görüşme tanığı

Adı, soyadı:

Adres:

Tel.

İmza:

Katılımcı ile görüşen hekim

Adı soyadı, unvanı :

Adres :

Tel.

İmza

## ARAŞTIRMA AMAÇLI ÇALIŞMA İÇİN AYDINLATILMIŞ ONAM FORMU

(Kontrol Grubu)

*(Araştırmacının Açıklaması)*

Otizmli çocuğa sahip olan annelerin bakım yükü, çift uyumu, algılanan sosyal destek, duygu dışavurumu, yaşama doyumu, travma sonrası gelişimi ile ilgili yeni bir araştırma yapmaktayız. Araştırmanın ismi “Otizmli Çocuğa Sahip Olan Annelerin Bakım Yükü, Çift Uyumu,Algılanan Sosyal Destek, Duygu Dışavurumu, Yaşam Doyumu ve Travma Sonrası Gelişimi Açısından İncelenmesi”dir.

Sizin de bu araştırmaya katılmanızı öneriyoruz. Bu araştırmaya katılıp katılmamakta serbestsiniz. Çalışmaya katılım gönüllülük esasına dayalıdır. Kararınızdan önce araştırma hakkında sizi bilgilendirmek istiyoruz. Bu bilgileri okuyup anladıktan sonra araştırmaya katılmak isterseniz formu imzalayınız.

Bu araştırmayı yapmak istememizin nedeni, otizmli çocuğu olan ailelerde, çocuğun özür derecesine göre getirdiği bakım yükünün ağırlığıyla aile üyelerinin psikolojik sorunlar yaşaması ve bu yükün annelerde yoğunlaşması, yaşadıkları bu travma sonrasında yaşamlarında nelerin değiştiğine ve ne yaşadıklarına yönelik çalışmalara ihtiyaç duyulmasıdır. Yakın Doğu Üniversitesi Sosyal Bilimler Enstitüsü Uygulamalı (Klinik) Psikolojisi Anabilim Dalları’nın ortak katılımı ile gerçekleştirilecek bu çalışmaya katılımınız araştırmanın başarısı için önemlidir.

Eğer araştırmaya katılmayı kabul ederseniz doldurduğunuz formlar istatistiksel karşılaştırma amaçlı kullanılacaktır. Doldurduğunuz cevap formlarıyla, kişisel bilgileriniz ayrı zarflara konulacak ve gizlilik sağlanacaktır.

Bu çalışmaya katılmanız için sizden herhangi bir ücret istenmeyecektir. Çalışmaya katıldığınız için size ek bir ödeme de yapılmayacaktır.

Sizinle ilgili tıbbi bilgiler gizli tutulacak, ancak çalışmanın kalitesini denetleyen görevliler, etik kurullar ya da resmi makamlarca gereği halinde incelenebilecektir.

Bu çalışmaya katılmayı reddedebilirsiniz. Bu araştırmaya katılmak tamamen isteğe bağlıdır ve reddettiğiniz takdirde size uygulanan tedavide herhangi bir

değişiklik olmayacaktır. Yine çalışmanın herhangi bir aşamasında onayınızı çekmek hakkına da sahipsiniz.

*(Katılımcının/Hastanın Beyanı)*

Sayın Gülbahar Baştuğ ve Güliz Çetinbakış tarafından Psikoloji Anabilim Dalı'nda bir araştırma yapılacağı belirtilerek bu araştırma ile ilgili yukarıdaki bilgiler bana aktarıldı. Bu bilgilerden sonra böyle bir araştırmaya “katılımcı” olarak davet edildim.

Eğer bu araştırmaya katılırsam araştırmacı ile aramda kalması gereken bana ait bilgilerin gizliliğine bu araştırma sırasında da büyük özen ve saygı ile yaklaşılacağına inanıyorum. Araştırma sonuçlarının eğitim ve bilimsel amaçlarla kullanımı sırasında kişisel bilgilerimin ihtimamla korunacağı konusunda bana yeterli güven verildi.

Projenin yürütülmesi sırasında herhangi bir sebep göstermeden araştırmadan çekilebilirim (Ancak araştırmacıları zor durumda bırakmamak için araştırmadan çekileceğimi önceden bildirmemin uygun olacağının bilincindeyim). Ayrıca tıbbi durumuma herhangi bir zarar verilmemesi koşuluyla araştırmacı tarafından araştırma dışı tutulabilirim.

Araştırma için yapılacak harcamalarla ilgili herhangi bir parasal sorumluluk altına girmiyorum. Bana da bir ödeme yapılmayacaktır.

İster doğrudan, ister dolaylı olsun araştırma uygulamasından kaynaklanan nedenlerle meydana gelebilecek herhangi bir sağlık sorununun ortaya çıkması halinde, her türlü tıbbi müdahalenin sağlanacağı konusunda gerekli güvence verildi. (Bu tıbbi müdahalelerle ilgili olarak da parasal bir yük altına girmeyeceğim).

Araştırma sırasında bir sağlık sorunu ile karşılaştığımda; herhangi bir saatte, araştırmacı Güliz Çetinbakış'ı +90 533 436 19 14 (cep) no'lu telefondan ve [gulizden@gmail.com](mailto:gulizden@gmail.com) internet adresinden arayabileceğimi biliyorum.

Bu araştırmaya katılmak zorunda değilim ve katılmayabilirim. Araştırmaya katılmam konusunda zorlayıcı bir davranışla karşılaşmış değilim. Eğer katılmayı reddedersem, bu durumun tıbbi bakımına ve hekim ile olan ilişkiye herhangi bir zarar getirmeyeceğini de biliyorum.

Bana yapılan tüm açıklamaları ayrıntılarıyla anlamış bulunmaktayım. Kendi başıma belli bir düşünme süresi sonunda adı geçen bu araştırma projesinde “katılımcı” olarak yer alma kararını aldım. Bu konuda yapılan daveti büyük bir memnuniyet ve gönüllülük içerisinde kabul ediyorum.

İmzalı bu form kâğıdının bir kopyası bana verilecektir.

Katılımcı

Adı, soyadı:

Adres:

Tel.

İmza

Görüşme tanığı

Adı, soyadı:

Adres:

Tel.

İmza:

Katılımcı ile görüşen araştırmacı

Adı soyadı, unvanı :

Adres :

Tel.

İmza

## APPENDİX 2. SOCİO-DEMOGRAPHİC FORM

### Sosyodemografik Veri Formu

Bu araştırma, otizm tanısı olan çocukların annelerinin psikolojik sorunlarını değerlendirmek üzere yapılmaktadır. Bu amaçla sizden bazı soru ve ifadelerden oluşan bir anket setini doldurmanız istenmektedir. Alınan bilgiler kişisel olarak değerlendirilmeyecek, sadece bilimsel araştırma amacıyla kullanılacaktır. Araştırmaya katılmanız otizm tanılı çocuğa sahip olmanın anneler üzerindeki etkisini görme anlamında büyük önem taşımaktadır; bu nedenle, cevap verirken samimi ve dürüst olunuz. Katıldığınız için teşekkür ediyoruz.

#### ANNEYE İLİŞKİN BİLGİLER:

##### Ad Soyad:

##### Yaş:

1. Eğitim durumu (yıl olarak):
2. Çalışıyor musunuz? Evet (.....) Hayır(.....)
3. Mesleğiniz: \_\_\_\_\_
4. Nerede oturuyorsunuz? Köy (.....) İlçe (.....) İl (.....)
5. Medeni durum: Evli (.....) Boşanmış (... ) Dul (.....)
6. Boşandıysanız ne kadar süredir? \_\_\_\_\_
7. Çocuk sayısı: Bir (....) iki (.....) üç (.....) diğer (...)
8. Aile içinde kimlerle yaşıyorsunuz?
  - a. Eşim ve çocuğum ya da çocuklarımla
  - b. Ben ve çocuğum ya da çocuklarımla
  - c. Diğer.....
9. Aile bireyleri içinde başka engelli birey var mı? Evet (....) Hayır (....)
10. Aile bireyleri içinde kronik rahatsızlığı olan başka birey var mı? Evet (....) Hayır (....)
11. Otizm tanılı çocuğunuzun bakımı ve sorumluluklarıyla ilgilenen sizin dışınızda aile bireyleri kimler?
  - a. Sadece eşim
  - b. Eşim ve çocuklarım
  - c. Eşim, çocuklarım ve akrabalarımız
  - d. Sadece ben
  - e. Diğer.....
12. Herhangi bir fiziksel hastalık için şu an bir tedavi görüyor musunuz?
13. Evet ( belirtiniz: \_\_\_\_\_) Hayır ( )
14. Herhangi bir psikiyatrik rahatsızlığınız var mı?
15. Evet ( belirtiniz: \_\_\_\_\_) Hayır ( )
16. Var ise, bunun için şu anda bir ilaç kullanıyor musunuz?
17. Evet ( belirtiniz: \_\_\_\_\_) Hayır ( )

ÇOCUĞA İLİŞKİN BİLGİLER (Otizm tanılı olan çocuğunuzu dikkate alarak cevaplayınız)

1. Yaşı : \_\_\_\_\_
2. Cinsiyeti : Kız ( ) Erkek ( )
3. Otizm tanılı çocuğunuzun kardeş sırasındaki yeri?  
Tek çocuk (...) 1.çocuk (...) 2.çocuk (...) 3.çocuk (...)
4. Öğrenim durumu? (devam ettiği ve/ veya en son tamamladığı okul)  
Okula gitmiyor (.....) Özel eğitim ve Rehabilitasyon Merkezi (....) Otistik Çocuklar Eğitim Merkezi (OÇEM) (....) MEB Özel Eğitim Alt Sınıfı (...) İlköğretim (.....) Lise (.....) Üniversite (.....)
5. Engellilik Yüzdesi ve tanı (Sağlık Kurulu Raporunda belirtildiği şekliyle): \_\_\_\_\_
6. Çocuğunuza ilk tanı ne zaman konuldu? \_\_\_\_\_
7. Çocuğunuzda otizme eşlik eden başka sorunlar var mı? Evet (.....) Hayır (.....)
8. Cevabınız “Evet”ise ;
9. Sara (epilepsi) (..) Uyku problemleri(..) Takıntılı davranışlar (..) Uygunsuz korku (..) Katı gıdaları reddetme (..) Alerjik reaksiyonlar (..) Kabızlık (..) İşitme kaybı (..) Üstün zekalılık (..) Zeka geriliği (..)
- 10.Çocuğunuz günlük yaşamda size ne kadar bağımlı? :  
Yürüme : Bağımlı Yarı Bağımlı Bağımsız  
Beslenme : Bağımlı Yarı Bağımlı Bağımsız  
Giyinme-Soyunma : Bağımlı Yarı Bağımlı Bağımsız  
Temizlik : Bağımlı Yarı Bağımlı Bağımsız  
Tuvalet : Bağımlı Yarı Bağımlı Bağımsız
- 11.Eğitim ve Rehabilitasyon Merkezine kaç yıldır devam ediyorsunuz?  
.....yıl
- 12.Çocuğunuzun Eğitim ve Rehabilitasyon programını yeterli buluyor musunuz?  
Evet (.....) Hayır (.....) Cevabınız hayır ise önerilerinizi yazınız.....
- 13.Çocuğunuzun kullanması gereken ilaçlar var mı? Evet (..) Hayır (..)
- 14.Cevabınız “Evet”ise aldığı ilaçları yazınız.  
.....
- 15.Çocuğunuzun uygulaması gereken egzersizleri var mı? Evet (..) Hayır (..)
- 16.Cevabınız “Evet” ise egzersizleri yazınız.  
.....



### APPENDIX 3. AUTİSM BEHAVİOR CHECKLİST (ABC)

#### ODKL

#### 1. Otizm Davranış Kontrol Listesi

Adı Soyadı:

Doğum Tarihi:

Dolduran Kişi:

Doldurma Tarihi:

Yönerge: Çocuğu en iyi tanımlayan maddenin karşısındaki sayıyı daire içine alınız. Eğer ifade çocuğu tanımlamıyorsa boş bırakınız.

	Duyusal	İlişki kurma	Beden ve Nesne kullanımı	Dil becerileri	Sosyal ve Özbakım
1-Kendi etrafında uzun süre döner.			4		
2-Basit bir işi öğrenir, fakat çabucak unuttur.					2
3-Sosyal / çevresel uyaranlara çoğu zaman dikkat etmez.		4			
4-Basit emirleri bir kere söylendiğinde yerine getirmez(ör:otur, burayagel, ayağa kalk).				1	
5-Oyuncakları uygun şekilde kullanmaz (ör. tekerlekleri döndürür).			2		
6-Öğrenme sırasında görsel ayırt etmesi zayıftır (büyüklük, renk ya da pozisyon gibi bir özelliğe takılır kalır).	2				
7-Sosyal gülümsemesi yoktur.		2			
8-Zamirleri ters kullanır (ben yerine sen).				3	
9-Belirli nesneleri bırakmamak için ısrar eder.			3		
10-İşitmiyor gibi görünür, bu nedenle bir işitme kaybı olduğu kuşkusu uyandırır.	3				
11-Konuşması detone ve aritmetiktir.				4	
12-Kendi kendine uzun süre sallanır.			4		
13-Kendisine uzanıldığında kollarını uzatmaz(ya da bebekken uzatmazdı).		2			
14-Günlük programındaki, çevredeki değişikliklere aşırı tepkiler verir.					3
15-Başka insanların arasındayken çağrıldığında kendi ismine tepki vermez(Ayşe, Can, Zeynep).				2	
16-Kendi etrafında dönme, parmak ucunda yürüme, el çırpma gibi davranışları keserek birden bağırır ve ani hareketler yapar.			4		
17-Başka insanların yüz ifadelerine ve duygularına tepkisizdir.		3			
18-“Evet” ya da “ben” sözcüklerini nadiren kullanır.				2	
19-Gelişiminin bir alanındaki özel yetenekleri zeka geriliği kuşkusu dışı niteliktedir.					4
20-Yer bildiren sözcükleri içeren basit emirleri yerine getirmez (örn.; “topu kutunun üstüne koy” ya da “topu kutunun içine koy”).				1	
21-Bazen yüksek bir sese sağır olduğunu düşündürürcesine “irkilme” tepkisi göstermez.	3				
22- Ellerini amaçsızca sallar.			4		
23-Büyük öfke nöbetleri ya da sık sık küçük öfke nöbetleri geçirir.					3
24-Göz temasından aktif bir şekilde kaçınır.		4			
25-Dokunulmaya ya da tutulmaya karşı koyar.		4			
26-Bazen çürükler, kesikler ve iğne yapılma gibi acı verici uyaranlara hiç tepki vermez.	3				
27-Gergin ve kucaklanılması güçtür (şimdi ya da bebekken).		3			
28-Kucaklandığında pelte gibidir (sarılmaz, tutunmaz).		2			
29-İstediği şeyleri göstererek elde eder.				2	
30- Parmak uçlarında yürür.			2		
31-Başkalarını ısıarak, vurarak , tekmeleyerek incitir.					2
32-Cümleleri defalarca tekrarlar.				3	
33-Oyun oynarken başka çocukları taklit etmez.		3			
34-Gözlerine parlak bir ışık tutulduğunda genellikle gözlerini kırpmaz.	1				

35-Başını vurarak, ellerini ısırarak kendine zarar verir.			3		
36-İhtiyaçlarının hemen yerine getirilmesini ister. Bekleyemez.					2
37-İsmi söylenen beş nesneden daha fazlasını işaret ederek gösteremez.				1	
38-Hiç arkadaşlık ilişkisi geliştiremez.		4			
39-Birçok sese kulaklarını kapatır.	4				
40-Sık sık nesneleri döndürür, çevirir ve çarpar.			4		
41-Tuvalet eğitimine ilişkin sorunları vardır.					1
42-İsteklerini ve ihtiyaçlarını belirtmek için ya hiç konuşmaz ya da bir günde kendiliğinden kullandığı sözcük sayısı beşi geçmez.				2	
43-Çoğunlukla korkar ya da çok kaygılanır.		3			
44-Gün ışığı karşısında gözlerini kısar, kaşlarını çatar yada gözlerini kapatır.	3				
45-Yardımsız kendisi giyinemez.					1
46-Sesleri ya da sözcükleri sürekli tekrar eder.				3	
47-Bakışları insanları "delip geçer."		4			
48-Başkalarının cümlelerini ya da / ve sorularını tekrarlar.				4	
49-Çoğunlukla çevresindekilerin ve tehlikeli durumların farkında değildir.					2
50-Cansız şeylerle oynamayı ve zaman geçirmeyi tercih eder.					4
51-Çevresindeki nesnelere dokunur, koklar ve / veya tadar.			3		
52-Yeni bir kişiyle karşılaştığında sıklıkla hiçbir görsel tepki vermez.	3				
53-Nesneleri sıralama gibi karmaşık ritüeller içine girer.			4		
54-Çok zarar vericidir, oyuncaklarını ve ev eşyalarını kısa zamanda kırar.			2		
55-Gelişimsel gecikme belirtileri 30. ayda ya da daha önce ortaya çıkmıştır.					1
56-Gün içinde kendiliğinden, iletişimi başlatmak için kullandığı ifadelerin sayısı otuzu geçmez.				3	
57-Uzun süreler boşluğa bakar.	4				
TOPLAM:					

## APPENDIX 4. ZARİT CAREGIVER BURDEN SCALE (ZCBS)

### Zarit Bakıcı Yükü Ölçeği

Aşağıda insanların bir başka insanın bakımını üstlendiğinde kendini nasıl hissedebileceğini yansıtan ifadelerden oluşan bir liste yer almaktadır. Her ifadeden sonra ne kadar sık böyle hissettiğinizi belirtin: Asla, nadiren, ara sıra, oldukça çok, nerdeyse her zaman şeklinde. Yanlış yada doğru cevap bulunmamaktadır.

	Asla	Nadiren	Ara sıra	Oldukça sık	Nerdeyse her zaman
1- Yakınınzla geçirdiğiniz zaman yüzünden kendiniz için yeterli zamanınız olmadığını hisseder misiniz?	1	2	3	4	5
2- Yakınınzı bakma ve aileniz yada işinizle ilgili diğer sorumlulukları yerine getirmeye çalışma arasında kalmaktan dolayı kendinizi sıkıntılı hisseder misiniz?	1	2	3	4	5
3- Yakınınzla birlikteyken kırgınlık hisseder misiniz?	1	2	3	4	5
4- Yakınınzın şu anda ailenin diğer üyeleri ya da arkadaşlarınızla olan ilişkinizi olumsuz şekilde etkilediğini hissediyor musunuz?	1	2	3	4	5
5- Yakınınzın geleceği ile ilgili korkuyor musunuz?	1	2	3	4	5
6- Yakınınzın size bağımlı olduğunu düşünür müsünüz?	1	2	3	4	5
7- Yakınınzla birlikteyken kısıtlanmış hisseder misiniz?	1	2	3	4	5
8- Yakınınzla uğraşmaktan dolayı sağlığınızın bozulduğunu hissediyor musunuz?	1	2	3	4	5
9- Yakınınz yüzünden istediğiniz düzeyde bir özel hayatınız olmadığını düşünür müsünüz?	1	2	3	4	5
10- Yakınınzı bakmanız nedeniyle sosyal hayatınızın bozulduğunu hissediyor musunuz?	1	2	3	4	5
11- Yakınınz nedeniyle arkadaşlarınızı davet etmekten rahatsızlık duyar mısınız?	1	2	3	4	5
12- Yakınınzın sanki sırtını dayayabileceği tek kişi sizmişsiniz gibi, sizden ona bakmasını beklediğini düşünür müsünüz?	1	2	3	4	5
13- Kendi harcamalarınıza ek olarak yakınınzı bakacak kadar paranız olmadığını düşünür müsünüz?	1	2	3	4	5
14- Yakınınz hastalandığından beri yaşamınızı kontrol edemediğinizi hissediyor musunuz?	1	2	3	4	5
15- Yakınınzın bakımını biraz da başkasına bırakabilmiş olmayı diler misiniz?	1	2	3	4	5
16- Yakınınzla ilgili ne yapacağınız konusunda kararsızlık hisseder misiniz?	1	2	3	4	5
17- Yakınınz için daha fazlasını yapmanız gerektiğini düşünüyor musunuz?	1	2	3	4	5
18- Yakınınzın bakımı ile ilgili daha iyisini yapabilirdim diye düşünür müsünüz?	1	2	3	4	5
19- Tümünü değerlendirildiğinizde yakınınzın bakımı ile ilgili kendinizi ne kadar yük altında hissedersiniz?	1	2	3	4	5

## APPENDİX 5. DYADİC ADJUSTMENT SCALE (DAS)

### Çiftler Uyum Ölçeği

Birçok insanın ilişkilerinde anlaşmazlıkları vardır. Lütfen aşağıda verilen maddelerin her biri için siz ve eşiniz arasındaki anlaşma veya anlaşmama ölçüsünü aşağıda verilen altı düzeyden birini seçerek belirtiniz.

	Her zaman anlaşırız	Hemen hemen her zaman anlaşırız	Nadiren anlaşamayız	Sıkça anlaşamayız	Hemen hemen her zaman anlaşamayız	Her zaman anlaşamayız
1.Aileyle ilgili parasal işlerin idaresi						
2.Eğlenceyle ilgili konular						
3.Dini konular						
4.Muhabbet- sevgi gösterme						
5.Arkadaşlar						
6.Cinsel yaşam						
7.Geleneksellik (doğru veya uygun davranış)						
8.Yaşam felsefesi						
9.Anne, baba veya yakın akrabalarla ilişkiler						
10.Önemli olduğuna inanılan amaçlar, hedefler ve konular						
11.Birlikte geçirilen zaman miktarı						
12.Temel kararların alınması						
13.Ev ile ilgili görevler						
14.Boş zaman ilgi ve uğraşları						
15.Mesleki kararlar						
16. Ne sıklıkla boşanmayı, ayrılmayı yada ilişkinizi bitirmeyi düşünür yada tartışsınız?						
17.Ne sıklıkla siz veya eşiniz kavgadan sonra evi terk edersiniz?						
18.Ne sıklıkla eşinizle olan ilişkinizin genelde iyi gittiğini düşünürsünüz?						
19.Eşinize güvenir misiniz?						
20.Evlendiğiniz için hiç pişmanlık duyar mısınız?						
21.Ne sıklıkla eşinizle münakaşa edersiniz?						
22.Ne sıklıkla birbirinizin sinirlenmesine neden olursunuz?						
23. Eşinizi öper misiniz?						
24. Siz ve eşiniz ev dışı etkinliklerinizin ne kadarına birlikte katılırsınız?						
<b>Aşağıdaki olaylar siz ve eşiniz arasında ne sıklıkta geçer?</b>						
25. Teşvik edici fikir alışverişlerinde bulunmak						
26. Birlikte gülmek						
27. Bir şeyi sakince tartışmak						
28. Bir iş üzerinde birlikte çalışmak						
<b>Eşlerin bazı zamanlar anlaşıkla, bazen anlaşamadıkları konular vardır. Eğer aşağıdaki maddeler son birkaç hafta içinde siz ve eşiniz arasında görüş farklılığı veya problem yaratıyorsa belirtiniz (Evet veya Hayır'ı işaretleyiniz)</b>						
	Evet	Hayır				
29. Seks için çok yorgun olmak						
30. Sevgi göstermemek						

31. Aşağıda ilişkinizdeki farklı mutluluk düzeyleri gösterilmektedir. Orta noktadaki ‘Mutlu’ birçok ilişkide yaşanan mutluluk düzeyini gösterir. İlişkinizi genelde değerlendirdiğinizde mutluluk düzeyinizi en iyi şekilde belirtecek olan seçeneği lütfen işaretleyiniz.

( ) Aşırı mutsuz

- ( ) Oldukça mutsuz
- ( ) Az mutsuz
- ( ) Mutlu
- ( ) Oldukça mutlu
- ( ) Aşırı mutlu
- ( ) Tam anlamıyla mutlu

32. Aşağıda belirtilen cümlelerden ilişkinizin geleceği hakkında ne hissettiğinizi en iyi şekilde tanımlayan ifadeyi lütfen işaretleyiniz.

- ( ) İlişkimin başarılı olmasını çok fazla istiyorum ve bunun için yapamayacağım hiçbirşey yoktur.
- ( ) İlişkimin başarılı olmasını çok fazla istiyorum ve bunun için yapabileceklerimin hepsini yapacağım.
- ( ) İlişkimin başarılı olmasını çok fazla istiyorum ve bunun için payıma düşeni yapacağım.
- ( ) İlişkimin başarılı olması güzel olurdu, fakat bunun için şu anda yaptıklarımın daha fazlasını yapamam.
- ( ) İlişkimin başarılı olması güzel olurdu, fakat bunun için şu anda yaptıklarımın daha fazlasını yapmayı reddederim.
- ( ) İlişkim asla başarılı olmayacak ve ilişkinin yürümesi için benim daha fazla yapabileceğim bir şey yok.

## APPENDİX 6. MULTİ-DİMENİONAL SCALE OF PERCEİVED SOCIAL SUPPORT (MPSSS)

### Çok Boyutlu Algılanan Sosyal Destek Ölçeği

Aşağıda 12 cümle ve her birinde de cevaplarınızı işaretlemeniz için 1 den 7'ye kadar rakamlar verilmiştir. Her cümlede söylenenin sizin için ne kadar çok doğru olduğunu veya olmadığını belirtmek için o cümle altındaki rakamlardan yalnız bir tanesini daire içine alarak işaretleyiniz. Bu şekilde 12 cümlenin her birinde bir işaret koyarak cevaplarınızı veriniz. Teşekkür ederim.

1. Ailem ve arkadaşlarım dışında olan ve ihtiyacım olduğunda yanımda olan bir insan (örneğin, flört, nişanlı, sözlü, akraba, komşu, doktor) var.

Kesinlikle hayır 1, 2, 3, 4, 5, 6, 7 kesinlikle evet.

2. Ailem ve arkadaşlarım dışında olan ve sevinç ve kederlerimi paylaşabileceğim bir insan (örneğin, flört, nişanlı, sözlü, akraba, komşu, doktor) var.

Kesinlikle hayır 1, 2, 3, 4, 5, 6, 7 kesinlikle evet

3. Ailem (örneğin, annem, babam, eşim, çocuklarım, kardeşlerim) bana gerçekten yardımcı olmaya çalışır.

Kesinlikle hayır 1, 2, 3, 4, 5, 6, 7 kesinlikle evet

4. İhtiyacım olan duygusal yardımı ve desteği ailemden (örneğin, annemden, babamdan, eşimden, çocuklarımdan, kardeşlerimden) alırım.

Kesinlikle hayır 1, 2, 3, 4, 5, 6, 7 kesinlikle evet

5. Ailem ve arkadaşlarım dışında olan ve beni gerçekten rahatlatan bir insan (örneğin, flört, nişanlı, sözlü, akraba, komşu, doktor) var.

Kesinlikle hayır 1, 2, 3, 4, 5, 6, 7 kesinlikle evet

6. Arkadaşlarım bana gerçekten yardımcı olmaya çalışırlar.

Kesinlikle hayır 1, 2, 3, 4, 5, 6, 7 kesinlikle evet

7. İşler kötü gittiğinde arkadaşlarıma güvenebilirim.

Kesinlikle hayır 1, 2, 3, 4, 5, 6, 7 kesinlikle evet

8. Sorunlarımı ailemle (örneğin, annemle, babamla, eşimle, çocuklarımla, kardeşlerimle) konuşabilirim.

Kesinlikle hayır 1, 2, 3, 4, 5, 6, 7 kesinlikle evet

9. Sevinç ve kederlerimi paylaşabileceğim arkadaşlarım var.

Kesinlikle hayır 1, 2, 3, 4, 5, 6, 7 kesinlikle evet

10. Ailem ve arkadaşlarım dışında olan ve duygularıma önem veren bir insan (örneğin, flört, nişanlı, sözlü, akraba, komşu, doktor) var.

Kesinlikle hayır 1, 2, 3, 4, 5, 6, 7 kesinlikle evet

11. Kararlarımı vermede ailem (örneğin, annem, babam, eşim, çocuklarım, kardeşlerim) bana yardımcı olmaya isteklidir.

Kesinlikle hayır 1, 2, 3, 4, 5, 6, 7 kesinlikle evet

12. Sorunlarımı arkadaşlarımla konuşabilirim.

Kesinlikle hayır 1, 2, 3, 4, 5, 6, 7 kesinlikle evet

## APPENDIX 7. EXPRESSED EMOTION SCALE (EES)

### Duygu Dışavurum Ölçeği

**AÇIKLAMA:** Aşağıda hastanızla aranızdaki ilişkinin bazı yönlerini tanımlayan cümleler vardır. Lütfen hastanızı düşünerek cümleleri okuyun ve tanımlanan durumların size uygun olup olmadığını belirtmek üzere doğru (D), yanlış (Y) şeklinde işaretleyin. Bunu yaparken son bir yılınızı düşünün.

- (D) (Y) 1. Onun bazı şeyleri kasten yaptığını düşünüyor ve öfkeleniyorum.
- (D) (Y) 2. Onun hasta olduğuna inanmıyorum.
- (D) (Y) 3. Onunla sohbet etmekten hoşlanıyorum.
- (D) (Y) 4. Benim için onun istekleri, diğer aile üyelerinin isteklerinden daha önemli.
- (D) (Y) 5. Onunla ilgili her şeyi, kendine ait özel meselelerini bile araştırıp öğrenmeye çalışıyorum.
- (D) (Y) 6. Onun varlığı beni deli ediyor.
- (D) (Y) 7. Düşünüp düşünüp yanıyorum ne hata yaptık diye.
- (D) (Y) 8. Onun bazı yönlerini beğeniyor ve takdir ediyorum.
- (D) (Y) 9. Ona sık sık öğüt veriyorum.
- (D) (Y) 10. Onunla uyuşamıyoruz.
- (D) (Y) 11. Bıraktım artık ne hali varsa görsün.
- (D) (Y) 12. Aile içinde onun her şeyiyle ben ilgileniyorum.
- (D) (Y) 13. Ona kırılıyor, güceniyorum.
- (D) (Y) 14. Onun fikirlerini sonuna kadar dinlerim.
- (D) (Y) 15. Onun üstüne titrerim.
- (D) (Y) 16. Onunla birlikteyken başka bir şeyle ilgilenmiyorum, ilgim sürekli onun üstünde oluyor.



- (D) (Y) 17.O benim hayatımı yaşamama engel oluyor.
- (D) (Y) 18.O hasta oldu diye dünya başıma yıkılmış gibi hissediyorum.
- (D) (Y) 19.Onun yaptığı işleri beğenmiyorum.
- (D) (Y) 20.Onun giyim kuşamını beğenmiyorum ve ona bunu söylüyorum.
- (D) (Y) 21.Ondan benim beklediğim gibi davranmasını istiyorum.
- (D) (Y) 22.Ona en ufak bir şey olacak diye endişeleniyorum.
- (D) (Y) 23.Onun her şeyiyle ben ilgileniyorum.
- (D) (Y) 24. “Ondan ah bir kurtulsam!” diye düşündüğüm oluyor.
- (D) (Y) 25.Huzursuz ve keyifsiz olduğunda anlıyor ve ondan uzak duruyorum.
- (D) (Y) 26.Onun kendi işlerini sıralı ve düzenli yapması için onu sık sık ikaz ediyorum.
- (D) (Y) 27.Hastaneye yatması beni perişan ediyor, ondan ayrılmaya hiçdayanamıyorum.
- (D) (Y) 28.Biz birbirimize benziyoruz.
- (D) (Y) 29.Onun yanlışlarını düzeltmesini istiyorum.
- (D) (Y) 30.Onunla iyi anlaşıyorum.
- (D) (Y) 31. Aklım fikrim hep onda, başka hiçbir şey düşünemiyorum.
- (D) (Y) 32.Kendini düzeltmesi için onu sık sık eleştiriyorum.
- (D) (Y) 33.Ondan uzak kalmak istiyorum.
- (D) (Y) 34.Basıma bir sürü dert açıyor.
- (D) (Y) 35.O olmasa bütün işler yoluna girecek.
- (D) (Y) 36. Bir zorlukla karşılaştığımda bu zorlukla başa çıkabiliyorum.
- (D) (Y) 37.Onun her şeyi ile ilgilenmek bana zevk veriyor.

(D) (Y) 38.Öfkelendiğinde ondan uzak durmam, onu yatıştırmak için uğraşırım.

(D) (Y) 39.Huzursuz ve keyifsiz olduğunda onunla konuşmaya,sohbet etmeyeçalışırım.

(D) (Y) 40.Onun, hastalığını abarttığını düşünüyorum.

(D) (Y) 41.Onun morali bozuk olduğunda genellikle ben destek oluyorum.

**APPENDIX 8. SATISFACTION WITH LIFE SCALE (SWLS)****Yaşam Doyumu Ölçeği**

Aşağıdaki ifadelerle katılıp katılmadığınızı görüşünüzü yansıtan rakamı maddenin başındaki boşluğa yazarak belirtiniz. Doğru ya da yanlış cevap yoktur. Sizin durumunuzu yansıttığını düşündüğünüz rakam bizim için en doğru yanıttır. Lütfen, açık ve dürüst şekilde yanıtlayınız.

7 = Kesinlikle katılıyorum

6 = Katılıyorum

5 = Çok az katılıyorum

4 = Ne katılıyorum ne de katılmıyorum

3 = Biraz katılmıyorum

2 = Katılmıyorum

1 = Kesinlikle katılmıyorum

\_\_\_\_\_ Pek çok açıdan ideallerime yakın bir yaşamım var.

\_\_\_\_\_ Yaşam koşullarım mükemmeldir.

\_\_\_\_\_ Yaşamım beni tatmin ediyor.

\_\_\_\_\_ Şimdiye kadar, yaşamda istediğim önemli şeyleri elde ettim.

\_\_\_\_\_ Hayatımı bir daha yaşama şansım olsaydı, hemen hemen hiçbir şeyi değiştirmezdim.

## APPENDIX 9. POSTTRAUMATIC GROWTH INVENTORY (PTGI)

### Travma Sonrası Gelişim Ölçeği

Aşağıda ciddi yaşam olaylarından sonra ortaya çıkabilecek bazı değişiklikler verilmektedir. Her cümleyidikkatle okuyunuz ve yakınınızın tanı almasından sonra belirtilen değişikliğin sizin için ne derece gerçekleştiğini aşağıdaki ölçeği kullanarak belirtiniz.

0= Yakınım hasta olduktan sonra böyle bir değişiklik yaşamadım

1= Yakınım hasta olduktan sonra bu değişikliği çok az derecede yaşadım

2= Yakınım hasta olduktan sonra bu değişikliği az derecede yaşadım

3= Yakınım hasta olduktan sonra bu değişikliği orta derecede yaşadım

4= Yakınım hasta olduktan sonra bu değişikliği oldukça fazla derecede yaşadım

5= Yakınım hasta olduktan sonra bu değişikliği aşırı derecede yaşadım

	Hiç					Aşırı derece
1. Hayatıma verdiğim değer arttı.	0	1	2	3	4	5
2. Hayatımın kıymetini anladım.	0	1	2	3	4	5
3. Yeni ilgi alanları geliştirdim.	0	1	2	3	4	5
4. Kendime güvenim arttı.	0	1	2	3	4	5
5. Manevi konuları daha iyi anladım.	0	1	2	3	4	5
6. Zor zamanlarda başkalarına güvенеbileceğimi anladım.	0	1	2	3	4	5
7. Hayatıma yeni bir yön verdim.	0	1	2	3	4	5
8. Kendimi diğer insanlara daha yakın hissetmeye başladım.	0	1	2	3	4	5
9. Duygularımı ifade etme isteğim arttı.	0	1	2	3	4	5
10. Zorluklarla başa çıkabileceğimi anladım.	0	1	2	3	4	5
11. Hayatımı daha iyi şeyler yaparak geçirebileceğimi anladım.	0	1	2	3	4	5
12. Olayları olduğu gibi kabullenmeyi öğrendim.	0	1	2	3	4	5
13. Yaşadığım her günün değerini anladım.	0	1	2	3	4	5
14. Hastalığımın sonrasına benim için yeni fırsatlar doğdu.	0	1	2	3	4	5
15. Başkalarına karşı şefkat hislerim arttı.	0	1	2	3	4	5
16. İnsanlarla ilişkilerimde daha fazla gayret göstermeye başladım.	0	1	2	3	4	5
17. Değişmesi gereken şeyleri değiştirmek için daha fazla gayret göstermeye başladım.	0	1	2	3	4	5
18. Dini inancım daha da güçlendi.	0	1	2	3	4	5
19. Düşündüğümde daha güçlü olduğumu anladım.	0	1	2	3	4	5
20. İnsanların ne kadar iyi olduğu konusunda çok şey öğrendim.	0	1	2	3	4	5
21. Başkalarına ihtiyacım olabileceğini kabul etmeyi öğrendim.	0	1	2	3	4	5

## APPANTIX 10. ETHICAL ACCEPTANCEFORM

## APPENDİX 11. CV

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**GÜLİZ ÇETİNBAKIŞ**

#### PERSONAL INFORMATION

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- Nationality: Turkish
- Date of Birth: 03.06.1972
- Place of Birth: Balıkesir/Turkey
- Gender: Female

#### CAREER

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2015-2016 ----- Physiological Counselor at Private Çekirge Doğa Anadolu High School

2009-2013 ----- Physiological Counselor at Private Levent Collage

2000-2009 ----- Physiological Counselor at Private Bilfen Education Institutions

2000-2009 ----- Physiological Counselor at Private İstek Vakfı Belde High School

#### EDUCATION

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1989-1993: Bachelor Science at İstanbul University, on Physiology

1987-1989: Balıkesir High School

1985-1987: Karesi Junior High School

1980-1985: Dumlupınar Elementery

## İNTİHAL RAPORU